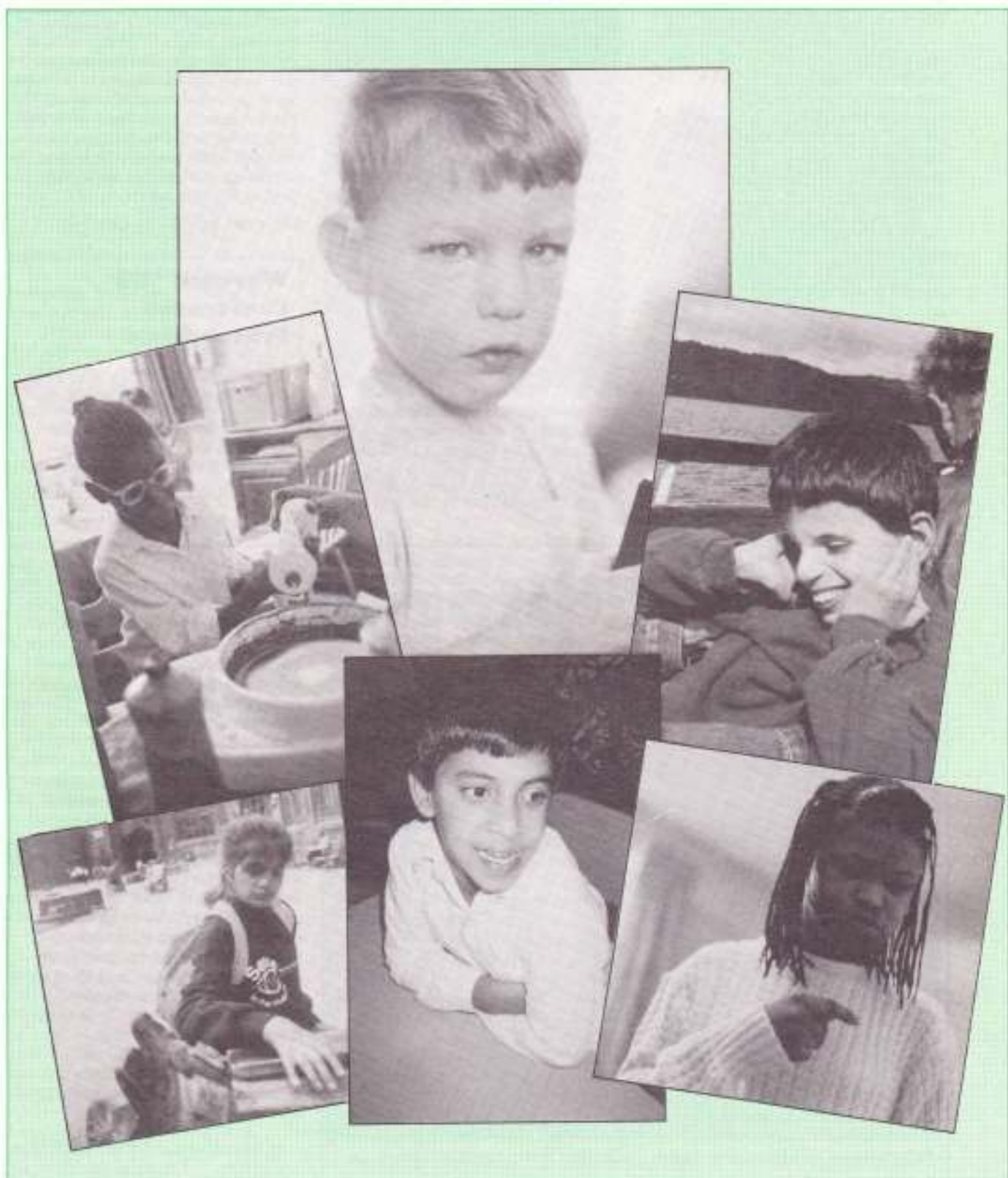


# Deaf-Blind Education

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

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**Deaf-Blind Children of the World:  
We have reports from more than 20 countries**

# Vice-Chairman's Letter

Dear friends,

It is a great pleasure for me to write this letter to you, even though it has come about because the illness of our Chairman, John McInnes who we hope will soon be fully recovered. I very much missed John at the European Deaf-Blind Conference in Warwick, England last August.

It was a challenge for me to replace him as chairman when the Executive Committee of the IAEDB met. Most of the committee members attended the five meetings we had, two of which were only for the European region. I would like to mention some decisions made during the meetings.

The next European Conference of the IAEDB will be held at Potsdam, East Germany, 1993. When the International Conferences were started it was our intention to provide information, ideas, techniques and contacts for young teachers and other workers. This next Conference will be programmed with this objective in mind.

A symposium for delegates of a higher scientific and academic level will be held at Sint Michielsgestel, Netherlands, at some time during

the next four years.

IAEDB Sub-Committees may be created by the Executive Committee. They are likely to be concerned with areas of special interest in the field of deaf-blindness. The Sub-Committee must inform the Executive Committee of budgets and proposals for activities and report back when requested.

Since 1962 no lecturer from the USSR has attended an IAEDB Conference, so therefore it created a very great impression at Warwick when we met Professor Valeriy Chulkov from Moscow. I am sure that he will be a valuable link between people in East and West Europe working with the deaf-blind. My hope for the future is that we will have more opportunities to share our knowledge and experiences with colleagues from Eastern Europe.

The Constitution Committee could not meet at Warwick because two of its members were absent. The next meeting will take place during one of the planning meetings for the next World Conference.

Planning for this next IAEDB World Conference, which will take place in Örebro, Sweden in August

1991 is well under way. The Programme Committee and the Nordic Planning Committee held meetings at Ekeskolan in Örebro this October.

The Conference theme has now been decided. It will be 'Quality of life — lifelong enrichment'. It is very necessary for the education of deaf-blind people to continue from youth to old age. The discussions will deal with all aspects of personal development throughout life. A 'First Announcement' will soon be distributed and I very much hope that 400—500 people will attend the Conference, which we are calling *Örebro '91. Welcome!*

Sonja Jarl, IAEDB Vice Chairman

## Warwick '89 Conference Proceedings

The proceedings of the Warwick Conference are being prepared.

We shall be able to give more details of their progress in our Spring 1990 edition.

## Editorial

When I look at the material in this fourth issue of *Deaf-Blind Education* I am struck by the extraordinary variety. Articles and news have come from different parts of the world, about different topics, from different types of people. There has been a mountain of material too — we have had to keep many contributions in reserve for future issues.

The locations of our articles come from five continents — from North America, Africa, Asia, Oceania and Europe. For this issue there is most from Europe, perhaps because of the IAEDB European Conference held this summer in Warwick, UK. Perhaps this also reflects that there are more developments currently in Europe than in many other parts of the world. But this is beginning to change, and I am confident that future issues will bring ever more

news of developments and ideas elsewhere.

The topics we cover seem equally diverse. In our 'On the Spot' feature (on page 11), Karl Jacobsen from Norway talks about his ideas on the early development of communication in deaf-blind children. Christine Martens and Bernadette van den Tillaart from Holland describe the feelings of parents, and give a fascinating example of co-operation between a family and a school, on p6.

The contributors also are a mixed bunch. On pp14-17 we find Dr Admiraal bringing a medical perspective to our work in his description of some of the syndromes causing deaf-blindness. On p29 Alexander Suvarov writes as a deaf-blind person with his thoughts about the importance of deaf-blind children learning about able-

bodied children. Other articles are written by parents, teachers, social pedagogues and administrators.

I hope that this cocktail provides everyone with some taste that they can recognise and enjoy. I hope also that it makes you feel that deaf-blind education is the responsibility of all of us. Education is not simply something for the classroom. A deaf-blind child needs to be guided to learn about the world, about himself and about other people. Every moment can be an educational moment, and all of us who are in contact with a deaf-blind child have a part to play in their education.

So keep on writing to us — wherever you live, whatever you are thinking about, whoever you are.

Paul Ennals

# Warwick '89

*IAEDB's European Conference was held in Warwick, UK, jointly sponsored by Sense and the Royal National Institute for the Blind (RNIB).*

Is there a distinctive European approach to the education of deaf-blind children? Or are the differences in philosophy and methods so great between different countries that the concept of a European approach is just an idle dream? The three hundred delegates at the Warwick University perhaps found an unexpected answer to that question.

Warwick '89 was our European conference. Mind you, some of the delegates took a very broad interpretation of 'European' — some of us did not realise that the USA, Canada, Ghana and New Zealand had joined the European community! We hold these European conferences every four years — the next one is at Potsdam in East Germany in 1993. The warmth of feeling, and the growing sense of community and commitment that can be felt within these conferences, is a clear indication that international links are a vital source of the strength and development in the field of multi-handicap and deaf-blindness in recent years.

The education of deaf-blind children and multiply-handicapped blind children is a very specialised field. Practitioners find it important to establish contacts with others in the field, and sometimes they have to travel a long way in order to do this. It is important always to be challenging your own approaches — considering new perspectives, analysing new ideas. At Warwick we had the opportunity to examine the Russian approach to deaf-blind education, and contrast it with the developments in Holland, Britain and other parts of Europe over recent years.

In Russia they have a long tradition of educating deaf-blind children. A special school was teaching deaf-blind children before the war. It was destroyed in 1941, but rebuilt again at Zagorsk near Moscow, and continued the long tradition of offering specialised education to deaf-blind children. In the 1950s the work of Meshcheryakov became well known,



*Dieter Bunck, Director of Bildungszentrum für Taubblinde, Hanover, Federal Republic of Germany, talks to Lucy Luganzo from the Kabarnet School, Kenya*

and his book *Awakening to life* was published in Britain. For many this account of the education of a range of deaf-blind children up to and including university level was an inspiration and a challenge. The tradition continued after his death, and the latest in the line in Russian research psychologists is Dr Valeriy Chulkov. Dr Chulkov presented the

philosophical backgrounds to the Russian approach, and showed some videos of the work at the school in Zagorsk, as well as in the experimental school in Moscow.

After many years of hearing about the Russian approach from a distance, many of us felt very reassured by what we heard and saw. The philosophical basis of their work is familiar — yes, there are some changes and there are some things that they stress more than we seem to, but the essence of the work reflects a similar belief in the development of deaf-blind children. Indeed, as the week went on and as other people presented the ideas and practice in other European countries, we all came to a realisation of the common roots from which our work has arisen. The early work of Vygotsky and Luria, the founding philosophers of Soviet special education, had deep influence on developments in the West. And the work of Western developmental psychologists, including the behavioural scientists, can be seen influencing the Russian methods.

In recent years it is Holland that has been setting the pace in the field of deaf-blind education. The school at Sint-Michielsgestel has been a source of ideas, research and training that has greatly influenced work in this country and elsewhere. The main exponent, Jan van Dijk, spoke and outline his approach.



*The Usher Syndrome Conference was held at Warwick too. A happy group in front of the ruins of Warwick Castle.*

This inspiring presentation, with his evident humanity combining with his scientific knowledge, showed how much we are now dependent upon combining ideas from different disciplines. Perhaps most people have thought of the van Dijk approach as being based on communication — always stressing the importance of interaction with the child and putting forward ideas of how to help children understand a complicated world. Yet here we heard him describing the great



*Jacques Souriau from Poitiers*

importance of understanding the more traditional sciences — of considering neuro-psychology, of studying behavioural approaches to learning. From the words of Jan and other speakers came the realisation that there are many common strands running through the work with deaf-blind children throughout Europe, on both sides of the Iron Curtain. The greatest variations in practice do not arise out of different philosophies — they arise out of different cultures and different levels of resources. In Russia, there is only the one specialised school for deaf-blind children. Children must attend there from all over Russia, travelling as far as three thousand miles. They have no systems for supporting families in the home, not out of disagreement with the idea but simply out of lack of resources. The Scandinavian countries are blessed with superbly designed and equipped schools. In Britain — well, we are just beginning to catch up now.



*A group of delegates from North America*

1992 will bring new opportunities for Europe. Perhaps the deaf-blind field is further ahead than many in the area of European co-operation. Already there is talk of a European staff-training project, preparing materials and courses to support people across the continent. Already there are regular programmes of seminars to develop understand of Usher syndrome. Already there are staff exchange programmes, and the regular organisation of European activity

weeks for deaf-blind young people.

The lecture theatre and the bars gave ample evidence of co-operation at a personal level between countries. And perhaps the greatest indicator of the spirit of the conference came from Dr Chulkov in his final presentation: 'We have come here to learn. If you can learn something from us, that is fine. The needs of deaf-blind children cross all boundaries, and together we can work for the benefit of all Europe's children'.

**Paul Ennals**

*“ Following five days of intensive exchange of ideas, of reappraisal of work practices, one is left with the feeling of having only touched the tip of the iceberg which the deaf-blind world represents.*

*Each afternoon, we were faced with having to choose one workshop among so many others and could not help but feel frustrated.*

*The highlights of the conference have undoubtedly been the experiences which parents shared.*

*Confronted by an array of thoughts regarding the different theories used in deaf-blind education, it is important that together with the parents we think about the reality of a deaf-blind child within his/her family, the reality of a deaf-blind adult within society at large, about his vocational and emotional future.*

*These were the issues raised by anxious parents during exchanges of ideas in the workshops.* ”

**Mamie Souriau  
France**

“ We, specialists working in the field of teaching children who are deaf-blind in the Soviet Union, have enjoyed meeting our colleagues from different countries and societies. We thank the UK Coordinating Group for giving us this opportunity: Paul Ennals, Rodney Clark, Tony Best and other people.

Education of multi-handicapped children with dual sensory impairments is a complicated process and it demands hard work from all of us. From this point of view it was necessary to share the information about different philosophies underlying the approaches to people who are deaf-blind. Thanks to the Conference we were able to learn many



scientific and practical things from experts from the Netherlands, Great Britain, France, West Germany and other countries. We collected very useful information in 'Open Sessions' where special interests met together.

The Conference on the whole was of great interest to us. We hope that in future we'll have more opportunities of sharing modern technology with our colleagues and that children who are deaf-blind will benefit from our collaboration.

The conference was one of the milestones in awareness of training deaf-blind children. We hope that is a stimulating event for all of us.

Dr Valeriy Chulkov, USSR

“ It has been a great pleasure for me to come to the Conference and to become familiar with philosophies and new approaches to sensory impairment with multi-handicap. I have enjoyed the opportunity to share ideas with participants from 28 countries. I have been stimulated and challenged by the speeches and presentations, especially by Dr Jan van Dijk's methods regarding individualised curriculum sequence and extended classroom models in programming students with multi-handicaps, social studies, etc.

I will pass these ideas on to others in Kenya through my report to our Ministry of Education about the Conference. I think we still need your support (which I hope will continue) in many ways, for example, with equipment and the training of teachers so that we shall be able to help all our deaf-blind people.

Many people don't know about deaf-blind education out here and much more must be done to educate the Third World Countries both from outside and from within. It will be better for we people from East Central and West Africa if we can come together to form an association for deaf-blind people as well as a parent's association so that we can give light to those others parts of Africa where this work for deaf-blind people has not reached — in order to educate soul, body and the minds of deaf-blind children. I hope my sisters from Ghana and my brothers from Tanzania are going to join me so that we can do something about his issue together. Finally I want to thank all those who sponsored and helped me to come to this most interesting Conference.



Lucy Lyoshi Logonzo  
Kabarnet School, Kenya.



## Mothercare

# Mothercare, and Parental Guidance

Who can forget the importance of the parents when we are working with a deaf-blind child? Certainly no-one who attended one remarkable joint presentation at the Warwick Conference, which provoked discussions throughout the week.

First, Catharina Martens gave an honest and moving account of her experiences as the mother of Annika, and spoke about her relationship with Sint-Michielsgestel, the Institute in Holland where Annika was educated. She opened her heart to her audience, and won many friends and admirers.

Then Bernadette van den Tillaart described the approach of the Institute in trying to support Mrs Martens. The combination of the two presentations — the honesty with which each talked about their problems and their feelings — produced a stimulating and emotional sermon. Here we publish extracts from both these talks.

I want to tell you something about the relationship between my daughter Annika and myself, and at the same time, about the relationship between the Institute and myself.

By the 'Institute' I mean: The Institute for the Deaf in Sint Michielsgestel, Holland and in particular the people that have been directly or indirectly concerned with Annika and me.

It is important to realise that everything I am going to say has been coloured by my own emotions and my subjective experience of the circumstances. I am talking for myself and do not express either the opinion of my husband, or the opinion of other parents.

When I reflect on the nine months pregnancy, I think of it as a happy period, full of expectation and enjoyment of what is to come. So far everything was going according to my plan.

My first disappointment came on 17 January, when I was told that I could not give birth at home, because the baby was too small, and therefore I had to go to the hospital. The image I had of giving birth at home, surrounded by familiar things and people whom I loved, was immediately cut short. Off to the hospital.

Yes, it turned out that Annika only weighed 4.5 pounds at birth. Therefore, she was put into the incubator and I was not

allowed to feed, feel or cuddle her. Twice a day, I was allowed to look at her from a distance. I felt happy to look at this little girl, who seemed to be healthy, and only had to grow a little before she could go home with me. I was a really happy person when after a few days I was allowed to feed her and wash her.

Then the moment arrived, when I had to go home. Unfortunately Annika had to stay behind. She was alright, so they said, she only had to grow a little more. Coming home like that, without my baby, was a very unhappy experience. Hardly anybody dared to pay me a visit, maybe because they did not know what to say to a mother without her

baby. It was all so different from what I had hoped for!

Hurray, finally she came home. When we took a closer look however, we noticed that her lovely blue eyes had a grey pupil. We hoped that we were imagining things. We were referred to the eye specialist when we visited the paediatrician. The eye specialist wanted to keep her in the hospital for a closer examination and research.

I did not want to leave her there on that particular Friday, because Annika was going to be baptised that Sunday. On Monday, they admitted her to the hospital. A small little being, from whom they seemed to draw blood from every possible place on her body for various tests. This went on for a whole week, and I was only allowed to feed her once a day and to give her a little wash.

Nobody informed me of anything. When she was four-and-a-half months old, Annika was operated on in the eye hospital in Rotterdam. The cataract of one eye was removed. They bandaged the eye and splinted her arms, to prevent her from touching the eye.

Everything became very difficult for her, not only feeding times, but also it was impossible to play with a toy and to put it into her mouth. All I could do was to sing little songs to her and stroke



Catherina Martens talks to Susan Allen from Florida

her hair. Then she got a cold, which prevented the operation on the other eye, which was supposed to take place the following week. Ten days later, after the operation on the other eye, I was told that Annika would need to wear glasses instead of contact lenses.

The eye specialist told me so, when I was sitting next to the bed of Annika and the idea frightened me very much. Annika was then six months old and I soon got used to her wearing the glasses.

We were happy that this was behind us and we could start a normal life. When she was nine months old, we discovered that her hearing test was not good. We were told not to worry; there was nothing abnormal, because she had been through such a traumatic experience that this could be the cause. They told me to come back in a few months time, but what to do in the meantime? That they did not tell me, and I was very worried.

I watched her with extra attention and noticed something was not right. I hoped things would turn out well. Then she had to go to the University Hospital for another examination. I was told that Annika could hardly hear anything. I had thought it could turn out to be like that, but still it came as a blow. There I was: I was on my own, I asked myself questions like for instance: what will become of her, when she cannot see nor hear well? And why did the doctor have to tell me this in an office, where we were being interrupted and disturbed by nurses going in and out?

We were referred to the Institute for the Deaf in Voorburg. Hometraining was started, which got us into a certain routine. And also I visited with Annika a rehabilitation centre three times a week. So, what more could I do? But unfortunately we noticed that Annika did not develop the way the other deaf children did. So we decided to consult the Institute for the Deaf in St. Michielsgestel.

A sympathetic letter arrived, followed by a house call. I asked the head of the hometraining department of St Michielsgestel what she thought of Annika. Her answer was that, although it was not her task to give an opinion, she thought that Annika belonged with them in their Institute. That day I had been told that I was expecting another baby and that same day I had the feeling of losing my Annika. Sorrow reigned, yet we wanted to do what was best for her. So we

## Parental Guidance, based on the concept of the locus of control

*Bernadette van den Tillaart*

The birth of a handicapped child has an enormous impact on the family. Without professional help most of the parents are unable to solve problems concerning management and education of the child. In establishing a family intervention programme it is important that the help offered to the parents meets their expectations and is adjusted to the strength or weakness of the family system.

For this reason a questionnaire has been developed by Robbroecks and Wels (1985) in the Netherlands. The purpose of the instrument is to analyse the educational situation, how the parents feel and what their needs are.

An important concept upon which the rather extended questionnaire is built, is the idea of locus of control. A distinction can be made between external locus of control and internal locus of control. By the former is meant that the person feels dependent and controlled by factors 'outside' him/her, such as fate (bad) luck, factors beyond his or her influence. When a person feels that despite difficult circumstances he/she is still able to influence the situation, then he or she has an internal locus of control.

In parental guidance these ideas are very important, because parents who feel 'controlled', will develop a very dependent attitude towards the professional. They will continually ask for help. While persons with internal locus of control will ask for a kind of help which will enhance coping skills, so that when new problems arise, they are able to solve them themselves.

In the case of Annika ...

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decided to send her to St Michielsgestel and hoped that everything would work out well. Annika was one-and-a-half years old then.

During the time before Annika went to this school a lot more happened. In spite of the fact that I thought I was coping with the problem, we were slowly getting ourselves into isolation as a family. Annika's eyes needed to be operated on once more, to remove a new cataract. In the hospital she was left to her own resources. Someone who cannot speak is unable to complain and often is forgotten. I spent my days at her side, while I felt everybody is ignoring us. But it was painful to find out that Annika could not ask for a drink when she was thirsty and so she did not receive anything.

When the baby was born, Annika was afraid of her. She was not two years old. She did not want to touch the baby and tried to push it away from my lap; she loved to sit on my lap herself and this baby was getting in her way. It was difficult to share the moments of loving and caring between the two children.

Then the moment arrived when Annika had to go to her new school

for one week. I accompanied her for the whole week, during which they did all kinds of tests. She did not realise what they were doing, but she was happy that her mummy was with her. What I found particularly agonizing was that they put her in 'swedish belts' in the afternoon and evening, which made her cry so much and which finally exhausted her into sleep. It was all getting on top of me at this stage.

In the middle of happy deaf children, I was starting to feel like a special case with my Annika, particularly when one of the children greeted his father with great enthusiasm, while I felt I knew so little about the feelings of my Annika. However, my reward came the next day, when Annika had missed me and with a big smile she came running to me and I had to hold her very tight.

On one of the open days, they asked me what I expected of Annika in the future. I told them that I hoped she would be able to become an independent human being, who could live independently in a small apartment.

Her first year in school was becoming a happy experience. I had to take Annika to school myself on

... In the case of Annika, a visually and hearing impaired rubella child with dyspraxia, the NVOS questionnaire revealed that the mother felt very dependent on and controlled by the institute where her daughter was enrolled.

From filling out the form and discussing the results, a parental guidance could be established with the goal of changing the mother's feeling of dependence into a feeling of internal control. The mother could indicate rather well in which areas she wanted help and in which she felt confident already. The areas in which we worked were:

- 1 Written information.
- 2 Stimulation of a good interaction between the mother and her daughter.
- 3 Responsibility for the education of Annika and understanding of the acceptance process.
- 4 Adjustment of the perspectives between the parents and the professionals.

### 1 Written Information

We provided written information about ways of interacting with deaf-blind children, and experiences of other parents, and discussed these with her.

### 2 Stimulation of a good interaction between the mother and her daughter

The mother indicates that the relation between her daughter and herself is not satisfying. Annika shows very ambivalent behaviour: should she attract or rebuff her mother. She does not want to say goodbye and hardly dares to say hello. Annika has a severe dyspraxia. She experiences herself constantly failing in communication. She is not able to develop a feeling of competence. Instead of exploration of the environment and the persons in it, Annika shows stereotyped and passive behaviour. She rejects the persons who want to do an activity with her.

Because of the strange signal repertoire...

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Monday, and on Fridays at the end of the school week I had to travel by train and bus to take her home. We noticed slight improvements and the family felt more stable this year.

Unfortunately Annika did suffer from homesickness and we had to make the best of our being together in the weekends. It is a pity that the weekends are always too short for us, and the school week so long. Our

optimism was increasing as we noticed her improvements. Our expectations were high.

In the second year at the school, we were told that perhaps there was something wrong with her locomotion. This was preventing her from communicating. She was becoming difficult in her behaviour. I tried to point out to her the social side of life and the existence of her small sister. I liked to involve her in all sorts of ways in our family life. This I did in the firm belief that with all the life inside me, I would be able to make of Annika a confident and happy girl.

The school had now made arrangements for Annika to be accompanied on the train, and somehow I seemed to lose contact with the Institute. From one point of view I regretted this, but on the other hand I was happy with the break.

In the third year she was taught by one of her former teachers and Annika was happy at having her back. At home though, things did not improve and at times she seemed to hate me. She pinched me and kicked me, and I felt so

frustrated, that I slapped her at times. I was starting to doubt my own ability to do well and to make her happy. Things did change again, and by the end of the school year she behaved like the little girl I knew. The family was happy again.

Her fourth year was coming up now. Hopefully she would get a nice new teacher and I was hoping she would do as well as she had done the previous year. At the last moment however, Annika discovered that she no longer belonged to Group 1, but she was moved to Group 3 where she knew hardly anyone. She started to cry and screamed desperately, pulling me by the hair and behaving quite hysterically. I was very upset. The people in the Institute urged me to leave and although I did not want to leave her in this state, I had to. I felt desperate for her and completely powerless. As a mother I was suffering deeply, because after all she was my child and I wanted to have her near me.

The weekends that followed this episode were trying and tiring. Annika was clearly angry with me and did not want to know me. In fact, she ignored me, I seemed to have let her down. The contacts with the Institute were mostly by telephone or letter and I felt, particularly because of the 120 km distance between our home and the school, that I was really out of touch. I felt I was in an 'impasse', I did not know what to do for Annika.

Although I loved her very much, the gap between us, because of her being away all week, was getting wider. Somehow I was convinced that Annika loved me too, but I did not know to make her love and my love pass one to the other. Since I could not come up with a solution to my problems, I got in touch with the social worker.

The talks I had with her and also the appointments that were made between the Institute and myself, helped me very much and made me feel happier. Annika also started to be happier, so the family became more stable again. This situation lasted until the end of '86 when problems started once more. I began to ask myself if it would ever stop.

Annika had decided she did not want to have anything to do with me. She ignored me. When I asked her for a little kiss, which she used to give me, she pushed me away. I was very unhappy and felt rejected. When she saw me sitting on the sofa, she just stood there and refused to join me. The same in the



mornings in our bedroom, if she did not see my husband there, she did not want to come into our bed any more. Only when she needed me for practical reasons would she come near me. When she did not need me for anything in particular, she even started to hit me.

Luckily, I was invited to attend the school lessons regularly and so I got a clearer picture of what was going on with Annika. Through a video and after talks, a lot of my questions were answered.

In the meantime Annika was then nine years old and had completed her seventh term. I had to come to some conclusions within myself, the 'why' and 'how' of my failing, where had mistakes been made, what had I done wrong, why did I feel so unhappy and lonely at times, while Annika was slowly but surely improving? My questions remained unanswered for the moment.

Looking back, I felt very disappointed in life, not where Annika was concerned, but in my own expectations and ideas of the future. All the time things turned out quite differently from what I had expected: the pregnancy, my daughter, the medical treatment and operations she had to undergo, then her deafness, her not being able to stay at a school for deaf children in the neighbourhood, the high expectations that everybody had in Sint Michielsgestel, the discovering that her locomotion did not function properly, another disaster; what will come next?

So much was going on in the mind of this cheerful child and I could hardly reach her. This child could be so difficult from time to time. When we heard about there being too much pressure on the eyeball, we got another shock. By telephone we were asked to give permission to operate. Of course, we had to give our permission, did we not? When the first signs of puberty appeared, they have to administer injections to delay this process, if not, she would always be a little lady of 1.5 metres (which is about 4.5 feet).

The relationship with the Institute had improved a lot in the meantime. The Rafael-department had made me feel at home. The people there were so enthusiastic and idealistic. I still remember the first words when we took her there: 'Annika will be very happy here. We will support everything which is to her advantage. For her it is a paradise'. It made me feel very

... Because of the strange signal repertoire and the dyspraxia of Annika, it is difficult to read her needs and to predict how she is going to react. If it is impossible to give regular and intense stimulation, the mother-child synchrony can not be established. According to Ainsworth the giving of a quick and adequate responsive reaction is a prerequisite in the interaction between the mother and child to come to a secure attachment relationship (Van Ijzendoorn e.a., 1985). When the educator can not give an adequate response, the world of the child becomes unpredictable, and the child can not learn that it can control the events in his life (external locus of control).

When we relate the information from Bowlby (1979) and Van Ijzendoorn e.a. (1985) with the observations, the behaviour of Annika seems to indicate an anxious attachment relationship. In Rafaël sometimes we see that the children start to build up attachment behaviour with the special person there, and only then are able to build up a more secure attachment relationship with the parents. With Annika, we saw that in adequate responsive interaction she developed a more secure attachment relationship with her two special persons in Rafaël.

To improve the interaction between Annika and her mother, Annika was given more overview over the presence and absence of her mother, at home and in Rafaël, and a video-tape was made to observe and get understanding of the interaction.

We videoed the interactions that took place between Annika and her mother, and discussed them with her. The video showed that Annika was being rejecting and aggressive when her mother initiated contact, or when Annika was unclear what her mother wanted of her. It seemed that Annika rejected her mother when the distance between them became too short too quickly. When her mother drew pictures with Annika, to give her an overview of what was expected, Annika behaved differently; she smiled at her mother and gave her a kiss.

In later sessions, Annika's mother was given the opportunity to try different strategies of communicating with Annika, while we videoed her from behind a one-way screen. The teacher could give extra advice during the session; Annika's mother tried the advice, and was later able to observe the results on the video.

We planned a programme of sessions every few weeks, when school staff could assist Annika's mother with her interactions with her child. Now, the mother has learnt to be more responsive to her daughter, and Annika has built up a better relationship with her. She greets her mother directly, and is able to say goodbye without feeling stressed. When she is with her mother she has enough confidence to try new activities. Her mother feels less dependent on professionals; she feels an internal locus of control.

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happy.

However, one day when I had to visit the oculist with Annika, I planned to stay with her at the Institute for the rest of the day. However, I had to leave before 5 o'clock. Rules are rules. This was very difficult to understand, I travelled three hours there and three hours back just to see the eye doctor with her and that was all? Whose interests were put first? Such a treatment was a shock to me. Did I deserve that? At that moment I had too many emotions of sorrow and I left at 5 o'clock.

Something similar happened a short time later. I was not allowed to join Annika for lunch, I had to leave her for one hour and could come back afterwards. This would be very upsetting for Annika, so I decided either to stay with her during the lunch or regardless take

her out. Finally, they allowed me to stay, but I could hardly eat anything at all. I was so upset, because I could not understand the reason for such a decision. I insisted to have a consultation with the rector of the Institute and the headmaster, they explained to me that there are rules, but no rule without an exception. Of course, I could join Annika for lunch under such circumstances. What a pity we had not discussed it before it all happened. But we were learning from these kinds of situations.

Looking back over the past year, I feel very satisfied, a lot has been done in different fields. I still visit Annika every week, she expects me and most of the time is very pleased to see me, which gives me a lot of encouragement to continue. During the visits I am allowed to watch my own child and to learn how to

### 3 Responsibility for the Education of Annika

The handicap of Annika means an unnatural course of education and also a home for Annika away from her family. By filling up the questionnaire of the NVDS, the mother indicated that sometimes it is difficult to keep the responsibility over the education of her daughter. Parents have always the end-responsibility. But, when a parent feels uneasy with an aspect of the education as it is carried out by the professional, it is, even when there is a good relationship, not self-evident that the parent will indicate this. Because, 'will they be just as nice to the child when the parent is experienced as an embarrassing person?' To give the mother the feeling that she could speak frankly, she has a meeting every four weeks with a trusted representative who is also well informed about the house rules. In this way the mother can keep the responsibility over the education of her daughter and is not dependent on the professionals. Together with the weekly visits, it gives her the feeling of having an own place in the institute as a parent, a feeling of internal locus of control.

### 4 Ideas of the Future

By some questions it is tried to bring together the perspectives of the parents and the professional. These questions are filled out by the parent, the teacher and the house-parent. The questions are: 'Where will the child live and what will it do later on?' and 'What kind of work do you think that the child can do as an adult?'

The adjustment of each others perspectives gives the opportunity to determine the goals of the IEP each time in agreement with one another. In this way it is less presumed that unclear situations, power conflicts and disappointments come up.

### Conclusions

By using a questionnaire it was possible to analyse the individual need of the parent and to establish a parental guidance programme. The development of a feeling of internal locus of control proved to be crucial in this case study. The parent became able to solve problems themselves or ask for adequate help to learn to cope with a new problem themselves, and the institutional organisation does not give help that is not needed. Especially, while improving the responsiveness of the mother, the methodology of the 'direct feed-back' gave good results. Early guidance of the parents is important as the child will experience sensitive responsiveness as early as possible, and, in shorter time the parents can gain a feeling of internal locus of control in coping with the problems of having a handicapped child.

Bernadette van den Tillaart

handle her. I also attend the playing programmes and participate in her daily school life. I can air my questions and needs during the evaluations and it gives me great joy to realise that, as a parent, I have my own place in the organisation.

Of course, there will always remain a certain uneasiness on my part, as it was not my own choice to share her upbringing with so many different people. This will continue to cause me a lot of unhappiness, especially when I realise that I miss a lot of the cheerful, sad and lovely moments of Annika's life.

In choosing the different subjects of the teaching programmes, the Institute often considered the home situation. For instance, going shopping in a department store. Annika had to learn that she was not allowed to touch all the interesting things she saw. Sometimes I was frightened that Annika, in one of her bad moods, would drop things and smash them, in which case it was no good crying over spilt milk. Turning this into a learning situation gives me encouragement. I can see she is making progress. She does not break things and obviously enjoys the outing. We will repeat these outings again and again to prevent us from getting into more isolation.

The question arising now is: who enjoys this outing most? Annika, because she likes going shopping in this way, Eveline, because she is proud of her clever sister, or her parents, who can undergo something with their two daughters in a happy and relaxed atmosphere?

Catharina M Martens  
Smeltink, The Netherlands

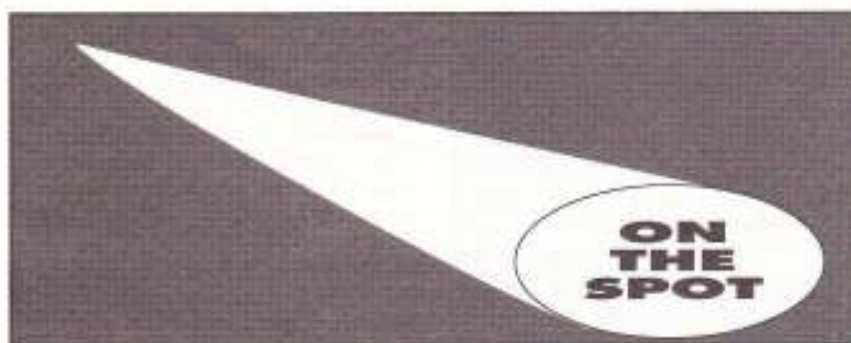
“ It has been a real pleasure to participate in this exceptional Conference! The keynote address by Tony Best set the tone which was followed throughout: many speakers referring to it in their own talks, indicating that it had established the overall theme of the Conference from the start. Just as the opening was brilliant so was the closing speech by Paul Ennals which reinforced the message given by Tony Best encouraging an attitude of cooperation, sharing and growing together and warning of the danger of becoming an 'instant expert'.

The Conference was extremely well organised by an ever helpful and cheerful staff. The social events provided a glimpse of one part of England and were so enjoyable that I feel sure that many people will want to pursue more 'British Experiences'.

It was valuable to have deaf-blind people and their families taking part throughout the meeting.

I am looking forward to attending the next IAEDB Conference. ”

Tina St Amand  
W Ross Macdonald School  
Canada



On the Spot is a regular feature in Deaf-Blind Education. Here an experienced practitioner in the field will put some questions to a colleague from abroad. We hope this section will provoke discussion, and help to bring us all together.

Karl Jacobsen's interest in multi-handicapped people began when he worked with them for five years in institutions. He read psychology and worked as a school psychologist, specialising in communication training for multi-handicapped people. He then joined the National Control Team for the Deaf-Blind in Norway for three years. Karl is now employed at Oslo University.

Here he answers questions put to him by Marjaana Suosalmi.

***The Norwegian Central Team for Deaf-Blind People is unique, could you please tell about its aims and functions?***

The National Central Team is the formal institution for diagnosing deaf-blindness in Norway. That means that no one gets the rights of a deaf-blind person unless they are diagnosed by 'the team'. What is unique about this is that all deaf-blind people are diagnosed by the same criteria, which should be the common Nordic functional definition of deaf-blindness. There has of course been a discussion about the interpretation of the different criteria over the years, due to new knowledge and changes of persons in 'the team'. But the main criteria have more or less remained the same during the eleven years 'the team' has existed. In this period 'the team' has established many useful contacts and working relationships with professionals in schools, clinics, homes, hospitals and universities to promote diagnosis in a proper way.

Because of their diagnostic responsibility, 'the team' are often the first specialist workers that deaf-blind people in Norway meet. 'The team' therefore gives them an explanation about what is offered to deaf-blind people by the Norwegian government — both rehabilitation and economic help. 'The team' also organises the start of rehabilitation.

One other unique result of 'the team's' work, is that we have, at any time, complete epidemiological statistics which include every deaf-blind person in Norway. The statistics are mainly used for two purposes:

- To uncover new and unfulfilled needs among the deaf-blind population, and initiate projects which may give an answer to how these needs may be fulfilled.
- To use in discussions with the authorities, to make them supply the financial resources we need.

***What effects do you think the work done by the Central Team has had on services provided for the different groups of deaf-blind people in Norway?***

'The team' works in a close relationship with the Norwegian Deaf-Blind Association, parents, institutions and schools for deaf-blind people, and the Eikholt Activity Centre. The impact 'the team' has had on services provided for deaf-blind people in Norway has often been in collaboration with one of these groups.

There are two important factors that make 'the team' central in all newly established and changing services provided for deaf-blind people in Norway.

- The first is the epidemiological statistics, which, at any time, can provide most of the epidemiological distributions among deaf-blind people and subgroups of deaf-blind people.
- The second is that 'the team' is neutral. It is self evident that the Deaf-Blind Association, parents, schools, institutions and activity centres have their own interests to take care of. The National Central Team is not in that position. It has no special interest to protect. Because of the epidemiological statistics and its neutrality, 'the team's' engagement in an emerging

service has a special value to the authorities.

***Tell us about recent highlights in deaf-blind work in Norway***

I have been asked this question in various forms before. Every time I have tried to answer it, the consequences have been angry phonecalls from people that I left out. So I have learned to answer this particular question in a general way.

The most promising change I have observed during the last years is an increase in published reports on both programmes used in training and the results from training. Putting my own work and practice in writing has also led to debates about programmes and increased awareness of the impact of different approaches in training programmes.

There is, at the present time, considerable work being done to establish new homes for deaf-blind youngsters. Some are already established, and some are planned. In the next three to four years the number of established deaf-blind units in Norway will probably be doubled or tripled.

The school system for deaf-blind people is under reorganisation. One of the aims of this reorganisation is to increase the interaction between professionals in different schools.

Several people are working with different kinds of assessment in different areas, and there is a strong tendency to formalise these assessment tools. There is also a strong tendency to link together the assessments and interventions, which means that knowledge about the deaf-blind person and the results from the assessments point directly to a specific intervention in the area assessed.

Two years ago parents of deaf-blind children split-off from the Association of Parents for Blind Children, and created their own association. These two years have shown that this decision was right.

***You are going to work on a project for the next two years. Tell us about the project.***

It is on vision assessment of multi-handicapped people. As you all know there are, and have been, many projects on vision assessment. So why this project? There are two special aims. The first is to uncover the capacity of the functional vision in multi-handicapped children. When one uses observations or optotype tests to assess vision, one depends on motor functions — like reaching out, pointing, grabbing,

etc. One also depends on cognitive functions like recognition and interest. Vision assessment methods which rely on other functions like motor and cognitive functions as response indicators for vision may go very wrong with multi-handicapped people, because we do not know if the functions we use as response indicators are fully developed. The importance of finding the capacity of functional vision is that if there is a higher capacity in vision than the multi-handicapped person shows when observed in daily life activities, it is critical to use this residual vision systematically. Systematic use of residual vision may elicit initiatives and increase the multi-handicapped persons activity. By activity and initiatives, the amount of interaction will increase, and interaction is of course the best way to facilitate cognitive development, and make it functional for the multi-handicapped person to use his or her motor capacity.

The second aim is to apply preferential looking (PL) tests that are based on gratings, to multi-handicapped people. The PL method has been used systematically in a few studies of vision acuity assessment of multi-handicapped people. The results from these studies are promising: there were only a very few, even among severely brain damaged people, that one did not manage to test. Of course there are also difficulties reported in the test situation when PL is used.

PL relies little on motor and cognitive functions as response indicators. The motor response is simply eye movement, which may not be easy, but not impossible, to read for the group with nystagmus or other eye motoric problems. The preference for contrast over non-contrast is inborn.

The few multi-handicapped people we have tested, numbering about 30, show better acuity on PL than on other acuity tests, or what is expected from observations. So the question arises; why do some multi-handicapped people not use the vision they have?

This might be from constraints in other functions, but it may also be because of the way we arrange the environment. The arguments for including PL in the test battery when one is testing vision in multi-handicapped people are given more completely in the paper 'WHAT'S SO GREAT ABOUT GRATINGS', which Ivar Lie and myself gave at



Karl Jacobsen

this year's conference in Warwick. The paper should be published in the proceedings of the conference.

**You have recently made some remarks on methods in deaf-blind education. What are the main points on developmental work?**

My simple viewpoint is that when one works in education for deaf-blind people, one has to have access to a number of methods and techniques, and pick the methods and techniques which are useful for the phenomenon one is facing. The contrary will be to have one method, for example a cognitive or behaviouristic method and try to solve all the problems one is facing in deaf-blind education by that single method.

An example I have used before is from communication training with deaf-blind people. When we do communication training we need to know the person we are training very well. The reason for this is obvious, but one of the most important things to know about the deaf-blind person one is training, is — when is the person already communicating? When the deaf-blind person already communicates we should not train him or her, but communicate with them.

The second area one needs to know something about when one trains a deaf-blind person to communicate is of course the phenomenon of deaf-blindness, and how this particular person is affected by the dual sensory loss.

Thirdly it is necessary to know about the phenomenon of communication development. My views on the theory of communication development are

influenced by biological and functional traditions which evolve and have consequences. One way of uncovering the elements in communication development is to study early interaction between the infant and its caregivers. A very short description of this interaction may be as follows:

The newborn infant has some inborn activities. The most important early inborn activity, regarding communication development, seems to be crying. It is not reasonable to think that the infant has any conscious meaning by this crying, but the parents interpret the infant's initiatives as having meaning and act as if the infant has a meaning. This phenomenon has come to be known as 'over interpretation'. 'Over interpretation' may be important in early communication development because by systematic reactions by the parents to the infant's behaviour the infant becomes aware of the behaviour's meaning, and may, because of the parent's systematic reactions, be able to use certain behaviours to achieve goals. An example of one such relationship between infant behaviour and a systematic reaction is crying and the appearance of food. The association between crying and food, is learned by the infant. The appearance of food involves also the appearance of a person, so by crying the infant gets both food and social interaction. The social interactions ensure that the infant learns new associations and new ways of taking initiatives. It seems to be critical that infants have these biological inborn activities early in life, and that these inborn activities are an onset mechanism for development.

In the early onset period it seems as though operant and classical conditioning are a reasonable way to explain the associations the infant learns between his own activity and its consequences. However, in the first year of life the young child's own cognitive development influences the young child's behaviour. One well known phenomenon in the first year of life is the development of intention. The young child starts to use its own activities intentionally, and to use other people as agents to achieve goals. There is a lot of debate about development of intention. This debate is a purely scientific one that is concerned with the problem that intention, like all cognitive activity, is impossible to study directly.

A common sense analysis of early

communication development may be that onset is very dependent on the infant's own inborn activities, and systematic reactions from the parents make the infant aware of the consequences of its own activities. During the first year of life the regularity of the parent's reactions makes the world predictable for the infant, and gives the infant an overview, so that the infant can start to develop cognitively and, for example, start to use communication intentionally.

If we look at an infant born deaf-blind, it is difficult to establish associations between the infant's activities and the consequences from the parents, for at least two reasons. The deaf-blind infant has few activities, and it is hard to make the infant aware that he is reacted to. The deaf-blind infant is typically characterised by passivity, and is therefore at high developmental risk. Such infants lack, because of double sensory loss, initiatives and activities that seem to be of such great importance for the onset of development. Lack of initiatives and activities may be the reason why it is so hard for parents and professionals to cope in interaction with deaf-blind infants and young children.

One way to improve the deaf-blind infant's communication is to do the opposite of what one has learned to do as a consequence of studying communication development where the infant has all senses intact: one starts with the cognitive part by using strongly built structures to give the young child an overview and a sense of predictability. If one succeeds with this methodological cognitive training, and achieves the goal of giving the child overview and predictability, one has trained the deaf-blind person in understanding. To transform this understanding to communication one possible way to go is to make small changes in the structure ('positive breakdowns'), because if we continue the structure there is no need for communication. One way to make a 'positive breakdown' is to look at an activity as a behavioural chain, and to break the chain where one knows that it is important for the deaf-blind person one is interacting with, to continue. Then one increases the probability of activity which is communicative from the deaf-blind person. One example is if one always ends the gymnastics session with a cup of tea. Every time when the gymnastics is over, the teacher

takes the deaf-blind person's hand and makes the sign for tea. After a few times it becomes very clear to the teacher that the deaf-blind person enjoys the tea after gymnastics. One day, after the gymnastics, the teacher deliberately tries to lead the deaf-blind person out of the room instead of going to the table where the tea is located. By this 'positive breakdown' the teacher gives the deaf-blind person a need to communicate because the deaf-blind person knows what he wants due to his overview, and the teacher also knows that the deaf-blind person wants, because the teacher has the same overview. If one is lucky in this situation, the deaf-blind person will make the sign for tea, and will get his tea and a comment like 'I forgot the tea' from the teacher. The activity from the deaf-blind person becomes an initiative and the teacher creates the association between asking for tea and getting tea. Now one is using behaviour modification by positive reinforcement of the deaf-blind person's initiatives, by reacting to them as communication.

This is similar to how onset of development starts with infants who have their senses intact. Infants with vision and hearing seem to get overview and predictability through regularity in reactions from parents. When the problems — as with deaf-blind infants, is passivity, it seems possible to go the other way around, and create overview by using cognitive training methods, where the adult has all the initiatives. When the deaf-blind person has an overview, it is possible with different techniques to elicit initiatives. These initiatives become communicative because the adult reacts to them in a systematic way.

Here I have not had space fully to describe the necessity to combine methods in deaf-blind education, but I gave a paper on the subject at the conference in Osimo in October 1988. The paper is called 'Combination of methods in deaf-blind education', and is in the proceedings published after that conference.

**“ Despite my efforts to keep pace with literature relevant to my work, reading doesn't bring concepts to life or provide concrete connections to the larger professional community. Because the committee selected a broad scope and high calibre of presentations, some of this linkage was strengthened.**

**Also, while it was sometimes difficult to hear, my awareness of how the attitudes and conditions of Americans is perceived by certain individuals in other cultures, was expanded. These perceptions were not all negative, but some were and I am already considering ways to change that.**

**Presenting the Conference exclusively in English created specific, but I think, solveable problems for both speakers and audiences. Thinking and speaking at length to sophisticated listeners about important concepts was, at the least, exhausting for presenters as evidenced by their frequent pauses and deep sighs.**

**And, is it possible that the audience missed some of those important concepts? There are many holes in my own notes that I wish I could fill with missed content. During my own presentation, I wondered if all of my points were clear to the non English speaking participants.**

**Might papers be translated into one or two languages before the conference? Would it be cost effective to have delegates purchase translated copy? Could speakers present in a preferred language with a translator to interpret for the audience?**

**A colleague of mine suggested that presenters outline key points of their presentations either on transparency (large black print against white please) or in handouts so that delegates could follow.**

**I'm glad I was there, it was worth the time. I'm**

**looking forward to the next one.**

**Harriet Ward  
Perkins School, USA.**

# Rare genetic syndromes associated with visual and hearing defects

**T**he simultaneous pathological manifestations in the eye and ear characteristic of various clinical syndromes and congenital and teratogenic diseases may be attributed in part to the analogous embryonic development of these two organs.

The eye and the ear are being developed in the same gestational period: the first twelve weeks.

Moreover there are a lot of anatomical similarities between these two organs, for example their common origin, analogies in circulation and neural innervation.

Because of this there are many diseases and symptom complexes which combine ocular and auditory features.

As an otologist I know about 250 syndromes associated with deafness of which there are about 80 'oculo-auditory syndromes'. These are excellently described in a book of L. S. Regenbogen and G. J. Coscas, *Oculo-Auditory Syndromes*, Masson Publishing Inc., USA (1985, ISBN 0-89352-225-2). As they point out in their book, it can be extremely important to have a thorough knowledge of these combined ocular and auditory syndromes. It will enable the ophthalmologist to suspect and recognise certain types of deafness, and the otologist to discover certain eye defects. Patients afflicted with this double sensorineural impairment require early and accurate diagnosis to receive appropriate counselling for future education and better understanding of their disease. Moreover, it is important that clinicians be aware that an eye or ear defect may be the first indication of possible disturbances in other, apparently unrelated, organs or systems. Early detection and diagnosis of such complex disorders will help in tracing and diagnosing other affected family members with hereditary conditions and will prevent unnecessary retardation of the social and educational development of these patients.

In the Institute of the Deaf at St. Michielsgestel in Holland there are

In this paper presented at the Warwick Conference, Dr Admiraal describes many of the genetic syndromes that we may encounter among deaf-blind children and young people, based upon his work among the deaf and deaf-blind population of Sint Michielsgestel, Holland

about 500 profoundly or totally deaf children. Looking to the cause of their deafness we get the following figures:

prenatal	20%
perinatal	10%
postnatal	15%
hereditary	40%
unknown	15%

These figures correlate quite well with the figures found when reviewing the literature.

When we take a closer look at the above-mentioned causes of deafness, we can make the following differentiation:

## Prenatal causes of deafness (20%)

- rubella
- cytomegalovirus
- toxoplasmosis
- congenital syphilis
- teratogenic medication

Because of similarities mentioned earlier between the embryonic development of the eye and ear, most of these prenatal causes of deafness are associated with ocular defects.

The congenital rubella infection, the most important prenatal cause of deafness, is well known for the syndrome consisting of:

- deafness
- heart defects
- eye defects (cataract, glaucoma, retinopathy)

## Perinatal causes of deafness (10%)

- lack of oxygen (hypoxia)
- jaundice
- ototoxic medication

Of these causes, lack of oxygen can harm the auditory system as well as the visual system. Furthermore, too much oxygen, for example during neonatal intensive care artificial ventilation, can also damage the retina with the result of visual impairment.

## Postnatal causes of deafness (15%)

- meningitis
- ototoxic medication
- chronic otitis media
- measles and mumps

In this group of causes of deafness there is hardly any association between deafness and visual impairment.

## Hereditary causes of deafness (40%)

can be divided into:

- deafness only (25%)
- deafness as part of a syndrome (15%)

Within this last group are the about 80 oculo-auditory syndromes.

**A**s you can see, in almost every group of causes of deafness there is a serious chance of visual impairment beside the deafness. As an estimation, there are about 20% visually handicapped children in the Institute of the Deaf in Holland. There are 15 children with Usher Syndrome in our Institute, and about 80 persons with this syndrome in our after-care. For them, we started a Centre for the auditory-visually impaired, for low-vision training, genetic explanation and advice, psychological counselling and ophthalmological explanation and advice.

### Usher Syndrome

The most important oculo-auditory syndrome is Usher Syndrome. Usher Syndrome is a combination of an almost always stable perceptible hearing loss and progressive retinitis pigmentosa. Usually, the hearing loss is present at birth and only later in life do the eye defects become manifest in the form of increasing night-blindness and visual field defects.

The incidence is autosomal recessive. This means that the parents, who are the carriers, both pass their Usher-gene to their children. Only when a person has two Usher-genes, will he have the syndrome.

Usher Syndrome can be divided into four types:

#### Type I

Profound congenital deafness with symptoms of retinitis pigmentosa manifesting themselves before adolescence (about 90%).

#### Type II

Moderate to severe congenital hearing loss with symptoms of retinitis pigmentosa manifesting themselves after adolescence (about 10%).

#### Type III

Progressive perceptible hearing loss with symptoms of retinitis pigmentosa manifesting themselves before adolescence (rare).

#### Type IV

Moderate to severe congenital hearing loss with symptoms of retinitis pigmentosa manifesting themselves after adolescence (like type II) but with a sex-linked inheritance, thus only affecting males (rare).

Because the etiology is not known, there is no causal cure for the syndrome.

### Treatment

regular ophthalmic care  
visual field tests  
visual acuity tests – glasses  
intraocular pressure – eyedrops  
cataract surgery  
low vision aids  
mobility training  
hearing aids  
genetic counselling  
psychological counselling  
– *be positive*

For many ophthalmologists and otologists any combination of retinitis pigmentosa and deafness is

usually described as Usher Syndrome.

While Usher Syndrome is indeed the most common form of retinitis pigmentosa and deafness, the differential diagnosis is extensive, consisting mainly of rarely seen entities, but the alternatives still must be considered.

The diseases which are the most similar to Usher Syndrome include:

Alstrom's syndrome  
Bardet-Biedl syndrome  
Cockayne syndrome  
Flynn-Aird syndrome  
Hallgren syndrome  
Kearns-Sayre syndrome  
Refsum's disease

### Alstrom's Syndrome

is characterised by the following symptoms:

#### Atypical retinal degeneration

In contrast to retinitis pigmentosa, in which there is a progressive loss of peripheral vision, in Alstrom syndrome there is a progressive loss of central vision and by a very young age only insignificant vision remains.

#### Hearing loss:

There is a progressive hearing loss starting in early childhood, slowly progressing to moderately

severe deafness in the second and third decade of life.

*Obesity*  
*Diabetes Mellitus*  
*Renal disease*  
*Normal intelligence*  
*Autosomal recessive inheritance*

#### Treatment:

regular ophthalmic care  
hearing aids  
diet  
medical therapy for the Diabetes Mellitus  
genetic counselling

### Bardet-Biedl's syndrome

is characterised by the following symptoms:

*Retinitis pigmentosa (70–90%)*  
most patients have atypical retinitis pigmentosa  
more rapid progression to severe visual impairment

*Hypogenitalism (55–65%)*  
more frequent in men than in women  
affected men extremely rarely have children

*Polysyndactyly (75%)*

*Mental retardation (70–85%)*  
mostly mild

*Obesity (75–90%)*  
most marked on the trunk, abdomen and thighs  
often more pronounced after

puberty  
not caused by excessive appetite

*Hearing loss (5–15%)*  
varying from slight hearing impairment to severe deafness  
sometimes progressive

*Urinary tract infections*  
*Cardiac disorders*  
*Autosomal recessive inheritance*

#### Treatment:

regular ophthalmic care  
low vision aids  
mobility training  
hearing aids  
medical treatment of urinary tract infections  
diagnosis of cardiac disorders  
genetic counselling

## Rare genetic syndromes associated with visual and hearing defects

(continued)

### Cockayne syndrome

is characterised by the following symptoms:

#### Ocular:

Pigmentary degeneration of the retina with secondary optic atrophy. The retinal degeneration is progressive, leading to visual loss. Generally, blindness occurs during the second decade of life.

#### Hearing loss:

There is a progressive hearing loss, developing during childhood, becoming moderate to severe in intensity.

#### Dwarfism

#### Premature senile facial appearance

#### Mental retardation

#### Progressive neurological disorders

#### Skin changes

#### Autosomal recessive inheritance

#### Treatment

- regular ophthalmic care
- cataract extraction, when indicated
- hearing aids
- physical therapy
- avoidance of ultraviolet radiation

### Flynn-Aird syndrome

is characterised by the following symptoms:

#### Ocular

- In most patients there is a severe myopia (90%)
- Bilateral cataracts develop in 50%
- Retinitis pigmentosa 20%
- Total blindness 5%

#### Hearing loss

There is a progressive hearing loss, starting in early childhood. The rate of progression can be quite variable and can result in a severe deafness.

#### Skin atrophy

#### Dental caries

#### Baldness

#### Muscular wasting

#### Stiffness of joints

#### Ataxia

#### Epilepsy

#### Mental retardation (not severe)

#### Autosomal dominant inheritance

#### Treatment:

- regular ophthalmic care
- visual acuity tests – glasses
- cataracts surgery
- visual field tests
- intraocular pressure – eyedrops
- hearing aids
- dental care
- physical therapy
- antiepileptic medicine

### Hallgren syndrome

is characterised by the following symptoms:

#### Ocular

The retinitis pigmentosa in this syndrome is the same as in Usher Syndrome but seems to have a somewhat more moderate rate of progression.

#### Hearing loss:

There is a congenital profound or total deafness.

### Kearns-Sayre syndrome

is characterised by the following symptoms:

#### Ocular

Progressive external ophthalmoplegia (progressive paralysis of the external eye-muscles)

#### Atypical retinitis pigmentosa

(in more than 50% there are no functional consequences like reduced visual acuity, visual field constriction or nyctalopia.)

#### Hearing loss

in about 50% there can be deafness in varying degrees the hearing loss is sometimes progressive usually it is more pronounced in the higher frequencies the age of onset can vary

#### Progressive cardiac defect

this may range from minor to severe cardiac conduction defects

#### (Progressive) ataxia

#### Mental subnormalities

#### Growth failure

#### Heredity unknown

#### Treatment:

- regular cardiac care
- medicine
- cardiac pacemaker
- regular ophthalmic care
- medicine for the weakness of the external eye muscles
- hearing aids
- genetic counselling

#### Mild ataxia, presenting as gait disturbances.

Vestibular tests show decreased or absent response.

#### Mental retardation and psychosis (20%)

It is not clear whether these may be environmental or social manifestations or whether the mental problems are directly related to the syndrome itself.

#### Autosomal recessive inheritance

#### Treatment:

see Usher Syndrome



**Refsum's syndrome**

is characterised by the following symptoms:

*Retinitis pigmentosa*

Age of onset can vary from early childhood to third decade starting with night-blindness, followed by visual field constriction. Central vision may be normal for many years.

Complicated by cataract in about 80%

Often miosis

*Hearing loss*

There appears to be mild variation in the degree of deafness.

Hearing loss most often begins in the second or third decade of life and progresses slowly, involving the higher frequencies in particular. Often the hearing loss is more severe on one side than in the other.

*Progressive peripheral polyneuropathy:*

Ataxia and weakness starting in childhood or in early adult life. The weakness particularly affects the legs and later the arms.

Muscle wasting and paralysis are slowly progressive, most marked distally in the extremities. Progressive loss of skin sensation, pain sensation, vibration and position sensation.

*Anosmia (35%)**Heart disease in varying degrees (35%)*

The syndrome is caused by an enzyme defect resulting in the accumulation of phytanic acid.

*Autosomal recessive inheritance***Treatment:**

dietary restrictions: diet free of chlorophyll, phytol or phytanic acid (butter, margarine, cream, animal fat, tomatoes, chocolates, etc.)

- regular ophthalmic care
- cataract extraction, when indicated
- hearing aids
- physical therapy
- cardiac check-up, medical treatment
- genetic counselling

**A**s you can see, the combination of retinitis pigmentosa and deafness is not restricted to Usher Syndrome.

A thorough knowledge of these syndromes (and this list is far from conclusive) will urge the clinician to further investigations looking for disturbances in other organs or systems. Interdisciplinary co-operation between ophthalmologists, otologists, geneticists, pediatricians, neurologists and cardiologists will enable a more accurate and earlier

diagnosis. This is extremely important, because, as you know, the earlier the diagnosis, the earlier the treatment can start. The sooner the treatment, the better the prognosis and the better the quality of life.

Finally I want to mention two other syndromes. These syndromes have been discovered quite recently. Probably they are much more common than first realised. These syndromes are:

CHARGE association

Zellweger syndrome.

**CHARGE**

stands for

- C**oloboma
- H**ear disease
- A**tresia choanae
- R**etarded growth
- G**enital hypoplasia
- E**ar anomalies/deafness

Other symptoms are:

- Mental retardation*
- Micrognathia*
- Cleft palate*
- Tracheosophageal fistula*

The most dangerous features of this association are the choanal atresia and the congenital heart defects.

Choanal atresia is a closure between the nasal cavity and the nasopharynx. If bilateral, the newborn presents severe respiratory distress. Intubation and/or surgery is necessary. Congenital heart defects can vary from minor malformations to aberrations that are not compatible with life. Surgery is not always possible.

The ocular manifestations range from iris coloboma without visual impairment, choroidal and/or optic disc coloboma to clinical anophthalmos.

The hearing loss ranges between mild and profound. Almost all patients have external auditory abnormalities.

Cleft palate and tracheosophageal fistula can be surgically corrected.

**Cerebro-Hepato-Renal syndrome of Zellweger**

is an autosomal recessive inherited disorder. It is characterised by the absence of a specific cell structure in brain, liver and kidney, caused by an enzymatic deficiency.

The symptoms of this syndrome are:

- neurological*
- hypotonia
- epilepsy
- absent reflexes
- psychomotor retardation

*ocular*

- nystagmus
- cloudy cornea

- cataract
- glaucoma
- atypical retinitis pigmentosa
- progressive hearing loss
- liver insufficiency
- renal insufficiency

A prenatal diagnosis is possible.

Although at first it was believed that the prognosis of this syndrome was very poor, it is now becoming apparent that there is much variability in the expression of this syndrome.

The less severely affected patients can be very well treated to overcome their oculo-auditory impairments.

## Parents at Conferences

The numbers of parents who attend Conferences which have an educational content has slowly increased over the years. I hope this process will continue, for, together with some twenty parents from various countries, Peter and I have been delegates at the Warwick '89 Conference and found it a most enjoyable and stimulating experience.

At one time, it was unheard of for parents to attend a Conference geared to education, let alone to make a contribution. I think Mrs Margaret Brock and I helped to change things when, together with an American mother of a deaf-blind girl, we spoke at the IAEDB (International Association for the Education of the Deaf-Blind) Conference at Perkins in August 1971. Before that we, as the 'Rubella Group' of parents, had organised very successful conferences of our own in 1961 and 1966, welcoming many educationalists as speakers and delegates. We followed this by two more in 1971 and 1976 with an 'International' one in 1981.

In 1980 the IAEDB Conference was held in Hanover when 14 parents from various countries were present. Here the parents met as a group for the first time and several times during the Conference. Following this the UK parents tried to set up an International Parents Group through the medium of a newsletter, but the language barrier proved to be too great a problem.

At the next IAEDB Conference in New York in 1984 I had been asked to organise a full morning session entitled 'Parents as Partners' and with contributions from parents from the UK, Australia, Germany, France and Canada and one from a teacher to keep the balance, this proved very popular. So much so that the IAEDB Executive passed a resolution from the parents 'that the parents' session become a fixture in future conferences and that, when possible, the parents of the host country should be responsible for the preparation of the session according to the chosen theme'. For the first time also, a parent was appointed to the Executive Committee.

Parents numbered 56 at the



*Peggy and Peter Freeman (right) in conversation with Prof. Valerij Chulkov (USSR) and Svetlana Vishneskaya (USSR), interpreter.*

IAEDB Conference in 1987 in Poitiers, France, this being greatly augmented by French parents on the day of the parents' session. The theme was 'The Role of Parents' Associations and Parent Training'. The session was attended by the French Minister of Education. The parents got together several times, lively meetings were conducted in French (more or less!). For the first time a parent from East Germany was amongst others who represented Belgium, Denmark, Canada, France, Holland, Norway, Spain, the US and, of course, the UK.

The previous year, 1986, the first European Conference was held in Bruges. Parents formed a good part of the UK contingent, but unfortunately there were few from other countries.

The Warwick '89 Conference which we attended in August is the second of the European Conferences to be held three-yearly. The parents met together each day over lunch (courtesy of the Sense Hospitality suite) and I know we all enjoyed

sharing our experiences (and photos) and helping each other when this was possible. I remarked to Rodney Clark during the Conference, that although parent participation was not obvious from the programme, parents had played a considerable part in the presentations and as delegates in discussions. His comment was that 'there was no longer any need to specifically mention parents as they were an integral part of conferences on the Deaf-Blind now'. Speak to any of the parents who have been to these conferences and they will tell you enthusiastically how much they enjoyed them — as a source of information and in making new friends amongst the professionals as well as parents and renewing old friendships that bind us all together through our children.

The next IAEDB World Conference is in 1991 in Sweden and the next European one in 1992 at Potsdam in East Germany. How about it?

**Peggy Freeman**

## Music: A vehicle for communication

Paul Hart works at Overbridge, Scotland's only Continuing Education Centre for deaf-blind young adults. In this paper, which he presented at the Warwick Conference, he describes the use of music sessions with deaf-blind students.

Overbridge offers a full training programme for twelve deaf-blind young people, some of whom have a variety of additional handicaps. All our students are potential candidates for individual music sessions and each student, including those with profound hearing loss, participates in weekly group music sessions. While recognising that there are many advantages in using music in the education of people with dual sensory impairment I will focus on how music is used within Overbridge to encourage communication by considering three questions.

- Apart from vocabulary, what skills will our students who are deaf-blind require in order that they might communicate?
- What will they communicate?
- How will they communicate their feelings?

### What Skills do our Deaf-Blind Students Require in Order to Communicate?

So that our students will have a desire to communicate, we have to provide them with training in three vital areas — confidence building, ability to use their own initiative and skills of anticipation.

There is little purpose in providing any of our students with extensive vocabularies of signs and/or symbols if we do not also provide them with situations in which they can use them. A student must be confident about using signs/symbols and have the necessary skills of initiative to want to use them. If we allow our students to become too dependent on us, then it is likely that we will limit their potential for growth in the field of communication. When we are considering building confidence, increasing use of initiative and teaching students how to anticipate events, then music can only be useful if it goes hand-in-hand with a philosophy which dictates that throughout the residential centre, the students must be allowed as much choice as it is possible to

provide. That is to say, there is no point building a student's confidence in a one-a-week music session, if for the remainder of the week the student is not involved in decision-making. Moreover, we must not destroy a student's confidence by forcing our own values and standards on him/her. This is particularly important for many deaf-blind people who display a variety of idiosyncratic behaviours, which staff may deem to be inappropriate or anti-social. These behaviours (e.g. flicking fingers against the head, tapping the body, light-gazing, blowing into their hands etc.) must not be discouraged or we risk forcing our students to withdraw again into their own world.

Three times a week in Overbridge there is a Group Music Session and each student will participate at least once. It is based on 'A Motion Programme for Handicapped People' which was developed by Else Hoest and Niels Sjoervad at Ungdomshjem Centre for Deaf-Blind in Denmark. We adapted this programme for use with our own students. Up to four staff and four students will participate in a session. The same tape of music lasting 30 minutes is played each time and all staff and students follow a set series of exercises.

The close physical contact of many of the exercises means that over a period of time the deaf-blind student learns to trust and be confident with the staff member. This growing confidence will lead to barriers being broken down in other areas of life and, in turn, the students ought to develop a greater willingness to interact, and thus communicate with staff members.

Recently some of our students have reached the stage where they no longer need to do the exercises with the help of a staff member, so this gives the opportunity to have two students working together. This should allow more opportunity for interaction between students, a vital area to develop. In common with many residential

establishments, we face a problem encouraging our students to communicate with one another. Perhaps their years of experience in various residential establishments has taught them that if they want actions or answers a staff member has to be approached. We must teach our students that they can interact meaningfully with fellow residents.

The absence of any verbal prompting during the Group session helps to train the students to rely on their memory to anticipate the order of the exercises. This ability to anticipate events is the key to learning for many deaf-blind people and we encourage its development. The Group Music Session is always done in the same place at the same time each week and thus becomes a marker.

We have recently introduced a method of employing recorded music as a 'clock' for the day. The day is divided into a number of sections and a specific piece of music is played each day at the same time. This gives those students with hearing one more clue as to the time of day. We hope that this will encourage them to communicate (e.g. if a student associates particular music with dinner-time, he may rise from his chair and sign 'dinner').

Taking effective steps to encourage a student to use his/her initiative is an extremely difficult problem which faces many in residential work. For example, it is relatively simple to teach someone the necessary steps in a bathing programme, but much more difficult to teach them to go for a bath spontaneously. Again, while music has a role to play, it is only useful if accompanied by an underlying ethos throughout the centre which asks staff constantly to guard against unnecessary intervention in our students' lives. Here we operate a 'non-directive' approach to some music sessions in which every sound or action made by a student is echoed by the staff member. Thus the student determines the mood and direction of any music session,

and through this can be taught how to manipulate their environment. Many of the residents of Overbridge spent many years in environments which encouraged them to be passive. A non-directive approach to music sessions can be a useful method of decreasing their passivity.

### What will they communicate?

Depending on which areas of need students are working on, music sessions can often complement the work being done to teach relevant signs. This would be in the form of action-songs, where the student would practice associating sign/symbols with specific words. For instance, one student is currently working on a dressing programme. While the dressing is obviously practised in his bedroom at the appropriate time of day, the signs for the various items of clothing can be taught in music sessions. A number of action songs have been composed, which involve the student responding to verbal and signed commands in the song with an appropriate action. Thus the student further practices his dressing in an enjoyable and informal setting and also learns the signs. Some action songs have been composed in order to practice signs associated with body awareness and table setting.

### How will they communicate their feelings?

Some of our students have already acquired a relatively extensive vocabulary and while we would continue to increase the number of signs they have, we must develop within these students the ability to express abstract feelings. Thus we have developed a type of music session which takes as its starting point an emotion such as anger, sadness, etc. The feeling is introduced using sign language, picture books and video and the subsequent improvisatory music session explores all the feeling and thoughts which emerge. At the end of the session the deaf-blind person discusses his feelings and this provides an opportunity for the introduction of new signs and concepts. This kind of music session is still at an early stage of development and we are building up the necessary resources to carry it to its full potential.

Paul Hart

## Association News

### Executive Committee

At the IAEDB European Conference held at the University of Warwick, England, from 6 to 11 August 1989 five meetings of the Association's Executive Committee were held, three for all members and two for members from the European Region.

Key discussion items and decisions are given in the paragraphs below.

The Committee welcomes nine new members as follows; their addresses can be found among the full list of the Committee on page 32.

### New Executive Committee Members

- Marion Obeng from Ghana
- Joan Kelly from Ireland
- Ruth Rosenbluth from Israel
- Joe Morrissey from Kenya replacing Grete Sperber who has returned to Germany
- Live Fuglesand from Norway, replacing Karl Henry Jacobsen
- Antonio Rebelo from Portugal
- Clemens Mkaali from Tanzania
- Graciela Ferioli from Argentina
- Jozef Mendrun from Poland

### Sub-Committees

At Warwick, new bye-laws were approved for the creation of sub-committees and these are:

- 1 Sub-committees may be created by the Executive Committee. They may be at international or regional level and are likely to be concerned with areas of special interest in the field of deaf-blindness.
- 2 All members of the Sub-Committee will be appointed by the Executive Committee and the members will elect their own Chairman and a Secretary. Members will be appointed for a period of three years but may be considered for re-election.
- 3 Expenses for Sub-Committee activities will be the responsibility of the Sub-Committee. The Executive Committee must be informed of budgets and fund-raising proposals for activities.

4 Sub-Committees must:

- a) inform the Executive Committee of proposals for activities.
- b) report back to the Executive Committee at intervals and when requested.

5 These regulations may be changed by the Executive Committee at any time.

These bye-laws effectively establish existing sub-committees i.e. those on our Constitution and on International Development. In addition three new European Sub-Committees have been approved:

- European Sub-Committee on Staff Development
- European Usher Syndrome Study Group
- European Study Group on Deaf-Blindness in Old Age
- A fourth, on Young Adults, has also been proposed.

### European Staff Development

Following the successful meeting in Italy in November 1988, a second workshop on Staff Development is to be held in Osimo in May 1990. A planning meeting is to be held in London in January. Interested readers should contact Rossano Bartoli or William Green at Lega del Filo D'Oro, Osimo. See page 31 for full details.

### Örebro '91

Planning meetings for the next World Conference were held at Warwick in August and following the fourth Helen Keller World Conference on Deaf-Blindness held in Stockholm in September/October 1989. See the Vice-Chairman's letter on page 2 for further details.

### Membership Fees

The Executive Committee generally agreed that membership fees should remain at the current rates with an element added for inflation. The new rates will be levied following the next World Conference (i.e. from 1992) and a suggestion that fees be included in the Registration fee for Örebro was welcomed but referred to the Nordic Planning Committee to consider its ramifications for their budgeting and pricing policies.

It was also agreed that Institutional Members of IAEDB pay a £50 (\$80) fee per annum from 1992.

### International Development

IAEDB's programme of International Development, concentrating particularly on countries without or with only emerging deaf-blind educational programmes, is being spearheaded by Mike Collins of Perkins School for the Blind in Boston USA. Articles have been placed in international newsletters seeking contacts and information about programmes and a comprehensive data base and mailing list is being established. Recently there have been reports received of growing programmes in Spain, Portugal, Jamaica, Argentina, Brazil, Columbia, Uruguay, The Phillipines and Poland.

Reports have also been received from isolated workers in Thailand, Indonesia, Kenya & Ghana.

In addition, a new National Coalition on Deaf-Blindness has been formed in the USA following the closure of the Regional Centres by the Reagan government in the first half of the 1980's.

With emerging *Glasnost*, IAEDB is enjoying much stronger relations with Eastern Bloc countries and it is anticipated that the siting of the next European Conference in East Germany (see below) will see the increasing growth of awareness, co-operation and a regional structure between them.

### Next European Conference

The next Conference will be held in Potsdam, East Germany, in early August 1993. A Programme Planning Committee will be formed after Örebro '91.

A seminar with international speakers on Usher Syndrome is to be held in Potsdam this November.

### Fifth European Usher Syndrome Study Group Warwick, England August 4 — 6, 1989

The European Usher Syndrome Study Group met in Warwick prior to the IAEDB Meeting. The Study Group which first met at St. Michielsgestel in Holland in 1985 has grown considerably and now encompasses more disciplines. In Warwick 33 people drawn from education, paediatrics, audiology, the caring professions, ophthalmology and psychiatry came together for two days to share and study. This year we were also glad

to welcome three members from Spain and Paddy Rowland back again from the Irish Republic.

Three parents joined the group and widened its interest by their insights gained from learning about Usher Syndrome in their children.

Dr Lea Hyvärinen, an ophthalmologist from Finland with long experience in working with people who have Usher Syndrome emphasised the need for strict communication guidelines when deaf people are tested, particularly when using an interpreter.

The need for an agreed screening programme for deaf children within the school population, to pick up visual impairments was an issue which most European countries raised, particularly Switzerland and England. We hope to have made progress on a procedure in time for the next meeting.

Dr Ann Gardner from Sweden gave an excellent paper in which she reviewed the literature on psychiatry and Usher Syndrome and also some of the coping strategies which those with Usher employ in order to get by in life.

A Mini Conference on Usher Syndrome which was open to a wider British audience was held at the close of EUSSG.

About 90 people came to hear Professor John Marshall speak about progress in gene mapping

which held out a hope, however distant, for people with Usher and for the children who might be born in the 1990's.

The next formal meeting is planned to be held close to the World Conference of IAEDB in Örebro in Sweden in 1991. Next year (1990) in Hanover in the summer there will be a meeting to plan the programme.

Proceedings of the Fifth EUSSG will be available shortly. For copies please write to Mary Guest (EUSSG) c/o Sense, 311 Gray's Inn Road, London WC1X 8PT. Please enclose £5 sterling, a Eurocheque or money order to cover cost of postage and packing — two copies £7.

### Distinguished Service Award

At the World Conference in Poitiers in 1987, the first IAEDB Distinguished Service Award was made to Joan Shields who opened and ran the Pathways Unit at Conover Hall School in England from 1951 to the mid-1980's. The next Award will be made at Örebro in 1991.

Readers are asked to consider suitable nominees and write to me in London giving a short biography of their nominee and the reasons for their nomination.

**Rodney Clark**  
Secretary, IAEDB

## LETTER

Many readers will remember Kurt Vinterhoj from his pioneering work in developing services for deaf-blind children and young people in Denmark. The last issue of 'Deaf-Blind Education' published one of his many articles. Kurt is now in Kenya, and here we publish an extract from a letter sent to Sense.

... Thank you for the teaching materials you posted on 1 June and which reached me on 15 August. It really is important for us in Kenya to receive support from abroad.

The materials are now in the library of the Kenyan Institute of Special Education (KISE). The videos have been shown for other lectures at KISE and to assessment teachers who are having their first information about deaf-blind children. We are planning an awareness programme about Usher Syndrome starting at the schools for the deaf.

The last three months I have been at KISE doing some work in their Information and Documentation Department and lecturing about deaf-blind children. In September I shall go to The Kabernet School for Deaf-Blind Children to run a three month in-service course for all the 22 teachers, later followed by a course for housemothers.

When I have picked up more information about this beautiful country and the work, my colleagues and I would like to write an article about it.

What do you say? Is it a possible topic for our next World Conference in Sweden, 1991, to focus on 'Strategies for Reaching Deaf-Blind Children in Developing Countries'?

I have asked our friends in Sweden if it is possible to put that in the programme.

Thanks again for the instructive, paedagogical and warm and touching videos you have sent us.

With all best wishes,

**Kurt Vinterhoj**  
Nairobi, Kenya

## Deaf-Blind Education in the Western USA

The known deaf-blind in the USA appear in the late nineteenth century when William Wade, later a friend of the famous Helen Keller, estimated that there were 54 deaf-blind persons in the whole country, 16 were children in schools. Perkins School for the Blind and the New York Institution for the Instruction of the Deaf each had three students.

In 1891, it was recommended by the American Association of the Instructors of the Blind that all deaf-blind pupils should be educated in schools for the blind.

Perkins School for the Blind established the first special department for the deaf-blind in 1933.

Then in 1937, the New York Institute for the Education of the Blind opened the second deaf-blind department.

In the far west of the United States the third deaf-blind training programme was started in 1943 at the California School for the Blind (CSB).

Here the deaf-blind students were taught separately in the younger children's cottage. The school enlarged the building in 1949, and when completed Helen Keller came to dedicate the building, and it was named after her.

Miss Inis B. Hall was the first teacher of the deaf-blind at the California School for the Blind. She earned a reputation for teaching the deaf-blind at the Perkins School and helped establish the first deaf-blind department in the country there. She was a trained teacher of the deaf who had learned how to teach speech through the Vibration method called TADOMA.

The first deaf-blind student graduated from CSB in 1949, when there were seven deaf-blind students.

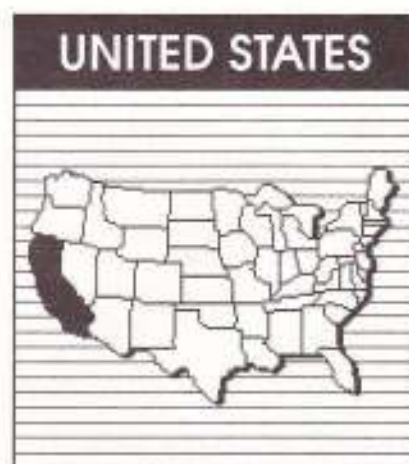
In 1964-65, a rubella epidemic hit the United States. Before this time about 140 deaf-blind were born each year, but the number of deaf-blind children born in the epidemic years rose to 2,000. In 1968, the CSB Deaf-Blind Department doubled in size and doubled again in 1969, due to the epidemic.

In 1969, the Deaf-Blind Institute was established for the parents of deaf-blind children. Parents would come and stay at the school with

their deaf-blind children. It was not only a time for education but a time for sharing among people who had a common bond because of their children.

In 1971, the Deaf-Blind Assessment Centre was established at the California School for the Blind. Deaf-blind children from the Southwestern Region (California, Arizona, Nevada, Hawaii, Guam, American Samoa, the Trust Territories of the Pacific, and the Navajo Nation) came to the School for a short period of time to be assessed. The Assessment Centre closed at the end of the 1982-83 school year, due to loss of Federal funding.

A career preparation programme was developed for deaf-blind teenagers by Charles Zemais and Willie Evans in 1974. Deaf-blind students worked in the School's Infirmary, in the pre-career workshop, and other places on campus, and later off



campus at businesses in the community.

The School moved to Fremont from Berkeley in 1980, and deaf-blind classes are still in operation on the campus.

from a History of the  
California School for the Blind

## The California School for the Blind

Today the California School for the Blind has 110 students, of these 25 are deaf-blind, most are mentally handicapped too. Eighty percent of our visually handicapped students have other handicaps. Our students are both daily attenders and residential. If they live less than four hours travelling time away the students go home at weekends, otherwise only at more extended holidays.

We run three kinds of study courses:

- 1 General or core curriculum studies are held in the local public schools supported by CSB teachers. A diploma is awarded on successful completion of study.

- 2 Applied Academics Programme — training in academic subjects is given but a major emphasis is placed on the acquisition of independent living skills and vocational training. These young adults stay in a group home and acquire domestic skills in their supported apartments.

- 3 Functional Skills. Some students who are most severely handicapped, these include most of our deaf-blind, need special intensive instruction. Subjects covered are daily living skills, age appropriate skills in all environments, language and communication, socialisation and vocational training.

Language instruction for deaf-blind students is based on total communication — including American Sign Language (ASL), finger-spelling manually coded english, oral/aural training and therapy, reading and writing using braille and large print. Some augmentation devices are also used in communication, both aural and visual.

Older deaf-blind students are involved in work on and off the campus. As jobs are available students may be found learning, for example, in restaurants, bowling alleys, convalescent hospitals, offices, such work skills as they are able to. In their last three years at CSB students are helped to plan for the future by developing an Individualized Transition Plan (ITP). Family members, school staff, adult services agencies and the student meet to discuss job possibilities, living arrangements and further training.

Parents and families are considered to be an integral part of the educational experience and are involved with many others in, for example, the annual review which each student has — to consider his progress, present status, and the setting of suitable achievement goals for the coming year. A parents and friends club meets monthly and family education seminars are held each year in the north and south of the State.

Peggy Campbell  
Assistant Superintendent CSB

## OCEANIA REGION

Early in 1989 a National Conference for Educators of the multi-sensorily disabled was held at the Royal Children's Hospital and hosted by the Deaf-Blind Care Association of Victoria. Over 140 delegates comprising parents, professionals and clients from a large number of states attended the conference and enjoyed a most stimulating programme.

Dr Jan van Dijk of St Michielsgestel of the Netherlands was the main speaker. As always he delighted his audience with his skillful lecturing presentation and obvious clinical and research knowledge. Dr van Dijk covered topics including the importance of attachment behaviour in the pre-language stages, the role of eupraxia as a predictor of later speech and language skills, the danger of 'learned helplessness' and growing self awareness in dual sensorily disabled children. In the closing session, Dr van Dijk and Ruth Carlin of the Deaf-Blind Care Association reported on a 12 year follow up study that they are currently undertaking on a sample of Rubella children from the Australian State of Victoria.

Heather Hewitt spoke on the importance of an emerging

concept of self in educational programming and placement, and suggested some strategies for enhancing a positive reality based self in disabled children. Mr Ric Thompson from the Department of Sport and Recreation conducted a session on leisure and life styles for people with disabilities. A session which generated considerable interest among delegates was one conducted by a parent giving a parent's perspective on services, and supported by two young deaf-blind persons sharing some of their experiences. Small group discussions on early intervention strategies, employment, accommodation and respite care, and a parent workshop allowed for much useful interchange between delegates. An educational panel which outlined services and professional training courses available in Victoria armed everyone with useful comparative information to take back to their respective states.

The Deaf-Blind Care Association is to be congratulated on hosting a very successful National Conference entitled, 'Education for Living. A Life Long Approach to People with a Multi-sensorily Disability'.

**Heather Hewitt**  
Chairman Oceania Region, IAEDB

## New Zealand

At Homai College in Auckland there is a purpose-built unit which at present caters for seven deaf-blind children on a full-time basis and also supports five others who are pre-school age or in facilities for intellectually handicapped children.

Three of the seven students are termly boarders, three are weekly boarders and one is a day student. Ages range from six years to 15 years. Three children are rubella handicapped with severe to profound hearing losses, but some have useful residual vision; two have retinopathy of prematurity, one being totally blind with a little residual hearing and the other with very little useful sight or hearing.

The remaining two children have Charge Association; both have useful amounts of residual vision and hearing, but some degree of intellectual handicaps. Programmes for these children are carried out with a 1:1.4 staff/pupil ratio and are individually tailored to meet each child's specific needs. Input for IEPs (Individual

Education Programmes) is requested from all those caring for the child, including parents, residential staff and medical and educational personnel.

Programme emphasis is on the attainment of communication and independent living skills.

The Unit also offers short or long term assessments for children for whom programme and placement is uncertain and additionally periods of parent training and in-service training for mainstream teachers and other involved professionals.

As yet there is no specific post-school provision for deaf-blind students in New Zealand, but it is to be hoped that the holding of the first ever deaf-blind conference in Auckland in 1987 and the organisation of deaf-blind support groups throughout the country will have increased awareness to the extent that this very pressing need will soon be met.

**Sheila Hale, RNZFB**  
Homai College for the Blind

## SOUTH AFRICA



Deaf-blind education was re-introduced to the black South Africans in 1987, more than forty years after it was ceased at Kuthwanong school for the deaf. The school is situated in the Orange Free State province at a homeland called Qwaqwa. It caters for all black deaf-blind children throughout South Africa. The children stay in a hostel for five months and are then escorted home for a month vacation with their parents.

The school programme includes individual training in the following areas:

- Language development
- Auditory training
- Visual training
- Adapted orientation and mobility training
- Self-help training
- Gross motor and fine motor activities

The children get daily medical check-ups from our two nurses in a well equipped mini-clinic which works in conjunction with the local hospital. After school the hostel staff continue with the afternoon activities which include swimming, free play and frequent walks to neighbouring villages and stores.

The teachers are usually trained in the education of either the deaf or the blind. Having been trained at Perkins in deaf-blind education, I now conduct in-service training for teachers who work with the deaf-blind children.

It is difficult to get motivation in this programme as we work in isolation. Our methods are mostly from book to practice. We hope to get a chance of sharing our success and learning from others in a conference or workshop situation.

**Samuel S Boshelo**  
Head of Dept for Blind & Deaf-Blind  
Thiboioha School

## SCOTLAND

Having just attended the European Conference in Warwick on 'Sensory Impairment with Multi-handicap' the world seems a much smaller place. It also means that writing this piece for Deaf-Blind Education is a less daunting and more personal task: more like communicating with good friends throughout the world.

One of the recurring issues during the Conference was that of staff training. I want to tell you a little about something we are doing in Scotland about this important topic. Before I tell you what we are doing, let me tell you why. Many of you may know Sister Ailish Massey who has done so much to develop the education of deaf-blind children in Scotland. Sister, after many years of total dedication to this work, has decided that her life of service as a Sister of Charity must take a different direction and she has left her post as headteacher of Carnbooth School for deaf-blind children, which is in Glasgow, Scotland. Sister Ailish had built up staff training materials over the years. The Scottish Education Department and, of course, many interested professionals were anxious to ensure that such an important resource would not be lost with her departure, so she was asked to take part in a project, funded by the Scottish Education Department, to develop these as a learning package which could be used after she left.

It is no easy matter to transform what has been delivered in person, into a format which is still as comprehensive, but must be conveyed instead by the printed work or video image. Financial and other support is essential. This was made available through the efforts of Alastair Milne. As Inspector for Special Needs, Alastair has fostered and ensured the success of so many developments in the education of children and young people with special needs, in particular visual impairment and deaf-blindness in Scotland.

The training materials are aimed primarily at all new staff at Carnbooth School, though they may prove useful for staff at other schools or institutions. They are designed for independent but supported study. There are eight modules with an average of five topics in each, the modules deal with topics at a progressively deeper level as the staff member's experience with the children

## Reports from Europe



increases. Each topic has specially written material, plus enclosed essential reading or references for further reading. Some topics are illustrated by videos which are being produced by Glasgow Educational Audio-visual Services. Required activities enable the staff member to try out what they have learnt. The initial trials of the material at Carnbooth will indicate how successful the transition has been from the conventional mode of staff training to the self-instructional mode.

Sister Ailish is being supported in the writing of the materials by Elizabeth Bryson, Senior Educational Psychologist who helped in planning staff training at Carnbooth; Morag Turner, Margaret Lee and myself from Moray House College, all of whom have contributed to staff training at Carnbooth. The production of

the package is being coordinated by Marion Blythman, Head of Professional & Curriculum Support Studies at Moray House College.

Any enquiries about this staff training initiative should be addressed to Marion Blythman at this address: Moray House College, Holyrood Road, Edinburgh EH8 9AQ, Scotland.

Marianna Buultjens

## BAVARIA (West Germany)

As many of our deaf-blind pupils (now numbering 35) are finishing school programmes in the next few years, we started to develop a follow-up institution in Würzburg.

We have to cope with a lot of problems: a diminishing number of staff members in charge, the deaf-blind adults differing strongly in social, cognitive and practical abilities, some of them developing behaviour problems which might be described in psychiatric terms.

Naturally our school programmes deal a lot with the training of self-independent, self-occupying behaviours and social abilities. We relate to the developmental approach of St Michielsgestel and try to integrate other methods, for example body-centred methods.

By home-based early intervention programmes in Bavaria we now serve eight children from two to five years. There is no rubella child among them, most of them were born prematurely.

Hanne Pittroff  
Department for the Deaf-Blind  
Goethestrasse 2  
8700 Würzburg  
Federal Republic of Germany

## BELGIUM

Services for the deaf-blind are still developing.

At the present we have a group home for adult deaf-blind lower functioning adults, and a home guidance project for children as well as for adults.

Volunteers work has been developed during the last year.

There is close cooperation between the Spermalle Institute, who have a department for deaf-blind children and the association of parents called 'Anna Temmerman vereniging'. Any contacts for more information should be directed to:

Spermalle-Institute  
Snaggaartstr. 9  
8000 Brugge  
Belgium

Marc Semuys



## SWITZERLAND

Switzerland has a federal political system which affects all aspects of public life, including those related to handicapped persons. Consequently the education and rehabilitation of blind, visually impaired and deaf-blind persons is not uniform throughout Switzerland.

Moreover, four languages are spoken in Switzerland — German, French, Italian and Romansch — and the characteristics and mentality of each linguistic region are different.

### Structures and Service for Blind, Visually Impaired and Deaf-Blind Persons

The Swiss National Association for Blind and Visually Impaired Persons (SZB) is the umbrella organisation which covers all the institutions and services in Switzerland. The Swiss National Association for Blind and Visually Impaired Persons provides its own services which are:

- Central Services
- Deaf-Blind Counselling
- Counselling for Optical Aids
- Staff Training and Further Education
- Technical aids

for deaf-blind children and adults. The following relates to services for deaf-blind children and adults.

### Structures and Services for Congenitally Deaf-Blind Children, Youths and Adults

Congenitally deaf-blind children from four to 18 years are educated in a specialised school in Zurich named 'Tanne'. The 'Tanne' school has 18 places. Each child benefits from an individualized assessment and evaluation programme. Beside the educational programme there are other facilities like articulation-training, physiotherapy, occupational therapy, painting and horse riding.

The continuation of the 'Tanne School' system is the 'Lärche', which provides living and working facilities for congenitally deaf-blind youths and adults from the age of 18. It has 13 places. Beside the sheltered workshop activities, there are provided additional facilities like physiotherapy, gymnastic, painting and horse riding. Within the two institutions 'Tanne' and 'Lärche' the 30 residents are assisted round the clock by about 60 employees.

The costs per day and per child at the school 'Tanne' are £179. (Staff members per child: 1.89)

The costs per day and per person at the home 'Lärche' are £109. (Staff members per person: 1.67)

These amounts are largely financed by the Federal Office of Social Security.

In 1988 building started on a new home for congenitally deaf-blind children, youth and adults. The centre is planned to cater for 46 residents. The cost of the new complex will be about 21 million Swiss francs which makes about £8.2 million. The Federal Office for Social Security and the Canton of Zurich have given major financial support to the project. Another £2 million will be provided by private donations. The home will be inaugurated in 1990.

### Definition, Statistics and Structures for Deaf-Blind Adults in Switzerland

There are approximately 300 deaf-blind persons in Switzerland. About 10 to 15% are totally deaf-blind. The others have some vision or/and hearing. About 50 persons are deaf-blind from birth (before speech development), 250 persons became deaf-blind in later life. Over 50% of deaf-blind people are elderly, 2/3 women and 1/3 men.

A person is considered as deaf-blind if she or he has such severely impaired vision and hearing that

the loss of one sense cannot be compensated by the other sense. In exceptional cases, a person may be considered as deaf-blind if she or he is severely handicapped in mobility and communication skills. For these 250 deaf-blind persons who became deaf-blind in later life, the following services are provided:

### Specialised counselling

- 10 regional areas with one social worker per area. These professionals followed specialised training courses within the field of deaf-blindness and are all trained as rehabilitation teachers.
- 3 occupational therapists
- 1 trainer for orientation and mobility as well as low vision
- 1 director of the department
- 1 secretary

### Specialised residential centres

For deaf-blind persons who have no capability to live independently there are five regional specialised residential centres with rehabilitation facilities.

**Erika Goergen**  
Director of Staff Training  
Swiss National Association for Blind  
and Visually Impaired Persons  
Rigistrasse 10  
6410 Goldau  
Switzerland

## ITALY

### Associazione Lega del Filo d'Oro

The 'Lega del Filo d'Oro' is a private association legally recognised by the Italian State with a Decree of the President (May 19, 1967).

The aims of the association are the assistance, rehabilitation, and, whenever possible, the mainstreaming of deaf-blind and multi-handicapped individuals. Within this context, research activity as well as teacher and parent training also takes place.

The association finds its realization in the 'Nostra Casa' Institute. The Institute involves medical, psychological and rehabilitation intervention. It is the only one in Italy to concentrate its activities with deaf-blind and multi-handicapped individuals.

The Nostra Casa Institute, founded in 1967, has also been recognised (by the Ministry of Education in 1976) as a Research

Centre. At present, the institute houses 23 pre-school children and school children (school department), 11 adolescents (post-school department) and 11 adults (Kaiorama Community).

Treatment of pre-school and school children is aimed at the following:

- acquisition of cognitive skills;
- acquisition of gross and fine motor skills
- learning of non-verbal communication systems;
- elimination of behavioural problems such as self-stimulation and self injury;
- development of adaptive social skills (e.g. toileting, grooming skills).

The adolescents are provided with activities aimed at generalizing abilities already acquired, and developing occupation and home skills. Those are planned in view of the subjects being returned to their

families or sent to sheltered workshops.

The adults live and work in three apartments located in a residential area of the city of Osimo. The objectives pursued with these individuals are:

- independent living skills;
- work/occupational skills;
- emotional development.

The work conducted with all of the subjects (children, adolescents and adults) is supervised by a psycho-educational/medical team.

Parents (who are from all areas of the country) are periodically invited to follow the intervention strategies implemented and spend time with their children. For this purpose, the institute uses three apartments. Parents are also exposed (twice a year) to courses dealing with intervention and interaction issues.

Teachers receive a two-year course before starting their work with the deaf-blind population. Their preparation is regularly updated through short courses and workshops. Moreover, national and international contacts are used to continue in the exchange of experiences and in the acquisition of new intervention and research technology.

Educational material is regularly published to further the preparation of teachers and parents on basic issues of special education with deaf-blind and multiply impaired individuals.

The research activity, co-ordinated by a Scientific Committee, is performed in the medical, psycho-educational, and social/organizational areas. Such activity is carried out with National and International Centres (e.g. University of Ancona and Salesi Children's Hospital, Italy; University of Nijmegen and University of Leiden, Holland; State University of New York, USA). Some of the research issues to date explored are:

- diagnostic methods for early detection of sensory and behavioural disorders;
- teaching techniques suitable for multiply impaired children;
- non-verbal communication systems;
- strategies for integrating severely and multiply impaired individuals in school, work and community.

## SPAIN

Since its foundation 50 years ago, the Spanish National Organisation of the Blind (ONCE) has always had a unit devoted to the delivery of services to deaf-blind children.

Two years ago we started a national programme and the Deaf-Blind Department was settled. Its function is the co-ordination of services and counselling to professionals, to families and to the deaf-blind themselves.

We began by a screening process and up to now we have identified 500 deaf-blind people in Spain.

Through our Department, new services in the field of education and rehabilitation are being opened.

As regards education, we may mention the following:

- Teacher training. On this aspect we have counted on the cooperation of Perkins School for the Blind, Mass., USA.
- Assessment and counselling at a national level. We have already registered 54 children in the Deaf-Blind Department (34 rubella cases).
- Opening of new units for deaf-blind children in ONCE's Educational Resource Centre 'Antonio Vicente Mosquete' in Madrid. Next September four units will begin working and they will take care of 16 children from six to 10 years old.
- Assessment and counselling of early stimulation programmes all over the country.

The Department prepares, translates and disseminates information, as for example, the 'International Newsletter for the Deaf-Blind'.

Our programme is quite new but it has grown a lot in a short period of time. We hope and expect that in the not too distant future we may offer new and expanded services for the deaf-blind.

For further information enquire to:

ONCE Spanish National Organisation of the Blind  
Jose Ortega y Gasset 18  
28005 Madrid  
Spain

## PORTUGAL

Casa Pia de Lisboa has opened the first school for deaf-blind children in Portugal. The work has been started with two children in Instituto Jacob Rodrigues Pereira, but soon a specific building will be under construction in Lisbon to provide an adequate school for deaf-blind children.

Two Portuguese teachers have been given a special training in deaf-blind children's education, under Dr Jan van Dijk's supervision at the Instituut voor Doven in Sint Michielsgestel. Dr Van Dijk and his technical team thoroughly diagnosed our two children last March during their stay in Holland together with their teachers.

The costs related to the personnel training will be charged to the German foundation 'Misereor'.

## NORWAY

In Norway great changes are taking place in the organisation of the care for the handicapped. This also has consequences for deaf-blind people.

Health care for the mentally retarded is being greatly decentralised. This group of people is living today in big central institutions, where the country has the financial responsibility. From 1 January 1991 it has been decided that all mentally retarded people will be moved back to their home communities. This will also happen to the group of congenitally deaf-blind people who live in these institutions as well. Naturally it is impossible for the small local communities to plan and run a good social-educational programme for one single deaf-blind person. This requires both professional and economic resources of a kind that no single community can provide. The National Central Team for the Deaf-Blind therefore is working to establish regional services for this group. We see the necessity of cooperation across commune and county borders. Our suggestion is that there be built housing units where four to five congenitally deaf-blind persons can live together. The local authorities who will be economically responsible, can buy places for their deaf-blind clients in these housing-units. The

## FINLAND

*We welcome this letter from the Chairman of the Finnish Deaf-Blind Association, Pirkko Virtunen.*

### Greetings.

The Finnish Association of the Deaf-Blind has again selected me as Chairman of the Association. In the course of my previous term of office I had a very interesting time; I experienced and felt things I had never dreamed of. I really love this Association and its work. Usher Syndrome decreases my ability to see and hear but the brains and heart are functioning excellently and, I hope, my sense too.

The Finnish Board of Association is responsible for our administration. In this role it is the employer of about 40 people. We have 11 regional secretaries in Finland and the same number of people are working in the Rehabilitation Centre for Deaf-Blind Children in Jyväskylä, a town in central Finland. We have in the Tampere Service House for the deaf-blind 12 staff and in the main office in Helsinki another seven people.

The Board of the Association has nine members, six are deaf-blind. The secretary is our executive director Kaija Salekari.

The main activity of our association is rehabilitation. In this work we can join both medical and rehabilitation expertise to the experiences of deaf-blind people themselves. We can use this knowledge to advantage in our course programmes. Our other main activity is to promote the interests of deaf-blind people.

Nowadays the Finnish government and communal public services are searching for efficiency by splitting services into smaller professional and independent groups. I believe that this is not good for deaf-blind people because they need very competent services which always take into consideration the changing situations of deaf-blind people generally and the changes in each individual's condition. Deaf-blind people need total care rather than treatment from split public services. The crucial responsibility of the Association is to promote total care for deaf-blind people.

I, and many others are happy that the Finnish Association was founded about 20 years ago — since then the members have had the chance to influence decisions made concerning themselves.

One very acute problem

concerning the Association is lack of interpreter services. Deaf-blind people cannot contact interpreters easily, they don't know enough about these services — and there are too few professional interpreters in Finland. A big problem is that the interpreters don't know enough about deaf-blindness. Some don't know that the range of communication skills and social ability are very variable among deaf-blind people.

One important mission we have is to introduce single people who are deaf-blind to one another, although these people and their disabilities may differ they need each other to share their skills — which helps them to get along. They may need some kind of good model of how to live and to care for themselves. Our Association, its officers and specialists and deaf-blind people together can create this model.

## SWEDEN

### Central Service of Translation into Braille for the Deaf-Blind

In 1987 the Swedish Institute for the Handicapped started a unique trial to serve deaf-blind persons with braille transcriptions. 140 out of a total of 1250 deaf-blind persons read braille in Sweden. The service meets the personal needs of the deaf-blind person who chooses individually what he/she wants transcribed into braille; e.g. personal letters, poems, addresses, family news, newspaper articles, even videograms in sign language. To make this possible the service also has to cover and supply information of actual topics and reviews.

A 'customer card' is set up in co-operation with each reader indicating personal interests and how the braille should be produced, e.g. double or single space between the lines. One aim of the project is to stimulate the interest and ability to read braille, another is to map the needs of such a service and suggest how it should be efficiently organised. Up till now 85 deaf-blind persons have taken advantage of the service, about 60 persons do it regularly. The project is financed through the Ministry for Social Affairs.

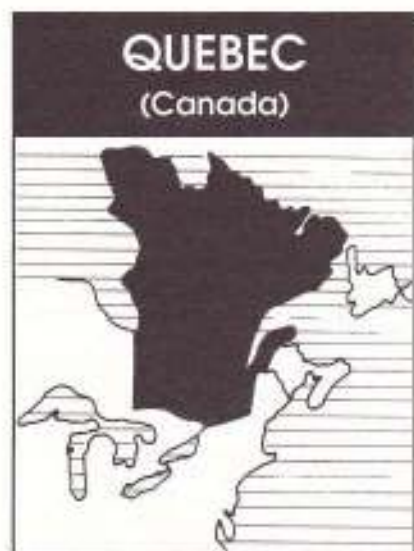
B. Furugren  
Bromma, Sweden

Directorate of Public Health has recommended that the Ministry of Health and Social Affairs shall give financial support to each deaf-blind person's housing need. At the time being it has not been decided who will be responsible for this financially. Several communities in Norway are now in the middle of planning these housing units while waiting with increasing impatience for governmental decisions in these matters. Such housing units and lifelong care is planned both for the deaf-blind who are today schemes for living in the institutions for the mentally retarded, and for those who live at home with their parents or in dormitories. This last group will also need permanent living and housing as they grow older. In Norway the tendency is that deaf-blind children live at home with the parents until they are in the middle of their teens. Our statistics show that 80% of all congenitally deaf-blind persons under the age of 16 live at home with their parents.

The organisation of the special schools in Norway is also undergoing great changes; this restructuring project is called 'Project - S'. At the outset the intent was to close down many of the existing special schools and to reorganise some schools into regional resource-centres. Naturally these plans have created a lot of debate. At this point in the discussion it seems that the special schools for the deaf will continue as before, but so far everything is unsettled. The needs of congenitally deaf-blind people are to be considered and put forward by a special ad hoc group within 'Project - S'.

Just a little word about something that has finally been arranged. For a long time work has been going on to establish a system of free guides for deaf-blind people on journeys within the country. This has finally been arranged. Now deaf-blind people in Norway are entitled both to travel on reduced fares and to bring a guide on all trips. The exception is when travelling by airplane, here the guide still has to pay. In spite of this it's a step in the right direction.

Live Fuglesang  
The National Central Team for the  
Deaf-Blind in Norway



In Québec residential services for deaf-blind adults have existed since 1900. We started rehabilitation services twelve years ago with three deaf-blind children. Since that time 345 deaf-blind people or people with vision and hearing impairment are known from information supplied by the public services (all ages).

The Institute Raymond Dewar (a rehabilitation centre for hearing impairment in Montreal) offers services to 120 of these people. A multi-disciplinary team works in the following areas:

- family counselling
- early stimulation (at the Centre and in the community)
- audiology
- physiotherapy
- speech and lip reading therapies
- tactile and visual sign language
- psychology
- technology and electronic aids

These services are offered in collaboration with the agencies for the blind. The team covers the whole province and we hope to open this year a new centre in Québec city. There is a great demand for counselling services for people who have Usher Syndrome so we have a team who are organising a counselling centre at the present time.

Since 1987 the provincial Government has accepted responsibility for its deaf-blind population and we hope that this will contribute to an amelioration of their condition of life.

Gilles Lefebvre  
Programme Surdi-Cecile  
Institut Raymond Dewar  
3600 Berri  
Montreal H2L 4G9, Canada



## The Deaf-Blind School Population in Japan

Regarding the population of deaf-blind children in Japan, the most complete survey so far has just been conducted by the National Research Institute for Special Education. The survey was based on the questionnaire sent out to 917 special schools of the country. 764 schools (83.1%) replied.

It was found that out of 764 schools, 144 (18.8%) had deaf-blind children in their enrollment. These 144 schools include all types of special schools as shown in the following chart:

Types of school	Number of schools
School for the blind	22
School for the deaf	23
School for the mentally retarded	52
School for the physically handicapped	26
School for the health impaired	19
Other	2
Total	144

The number of deaf-blind children enrolled in these schools were altogether 257 (usable replies: 129 schools).

50 of these children were deaf-blind with no additional handicaps. The sight of 12 of these children was 0.1 or less and their hearing was 90db or over.

The remaining 207 had other handicap(s) in addition to deaf-blindness. Of the 207, 102 had sight 0.1 or less, their hearing 90db or over.

Sadako Inamura

## Incidence of Congenital Rubella in Japan (1965 - 1985):

A nationwide survey of the number of deaf children with a history of maternal rubella attending special schools for the deaf in Japan.

Nationwide Rubella epidemics occurred in Japan in 1965-9 and in 1975-7. This paper reports a nationwide survey of deaf school children attending schools for the deaf in Japan, April 1984 - March 1985. Because a policy of integrating deaf children into ordinary schools has recently been adopted the authors believe that the number of cases of congenital rubella syndrome might be much greater than the 365 revealed in the survey (and than the 88 previously reported after investigations in 1970 and 1978 after each epidemic which revealed 49 and 39 cases respectively).

9,570 deaf school children attended 106 schools for the deaf in Japan (nationally, but excluding the Ryukyu Islands) in 1984/5, 365/8739 deaf children were identified with a history of maternal rubella (not serologically confirmed), 295 had deafness alone (80.8%), 16 (4.4%) also had cataract, 40 (11%) congenital heart disease and 14 (3.8%) cataract and congenital heart disease.

Because of the number of deaf children in ordinary schools, the authors calculate that the theoretical number of deaf school children with CRS (congenital rubella syndrome) should be 824. They conclude that a surveillance system for CRS should be established. (Rubella immunisation has only recently been introduced in Japan).

K. Ueda, K. Tokugawa,  
Y. Nishida, M. Kimura

American Journal of Epidemiology  
vol 124, no 5 807-815

(Summary — Pat Tookey, UK)



I work in the deaf-blind department of the Helen Keller Institute in Córdoba in Argentina. This is a large school with over 300 children offering a range of special educational programmes covering early intervention, schooling and pre-vocational training. All children are served by the early intervention programme — blind, deaf-blind and multiply-handicapped children — and at the age of three are admitted to the most appropriate educational programme. The Institute also

serves children with emotional problems. Approximately 50% of the children are multi-handicapped and are served wholly within the Institute, while the other 50% are mainstreamed and supported by staff from the Institute. In our department, there are currently seven deaf-blind children between the ages of four and 17, supported by four teachers. The causes of the children's disabilities are:

- 5 Rubella
- 1 Prematurity
- 1 Unknown.

All the children are relatively low-functioning and their programmes include:

- Daily living skills
- Sensory-perceptive
- Gross and fine motor skills
- Orientation and mobility
- Language development
- Pre-vocational skills

I was trained at Perkins School for the Blind in 1983-84, also taking courses at Boston College. My colleagues include Griselda Calleagori and Danuta Wujnacki. Danuta is currently at Perkins on an Orientation and Mobility course for students with low vision and multi-handicap including deaf-blindness. In addition to the seven

children in our unit, there are two higher-functioning children mainstreamed in the school for the deaf, supported by one of the teachers from the Helen Keller Institute. Córdoba is in the centre of Argentina and we are very concerned about the children we do not know and also those we do know who it is difficult for us to reach. There are a number of families in the north of Argentina for instance, who have visited the Institute and for whose children we have developed programmes in their local schools for deaf children or blind children. We are currently involved with the Latin American region of the World Blind Union whose General Assembly meets in two weeks time to consider the funding of a project to discover deaf-blind children and adults within Latin America. Provision for young adults is a major concern because there are currently no services to follow our pre-vocational training programme. One major development in our work will be a new post-graduate course in the teaching of multi-handicapped children which will start at our University in March 1990.

Graciela Ferioli

## FOURTH HELEN KELLER WORLD CONFERENCE, STOCKHOLM

# Deaf-Blind World Conference

The Fourth Helen Keller World Conference on Deaf-Blindness was held in Stockholm, Sweden, from 28 September to 3 October 1989. Extracts from a paper presented at this Conference are published overleaf, and future issues of 'Deaf-Blind Education' will publish more.

Below, Graham Hicks, one of the deaf-blind delegates from the UK, summarises the Conference.

This conference has been an overwhelming success with over 200 delegates taking part, approximately 60 of them deaf-blind, and gathered from over 30 countries around the world. Here we have had papers on many deaf-blind issues, both about the situation of deaf-blind people in their respective countries and about specific developments in education, employment, interpreter services, modern technological advances, public awareness etc.

Participating in this Conference, which at the time of writing is still in progress, leaves one with a feeling of having travelled many thousands of miles. At one moment, we are in the United States where services are relatively well-developed; the next, we are in the Middle East or Russia, where not only are services very different, but the culture in which they exist has a completely different nature. But, wherever we are, the basic picture is the same. Deaf-blind people are

making progress. They are striving to establish themselves in the environment within which they exist and with the resources which are available to them. We have seen and heard from many people, both personal accounts and those who speak about deaf-blindness in their nations as a whole. It is impossible to judge one paper as being more interesting than others, for all have been of high quality, and probably of equal importance in their own camp.

## Deaf-Blind People and People with Normal Vision and Hearing

Alexander Suvorov is deaf-blind and was educated at the Zagorsk School near Moscow, USSR. In this extract from a speech he delivered to the World Conference for Deaf-Blind People in Stockholm, Sweden, he puts forward some challenging ideas about the education of deaf-blind children.

The question concerning the attitude of the deaf-blind towards both people with normal vision and hearing and absolute strangers is a cardinal one, and for the deaf-blind it is verily a question of life and death. It is not so much a question of this or that means of communication as of this or that orientation of the deaf-blind personality. The most important thing here is the stand he himself takes — that of dependence or of co-operation. On this depends his mode of life — the life of a disabled person, who consciously or unconsciously isolates himself from everybody, or the personality of full life, which makes it possible for the deaf-blind to take part in the life of society and humanity in general and makes him, like any other normal person, a full-fledged member of different collectives and groups.

As long as children deal only with adults or with children, who are also deaf-blind they do not realise their own disability and therefore they do not aim to overcome it. In this way in a special institution there exists conditions for the child to consider his blindness and deafness to be a normal state.

But this is an illusion, and when it collides with the reality of everyday life the illusion of the 'normality' of deafness and blindness is dispelled and the consequences can be serious.

For example a myth may emerge of the existence of two mutually antagonistic worlds: that of the deaf-blind and that of sighted hearing people. Belief in this may lead a child to isolate itself from the 'enemies' who can see and hear — except perhaps for two or three special people who are regarded as friends. The deaf-blind person may become spiritually deaf-blind too.

We believe that this nightmare of 'spiritual' deaf-blindness can be avoided only by integrating deaf-blind children into the only world they can live in — the sighted hearing world, as early as possible.

They can learn the art of living only through communication with children with sight and hearing and as they are also children the deaf-

blind child will, naturally, compare himself with them and, as they can see and speak, he will inevitably turn on his disability all the time and will be forced to realise it. Of course, here serious work with children, who can see and hear (or to put it more broadly — with children, who may be blind, but with normal hearing) is called for. Their attitude to deaf-blind children should be built up by their mentors.

And then the disabled child, having become aware of his invalid limitation, will want to overcome it and thus become our most loyal ally and associate in the difficult task of surmounting it. In his communication with children with normal hearing he will willy-nilly have to use the national verbal language, in its oral and written form. With time he will gain the incentive to master the greatest number of means of communication possible. When he grows up he must be able to communicate with his neighbours, his colleagues and passers-by. For sure, this is not easy matter, and everything is, of course, highly individual, yet we expect precisely these aforementioned results from joint pedagogics and joint education of deaf-blind children and those with normal hearing.

The theory and practice of joint pedagogics is only just beginning in the USSR. The first man to work in this field and organise it was the former director of the Zagorsk boarding school for deaf-blind children, A V Apraushev. He invited children from the neighbouring school to visit the children's home, but at that time the attempt to create some sort of communication between these two groups of children failed. In 1980 a construction and pedagogical enterprise 'Rainbow' began to function. Students and children from senior grades work here. Their main assistance to the children's home was connected with house-keeping and they drew the inmates of the children's home into these activities. The 'Rainbow' organised hikes and festivals for the children and in a later day its employees began to teach children to play games and to use computers.

Today scientific workers of the Research Institute of General and Pedagogical Psychology of the USSR Academy of Pedagogical Sciences work on the organisation of joint pedagogics. This work is conducted under the guidance of the Candidates of Sciences (Psychology), Assistant Professor of the Moscow University, L F Obukhova. The organisers and co-ordinators of the work are A V Suvorov and L D Shavelson. We have already managed to take our children to a pioneer camp of the usual kind called 'Salute', which is located in the Leningrad Region. In 1988 four inmates of the children's home lived there (two of them were attached to one Young Pioneer detachment). In August 1989 we already brought eight children and they formed a special detachment. In spite of this isolation of an organisational order, the contacts of our children with those with vision and hearing were active enough. The special detachment even contributed to the creation of a free and easy atmosphere and of general goodwill.

It is two years now that the district headquarters of the House of Young Pioneers of the Babushinsky Region of Moscow is working in the children's home. On the initiative of the leader of the headquarters, M N Osinovsky, the Zagorsk Children's Home has become the concern of the most active pioneers. A special pioneer detachment 'Contact', which includes children of different ages, has been organised at the House of Pioneers. The children know the finger spelling alphabet and learn the Lorme code modified for the Russian language by N N and Y D Krylatov (both husband and wife are employees of our Institute; N N Krylatov is deaf-blind). Besides taking part in joint festivals and hikes, our pioneer detachment organises joint excursions.

Joint pedagogics envisages the inclusion of disabled children into the world of healthy people. At present disabled adults find their way into it on their own. With me joint pedagogical activities is the main opportunity to participate in the life of the great world.

# The Osimo Conferences

The proceedings of the last Osimo Conference which was held in November 1988 are available. Please apply to:

The Secretariat  
European Conference  
Proceedings 1988  
Lega del Filo d'Oro  
Via Montecerno 1  
60027 Osimo (AN)  
Italy

The price is 20,000 Lire including postage.

## European Conference on staff Development in Services to Deaf-Blind People 27 — 31 May 1990. First Invitation

This working conference will consider important aspects of training and supporting staff in their work with deaf-blind children and young adults. It will be of interest to all those involved in providing or organising training in this field, whether in schools, adult centres, associations, colleges or universities.

### Background

The previous conference was held in Osimo in 1988. On this occasion, participants from nine European countries explored many aspects of the philosophy and structure of staff development programmes and shared information and ideas regarding their format and content. Several initiatives grew out of this conference: the establishment of working parties for the joint production of training materials, an international seminar in Oslo in May 1989 and a large number of individual staff exchanges throughout Europe. In addition, there was a strong demand for a follow-up conference. The Lega del Filo d'Oro kindly offered to host this second conference.

The 1988 Conference demonstrated the diversity of approaches that are followed in Staff Development programmes throughout Europe. In the 1990 Conference we will examine some of the factors that have influenced how these approaches have developed, share information about the current state of European co-operation and explore possibilities of future joint progress.

### Programme

The Conference will begin at 10am on Sunday 27 May, 1990 and will close at 12 noon on Thursday 31 May. The following topics will be explored through plenary sessions and group discussion:

### 1 Factors influencing Staff Development

The ideas that we have about child development affect the way that we train our staff. In turn, the methods that we use for training our staff will affect their style of work with deaf-blind children. We shall examine the way that different philosophical backgrounds can influence the way we structure our Staff Development Programmes.

A number of other factors can affect how staff development programmes are planned. Speakers from different countries will be invited to identify the influence of factors such as:

- the functional level of the deaf-blind persons;
- geographical location of the centre and the support systems that are available;
- access to research literature and supervision.

### 2 European Co-operation

An evaluation of the progress achieved so far in the discussion on joint training materials, in exchange programmes and other meetings. Discussion of possible future areas of co-operation.

### 3 Exchange of Information, Ideas and Materials

Time will be allocated for participants to demonstrate some of the materials and share practical ideas in small working groups.

### Cost

The registration fee will be 500,000 lire. This will cover hotel accommodation for the nights of 26, 27, 28, 29 and 30 May, plus meals and all conference costs. Arrangements can be made, at extra charge, for participants to prolong their stay.

### Registration

Preliminary registration should be made no later than 20 December, 1989. A programme and further information will be sent to applicants in January 1990.

The maximum number of participants is 36. The organisers are keen to encourage as wide a representation as possible. It may therefore be necessary to limit the number of applicants from each country, so early application is advisable.

For all further information, please contact the Secretariat, European Conference on Staff Development, Lega del Filo d'Oro, Via Montecerno 1, 60027 Osimo (AN), Italy.

## Sint Michielsgestel

The house style and telephone number of the Instituut voor Doven in Sint-Michielsgestel, the Netherlands, have changed

As from now the Instituut voor Doven in Sint-Michielsgestel and the departments Eikenheuvel in Vught and Mariella/De Vingerd in Vught can be reached via one central number:  
(04105) 8111.

When calling from abroad, first dial the international access number, followed by:

31 4105 8111.

With the new telephone installation in use it is now also possible to dial the phone numbers in the institute directly. The number for direct dialling is:  
04105 8

For example: the telephone number of the information service in the Instituut is:  
358

For direct dialling you choose:  
04105 8358.

## Australian and New Zealand Association of Educators of the Visually Handicapped (ANZAEVH) Conference 1990

Date: 7 - 12 January 1990

Venue: Akoranga Campus on Auckland's North Shore

Theme: 'Te Ara Kotahitanga' (Planning and Working Together)

All enquires to:

Mrs Jennie Hill  
Programme Co-ordinator  
Homai College, Private Bag  
Manurewa  
Auckland  
New Zealand  
Phone (09) 266 7109

## Poitiers Conference

The proceedings of the 9th IAEDB Conference, which was held at Poitiers France in July 1987 are now available.

Please write to:

ANSPA  
(Association National Pour Les  
Sourds Avengles)  
18, Rue Etex  
75018 Paris  
France

Say which language text you require — French or English, and enclose a payment of 100 French francs, which includes packing and postage costs.

## Deaf-Blind Education

Deaf-Blind Education will appear twice yearly, the two editions will be dated January-June and July-December.

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

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

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

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