

# Deafblind Education

THE JOURNAL OF THE INTERNATIONAL ASSOCIATION FOR THE EDUCATION OF DEAFBLIND PEOPLE

**No. 10: June-December 1992**



**Holiday  
adventures**



# CHAIRMAN'S REMARKS

The next important event for our international association will be the Executive Meeting at Perkins School for the Blind, USA, 18-24 April, 1993. During our last meeting, we had decided to take advantage of this gathering for organising a symposium; it seems that members involved in activities at a national level often need to exchange views with other colleagues about matters on which

decisions are to be made or policies to be settled. The main outcome of this kind of symposium should be deciding on position statements. These recommendations worked out at a transnational level could be used at a national level by members who need support for their initiatives.

The symposium at Perkins will be on Adult Services. A questionnaire has already been

distributed all over the world, in order to collect all information about the situation as it is in the different countries and to list the problems which are to be solved. Besides, issues should arise from this questionnaire which will require Position Statements from IAEDB. Working groups will help the plenary meetings to make decisions.

A discussion on adult services seems to be very urgent since in many countries new services are being set up. IAEDB will have to express the need for a specific approach to Deafblindness. Making Deafblindness acknowledged as a specific handicap is still an objective in many places, especially when it comes to organising new services for young adults in a context of economic crisis.

Thus, the symposium will be of utmost importance for the future of Deafblind people. We are sure that it will be a success since many countries have already answered the questionnaire.

Jacques Souriau

## EDITORIAL

We had hoped that this edition of Deafblind Education would focus on services for congenitally deafblind adults but as yet little material has been forthcoming on this topic. I know that the IAEDB working group on congenitally deafblind adults is preparing a presentation for the April 1993 meeting of the Executive and I expect that as a result we will have a significant contribution at a later date to this newsletter. In the meantime in this edition of Deafblind Education we begin coverage of this subject with a description of the situation in the United Kingdom and information on the principles that Sense now follows in developing residential services for adults. Hopefully the next issue will focus on the approach in some other countries.

There are a lot of conferences happening around the world. For example the next IAEDB European conference is in Potsdam Germany later this year. It was originally planned as the first such conference in Eastern Europe and it was hoped that developments in deafblind education in the east as well as the west would be encouraged. In this edition of Deafblind Education we have exciting news from the Czech and Slovak Republics of recent developments. We hope that the initiatives described will be successful and that other new services will flourish. Hopefully the Potsdam conference will lead to benefits for deafblind children and adults throughout the new Europe and that IAEDB can support such work throughout the world.

In reading the articles in this Deafblind Education I was struck by the similarities between the situations in different places rather than the differences. We read that 'training [intervenors] is a long and very expensive exercise and I don't think here in Kenya we are ready yet for such an investment'. I am sure I have heard such statements with reference to many other countries!

In Czechoslovakia we hear that there was an 'opinion that there was only a very small number of deafblind people, so there was no need to provide care for them'. How many of us around the world even in countries with some existing services have had to try to deal with such opinion?

Similarly in few countries is it not the situation that 'children and young adults who were deafblind usually ended up in homes for the mentally handicapped.' We have more in common than some might at first think!

Finally, do not forget to tell us about your work and please include photographs.

Best wishes to you all,

Malcolm Matthews

## The 5th Helen Keller World Conference

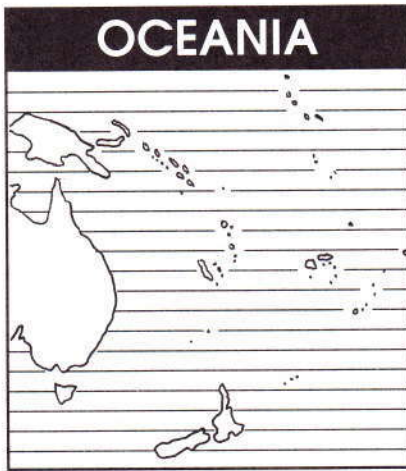
### Italy

**25-30 September 1993**

Many deafblind people, by the very nature of their combined visual and auditory handicap, live in complete isolation. Research carried out in Italy and other European countries demonstrates that many deafblind people have little personal contact, restricted recreational and social activities and limited vocational or occupational possibilities. Another of the consequences of deafblindness is that there is a total dependence upon others - be they family, friends or professionals.

Occasions when deafblind people can meet together or with others to





### Employment opportunities for disabled people

The Oceania Region is very pleased at the current cooperation from the Federal government on Employment Support Services.

An employment support service for people with multiple disabilities including sensory impairment has been established in Melbourne funded by the Federal Government.

The aim of the service entitled WorkNet, is to provide assistance for people with special needs who wish to enter open employment.

Workers with specialist training liaise between people with disabilities, employment agencies, employers and other agencies to increase employment opportunities. On-the-job advice and support is provided, and WorkNet sees education as being one of its major roles.

### Training

Conferences being held in the region next year which may be of interest to people in the field are as follows:

- a The Deafblind Care Association (Victoria) who have been prominent in promoting conferences in the field of deafblind education are in the process of organising another conference.

It is the second Australian Conference on Deafblindness to be held in Melbourne, Victoria at the Southern Cross Hotel on May 3 and 4, 1993 following the National Deafness Convention. The theme of the conference is *Coming Together*. Details may be obtained from Celestine Hare, telephone Australia (03) 482 1155, fax (03) 486 2092. The Association's postal address is **PO Box 267, Clifton Hill, Victoria, Australia 3068.**

- b The 'New Zealand Vision and Hearing Impaired Persons Society' is staging an International Conference in Auckland, New Zealand.

The title of the conference, which will run from May 6 to 10, is *Quality of Life and Independence for the Deafblind and Vision and Hearing Impaired into and beyond the 21st Century*.

Inquiries should be directed to the Society at **PO Box 37-498, Parnell, Auckland, New Zealand, telephone (09) 379 2424.**

### New organisations

The Western Australian Institute for the Blind is sponsoring the formation of a body in Western Australia to look specifically after the needs of deafblind people. This is a commendable effort by Western Australia as large distances and a small population in Australia often make it difficult to provide effective services for minority groups.

**Heather Hewitt  
IAEDB Executive  
Committee Member  
Australia**

discuss their conditions of life, their problems and their ideas and aspirations are extremely limited. For this reason the Helen Keller World Conference represents a special opportunity to meet together to compare services, resources, structures and the general quality of life.

The naming of the conference after Helen Keller is, of course, in recognition of a remarkable woman who is a model for life and hope for so many deafblind people.

To host a World Conference with such a large number of deafblind participants, truly constitutes an occasion for making acquaintances, exchanging experiences and for growth for all.

In addition, the aim of having a significant number of participants from developing countries does not only mean a contribution to the quality of life in particularly disadvantaged parts of the world but also to affirm as a value the principles of solidarity and recognition of all.

The title of the conference is **The**

**Quality of Life of Deafblind People: realities and opportunities.** Already in Örebro (Sweden) in 1991 the World Conference of professionals working with deafblind people discussed the concept of 'quality of life' and it will be interesting to have the contribution of deafblind people when going more into depth in this discussion.

The title takes into account a series of aspects which can be discussed, among which are: the real conditions of life in developing countries, education and vocational training, technical aids, demographic data and the training and development of staff.

The objectives of the conference are:

- to offer a real forum for discussion and debate particularly for the deafblind participant (to this end the organisation of the conference makes provision for a series of workshops to facilitate this type of relation between the participants, the majority of whom will be deafblind people);

- to promote the participation of deafblind people from developing countries and from all of Europe with a wider view than just the present EEC;
- to form significant collaborative links between participating countries and in particular between European countries and developing countries;
- to define a series of operational propositions and provide useful models for improvement of the quality of life;
- to gain agreement from individual participants that they promote the results of the conference in their respective countries.

For further information about the conference, please contact:

**The Conference Agency,  
Smit Congressi,  
Via Don Stuzo 41/43,  
60027 Osimo (AN), Italy  
Telephone 071 713 2350  
Fax: 071 713 3334**



Everyone likes holidays, and deafblind people are no exception. These two reports, from Russia and Ireland, demonstrate how taking deafblind people away from their usual routine and exposing them to new challenges and experiences can bring enormous developmental and educational benefits.

## Adventure in Fox Bay

**Irene Salomatina, Head of Department at the Rainbow Association, Moscow, describes a successful first camping trip to the Crimea for a mixed group of sighted, hearing and deafblind young people.**

The 'Fox Bay' project first came into our heads in November 1991. We were eager to organise a camping trip for deafblind children to Fox Bay in the Crimea, on the shores of the Black Sea. But the complicated situation in our country made us consider carefully whether it would be possible to realise this plan. In March 1992 we decided to take the risk.

In thinking about the programme for the camp we wanted our deafblind young people to understand that the Crimea was the land of sea and sun, mountains and springs, vineyards and the wild cornelian cherry... But the main idea was to help them to feel comfortable in a mixed group of people: deafblind, sighted-hearing, young and old.

A special camp for sighted, hearing teenagers was organised in July where they got acquainted with different tourist techniques and finger spelling. At the beginning of August they were ready to guide and to interpret for their deafblind peers at our camp, which we called 'Fox Bay'.

On 12 August, a cheerful group set off by train to the Crimea. Everyone was talking and fingerspelling, full of energy and hope, all ready for discovery and adventure – and there were some real adventures!

The 16 August was an ordinary day for most people in the world, but not for us. That was the day when our deafblind campers successfully scaled the Achki-Dug mountain and reached its 670m summit. It was not an easy task, truth to tell, but everyone could be proud that they had done it.

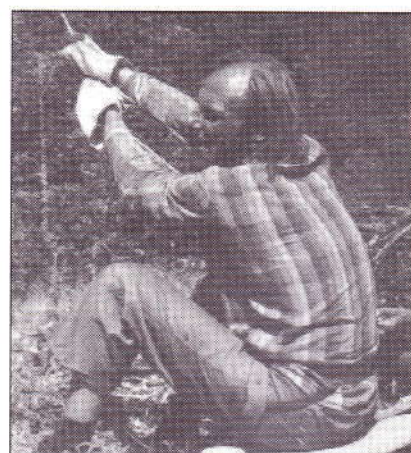
Five days later a small "Alpine-Camp" appeared in the mountains. A seven-metre rock climb with special safety provision was set up,



and four deafblind children managed to climb it. Have you ever seen a deafblind child full of happiness because he has just scaled a rock face? We have, and we will never forget it.

Of course, there was also the sea. We swam and lay in the sun, we built sandcastles and collected shells. Two weeks soon came to an end, which was a pity.

Last summer is over, but we are already thinking about the next one. A new project is ready to be put into action. Next time we want to go somewhere in the North. Why not?





# The Anne Sullivan Foundation Summer Project

The Anne Sullivan Foundation for the Deaf-Blind organised its second summer project this year. Thirteen deafblind children and young adults, and around twenty-five helpers, spent a week in two bungalows on the site of the Marian School for the Deaf in Cabra, Dublin. The summer project provides a holiday for the deafblind participants, with training for the helpers, and a high standard of care enabling the deafblind youngsters to show their potential and have a good time!

The summer project is part-funded by the European Community's HELIOS project, with participants from three European Community countries working for people with disabilities. In the case of the summer project, this involved Ray McLoughlin, Sr. Bernadette, Sr. Andres and many helpers from Ireland, Marij Vermeer from Holland and Martin Thomas and Heather Murdoch from the UK. Marij, Heather and Martin acted as consultants and trainers, running a two-day induction course for the helpers and planning appropriate activities for the holidaymakers.

The induction course began with a brief description of the difficulties of deafblind people regarding communication, information and mobility, and these were illustrated by activities carried out wearing blindfolds and earplugs. The rest of the two days was spent in considering appropriate ways of working with deafblind people – how to approach a deafblind person, how to give information on activities about to happen, how to develop routines and cues, how to guide a deafblind person appropriately, how to read and respond to the communicative signals they offer (including 'challenging' behaviour), how to massage feet and hands ... The course emphasised practical ways of working, and experiential learning. In addition to the summer project helpers, some staff working with deafblind youngsters in other settings attended the course.

The holidaymakers arrived the following day. Their ages ranged from 12 to 21 years, with a wide range of abilities and interests. The excellent ratio of helpers to holidaymakers ensured that contact, communication and a choice of activities were constantly on offer. A range of facilities were available throughout the week – a heated swimming pool on the school site, the use of a ball pool and bouncy castle

generously loaned by St. Vincent's Navan Road, a minibus (driven by Sr. Andrea) allowing trips to the beach, Dun Laoghaire and Phoenix Park, and a day trip to the zoo. The generosity of the Dominican sisters in Cabra, in loaning the bungalows, the pool and the bus, made a great contribution to the week. In addition, there were trips to the local shops, massage, walks, playing with toys and art and craft activities. Some of these involved one holidaymaker and their helper; the trip to the zoo involved everyone! Most activities involved small groups, with holidaymakers participating in activities that they had chosen or that offered them particular opportunities.

Each day followed the same basic programme, with breakfast, then a dance and movement routine, then activities, then dinner. After dinner, more activities were followed by tea, then the dance and movement routine, then free time and bed. For many of the holidaymakers, foot or hand massage was used to create a relaxing time between the end of an activity and the start of a meal. Others chose to walk on the grass outside the buildings. This programme was changed on the day of the zoo trip, with a picnic dinner eaten at the zoo.

The dance and movement routine used different music and equipment for each of four short sections. By the end of the week, many of the holidaymakers were anticipating and joining in with some of the movements, and many of those who had at first been unsure about the routine were relaxed and happy. The parachute was especially popular, with helpers as well as holidaymakers!

Communication was emphasised throughout the summer school. Object cues were established for the main activities, with the objects stored (clearly labelled) in the living room, where all the activities



started. Objects of reference and motor signals augmented the communication systems currently used by most of the holidaymakers, and many of them responded well to the information given. The helpers were encouraged to attach meaning to each holidaymaker's behaviour, observing and interpreting communicative signals, and allowing the holidaymakers time to take in information, consider, and respond to it. The ethos of offering real choices (and of moving at the holidaymakers' pace) was maintained throughout. This meant that those who were apprehensive about the bouncy castle, for example, could explore it, quietly and with support, rather than being expected to bounce and look happy straight away!

Some of the holidaymakers responded well to quiet, calm environments and activities. Others enjoyed a very consistent programme, with regular trips to the swimming pool, bouncy castle and ball pool. Still others relished a daily bus trip, visiting different places with different experiences. Some liked a varied programme, each day depending on their mood. All of them required skilful observation and careful thought for their wishes to be interpreted and met – and these were amply provided by the helpers.

Each holidaymaker and carer made a scrapbook during the summer school, with souvenirs of the week to help the holidaymakers remember and discuss the activities when they returned home. It was an enormously positive week, with a good environment, good organisation (thank you Sr. Bernadette), a good range of enjoyable activities, a high standard of empathy and care, and a good time had by all!

Heather Murdoch  
University of Birmingham



# Congenitally deafblind adults in the United Kingdom

Over the next few issues of *Deafblind Education* we will have articles on the situation of congenitally deafblind adults. As part of the work of the IAEDB, representatives from countries have been asked to answer questions on quality of life for congenitally deafblind school leavers and young adults. The first of these articles is based on questions answered by Bob Snow to describe the situation in the UK.

## Continuing education

**Do congenitally deafblind young adults and children in the UK receive adequate continuing education and vocational education after school age?**

The answer to this question depends on the background of the congenitally deafblind person involved. If the person is already in a special school or unit for congenitally deafblind people then the chances are quite good.

If the congenitally deafblind person is in a programme for 'people with special needs' but with no extra provision for congenitally deafblind people, then the chances of appropriate continuing education are significantly reduced.

There is a third group of people who are in hospitals or hostels who are over school-leaving age and have missed out on education. They have little or no chance of continuing education.

### What is the focus of further education?

The focus varies according to need but is mainly towards the furthering of independence and the continuing development of skills for life. It is still quite 'school' based but extends skills for wider application.

### What is the focus of vocational training?

The focus is towards meaningful occupation rather than employment. There has been some movement away from the concept of being 'a useful member of the community' by practicing meaningless workplace skills. The focus is now towards work skills having meaning for the individual rather than merely for the sake of appearing useful.

In the UK we are likely to combine continuing education and vocational training and think of them under the single term of 'further education'.

The best types of further education offers individual programmes focussed on congenitally deafblind persons interests, needs and communication and other skills.

It offers a range of choices with appropriate levels of support enabling the congenitally deafblind person to make choices and understand and control the factors affecting his or her life.

### If you think continuing education and vocational training is not adequate, describe the main obstacles and barriers.

Within the UK there is a statutory right to an appropriate education up to 19 years of age. This can still lead to problems of families having to fight for an 'appropriate' education for the congenitally deafblind child.

After 19 years this statutory right ends and funding issues become of primary importance. A congenitally deafblind individual has no 'right' to continuing education and obtaining funding is very difficult.

Also, pre 19 there is a single authority responsible whereas after 19 years there are several authorities who may (or may not) accept responsibility.

This uncertainty is one of many which affects the planning of enough appropriate post school placements.

Historically local authorities have placed the congenitally deafblind adults they are responsible for into general provision for people with special needs. Rarely have these general

provisions had the expertise to even cope with congenitally deafblind adults never mind help them to continue their education.

Poor links between statutory authorities have led to inadequately assessed congenitally deafblind persons coming out of school into unsuitable training environments with poorly trained staff and chronically low staffing levels.

Any planning which does exist is done by voluntary organisations – notably Sense – working against a background of insufficient funds.

## Policy

### Is there in the UK an official recognition of deafblindness as a separate handicap?

There is no easy answer to this question. Within education services (pre-19 years) the answer is 'yes' and this is starting to be reflected in the provision of new services. Within Social and Health services the answer is moving towards a 'yes' at 'government' level but with regard to services at a local level the answer is a very clear 'no' in almost all cases.

### Does the concept of deafblindness include congenitally deafblind adults (also multiple disabled)?

In the UK it is the inclusion of multiply disabled adults which can cause problems. The concept of deafblindness has always included the congenitally deafblind adults but has only recently begin to include the multiple disabled adult. Not everyone will accept this inclusion – especially parents who see the chance for services for the congenitally deafblind children as being better if they can stress the small and unique nature of the disability.



**Who takes administrative and economical responsibility for the provision of services for post-school congenitally deafblind people and at what level?**

- The Government
- Regional Authorities
- Local Authorities
- Private organisations, eg charities, but financed by authorities
- Private organisations, but financed by fundraising
- Parents' Associations
- Families alone
- Other?

All of the above may be involved and that is one of the reasons for the confusion.

A congenitally deafblind person is the legal responsibility of the Local Authority where he or she lives when they reach 19 years of age. They may or may not place the congenitally deafblind person in a post-19 provision. They may or may not provide a home if he or she can no longer live with parents.

If the congenitally deafblind person is in a residential home the government will provide some money towards the costs. Local authorities will provide the rest. Parents may also help the congenitally deafblind person to buy things and can be asked to contribute towards the cost of some services. Voluntary organisations will charge a fee to local authorities if they provide the service but will use fundraised money to promote the need for services to congenitally deafblind persons.

**Are there any special plans for the provision for congenitally deafblind adults in your country?**

At a national statutory level – No! There are a few initiatives at local statutory level.

Nationally, Sense has created a 'National Development Team' with a remit to enable Sense to carry out its Sense 2000 plan. This is a proposal to create appropriate housing and services for all congenitally deafblind adults in the UK through a network of regional centres of excellence.

This project is in its early days though and requires large amounts of, and as yet unfound, capital monies.

## Population

**Is there an overview of the population of the congenitally deafblind people?**

The figure of 25 per 100,000 population was the usual estimated figure. The only actual surveys done though have been local and have produced a figure of 40 per 100,000.

## Housing

**Are there any units specially adapted to the needs of congenitally deafblind adults?**

There are some units but the most common provision is long stay hospital.

**The units you know, do they provide what you would call adequate living conditions for congenitally deafblind adults according to the common norms of your country?**

Those which specialise in the congenitally deafblind do provide adequate living conditions.

Some which don't specialise have good physical care but don't give an acceptable quality of life because they do not provide appropriate services for the congenitally deafblind person.

**What characterises the best unit you know anywhere for congenitally deafblind adults?**

- Secure physical environment
- Environment geared to the needs of congenitally deafblind people
- Proper assessment
- Individual programmes
- Trained staff
- Variety of options for congenitally deafblind persons

**Describe barriers and obstacles related to housing**

These are some of the same barriers to good services described earlier.

It is difficult to separate housing from services but if one does then the main barriers to housing are cost, knowledge of what makes a good environment for the congenitally deafblind person, the general lack of awareness within social services of the needs of this client group and consequently the lack of services to support the congenitally deafblind people who might live in the houses.

## Support systems

By support system we mean a service unit, organisation of any kind or persons outside the units that provide consultancy to staff and families about what to do, how and why.

**Is there in your country a general support system that services units for congenitally deafblind adults?**

Sense and the RNIB both offer some support but this is mainly to non-specialised units. It is regionally very unbalanced and seriously underfunded.

**Is there an adequate medical support system?**

No. Medical support usually comes from normal health authorities and necessitates finding medical staff who are prepared to work with the units.

**Is there adequate basic training for staff working with congenitally deafblind adults?**

In most of the specialist units there is adequate basic training. In the non-specialist units there is virtually no appropriate training.

**Describe obstacles and barriers in the UK.**

There is no national statutory policy regarding congenitally deafblind people and therefore no balance of provision and therefore no specialist statutory funding.

Historically the development of services for congenitally deafblind people in the UK has been uncoordinated and has relied on the interest and enthusiasms of individual people and voluntary organisations. Additionally health and social service organisations are regional or locally structured and it is extremely difficult to establish any national provision which relies on funding from every local authority.

Even within the specialist field there are a variety of small local providers of services and Sense, the biggest charity working solely in this area, has never been able to secure funding or government support for a general support system – despite much effort. Sense is now establishing regional support systems but these are in their early days and are geographically very uneven.

There are variations in placements, abilities, needs of individuals and groups.

There is no coordination of post-school training qualification requirements. There is a growing awareness in the non-specialist world of the need for specialist training and qualifications but no coordinated route to finding this training and no specialist qualifications exist other than for teachers.



## Work possibilities

Do congenitally deafblind adults have the possibility to work or engage in meaningful activities according to their capacities?

In specialist provision this is a possibility but elsewhere – no.

## Handicrafts

Describe barriers and obstacles related to work.

### Attitude

- from specialist workers there is a feeling against 'work' because the culture of meaningless work has had to be fought against in recent years.
- meaningful work is sometimes being sought but the attitude of employers is not always supportive.

### Opportunities

- other than workshop type activities it is difficult to identify jobs which could be done without a level of support which would be very difficult to find.

## Social and cultural quality of life conditions

Do congenitally deafblind adults normally live in an environment where people communicate with them according to their capacities and special communication support systems?

Usually only if they are in specialist units.

Do congenitally deafblind adults have regular contact with their past (old school etc.)?

Rarely

Do they have regular contact with their families?

Sometimes

Do congenitally deafblind adults have friends?

Sometimes

Do congenitally deafblind adults have access to a common subculture?

Rarely

Do they have access to the culture of your country?

Rarely

Do congenitally deafblind adults live in natural units according to the norms of your country?

Sometimes

Do they have access to an equal family life according to the norms of your country?

Sometimes

Describe barriers and obstacles related to realising equal conditions related to social and cultural life.

Similar to those relating to previous comments on work. i.e.

- Attitude
- Ability
- Opportunity
- Communication
- Support

## Psychological conditions relating to quality of life

Describe barriers and obstacles related to realising equal conditions for psychological quality of life.

The answers to all of the questions in this section depend very clearly on where the congenitally deafblind adult is living, and thus the nature of the service being received.

Other than this consideration the biggest barrier to all is communication.

## Vision for the future

What in your mind would describe optimal life conditions for congenitally deafblind adults?

Equality in a responsive, interactional environment with opportunity for choice, independence and responsibility with:

- appropriate on-going education
- appropriate housing
- appropriate occupation
- appropriate leisure opportunities
- appropriate emotional support
- integration with the rest of the world
- access to information
- appropriate physical support

Is there a shared vision on behalf of congenitally deafblind post-school people among parents and staff?

Possibly yes but not agreement on best way to achieve it.

# Development and operation of residential services for adults

The following principles are used by Sense in developing and running residential services and in current work developing quality assurance. The basic principles underlying such work are:

- A sensory impaired multiple disabled person is a full citizen with rights and responsibilities and is entitled to dignity and respect.
- Services should be planned to meet the unique needs of each individual.
- Family and/or carers of a sensory impaired multiply disabled person should be included in planning for services.
- Sensory impaired multiply disabled people have the right to as independent a lifestyle as possible, with support services being provided to facilitate such a lifestyle.
- Sensory impaired multiply disabled people should have access to the full range of services, including primary care, education, social services, housing, welfare and recreational facilities.

In the development of residential services for deafblind adults, Sense believes the following areas must be given key consideration:

## Assessment

Sensory impaired multiply disabled and dual-sensory impaired people need to be correctly assessed. Assessment needs to take account of the importance of sensory impairment and include



consideration of the whole person. This will require a multiply disabled approach with input from the disabled person or an advocate and from family members or carers.

The importance of identifying the range of impairments and the way they are combined and the resultant effect cannot be over-emphasised. Early identification and full assessment will lead to effective developmental programmes and the possibility of planning for and providing the right services.

### Community Presence

Sensory impaired multiply disabled people have the right to live and spend their time in the community, not in facilities that give no access to other members of society. To this end Sense seeks alternative provision to long-stay mental handicap hospital for sensory impaired multiply disabled people.

The location of a service is important as this often determines the opportunity for meaningful involvement in community life. A residential service needs to be sited within easy reach of facilities – shopping, post office, GP, day centre facilities, recreational facilities, eg park, swimming pool. Proximity to public transport is important.

In planning and providing a residential service, equal weight should be given to meaningful day activities and access to community services.

### Relationships

Living in the community is not enough. Sensory impaired multiply disabled people need help and encouragement to mix with other non-handicapped people in the course of their daily lives. There should be opportunities for people to form valued relationships at home, in education, and during day and evening activities.

### Choice

A sensory impaired multiply disabled person has the right to make views known and have account taken of those views in the development of services. An important feature of the quality of life is the degree of choice that people can exercise. This can apply to small, everyday matters like drinking tea or coffee to major decisions such as where to live. Sensory impaired multiply disabled people usually have limited power to make decisions and look after their own interests. It follows that a sensory impaired multiply disabled person must have the right to an advocate and that services should

give priority to enabling informed choices to be made.

### Communication

However, of primary importance in enabling the development of relationships, enabling choice and decision-making and participation in community life, is the opportunity for communication with other people. Sensory impaired multiply disabled people (particularly those who need signed or tactile communication for both receptive and expressive communication) have the right to provision for their special communication needs and environments in which their best mode of communication is used consistently by all within the environment.

### Home

An option for sensory impaired multiply disabled young people should be to remain in the family home with support. As adults they must be able to move on to their own home with support. Such a transition should not occur as a result of a crisis, such as the deteriorating health of the carer, but should be actively planned for.

### Residential Provision

This must be designed to meet the needs of the individual sensory impaired person. This means that specialist requirements must be comprehensively provided for by the establishment. It is not enough for one or two staff members to be trained and able to communicate with a sensory impaired person. Placement in a group home designed around other needs is not adequate.

### Education and Developmental Input

Sensory impaired multiply disabled people will have had a significant developmental delay as a result of their impairment and often as a result of inappropriate education. Many begin to develop and extend formal communication, and challenging behaviour may change, when the person is a young adult, provided there is good continuing education. For many sensory impaired multiply disabled people, further education will initially be the best option. Further Education for a sensory impaired multiply disabled person should be a period of significant developmental opportunities. There must be a consistent and coherent approach across residential, educational, recreational and occupational

services. A community residential place should usually follow later after a period of say three to seven years. A sensory impaired multiply disabled person living a community residential home will usually continue to need a level of educational or developmental input to prevent regression and maintain quality of life.

The right provision for an individual will vary between individuals. It is clearly not possible to generalise about the needs of such a diverse population. As already stated, Further Education will be necessary for many people for some time. Long term residential provision should be available in a variety of ways within a region.

### Specialist requirements and support

These are essential as part of a comprehensive service. Specialist requirements might include access to low vision aids, access to environments that maximise stimulation of residual senses, opportunities for development, staff with expertise in facilitating development and staff with communication and signing skills.

### A comprehensive service

This will require a planned approach with special emphasis on transition between services such as occur when leaving school. It is very important to prevent regression at such times. Individual programmes that build on progress made will be needed.

### Changing Needs

Account must be taken of the changing needs of an individual that result from:

- improvements or deteriorations in their condition;
- developmental opportunities;
- reaching different stages in life;
- choices made by the individual.

As a consequence, constant evaluation of provision and the possibility of moving on to other provisions must be part of a comprehensive service.

### Staff

Sensory impaired multiply disabled people should have services provided by staff who are adequately prepared, trained and experienced and who have support, in-service training and supervision – including knowledge, skills, experience and expertise in sensory impairment and additional handicap.



# Sharing experiences

Asuncion Leyton, Co-ordinator on Deafblind programmes at the Organizacion Nacional de Ciegos writes on its first meeting to bring parents and professionals together to discuss deafblind children and young people.

The Monastery 'Santa María de la Vid' (Burgos) was a magnificent setting for holding a meeting between professionals, parents and students belonging to the deafblind units of the Centro de Recursos Educativos 'Antonio Vicente Mosquete' (Educational Resource Centre) of Madrid. This very new experience organised by the Blind and Deaf Department from June 19 to 21 proved to be a great success, according to all of the participants.

This encounter has been organised in order to enable the parents to continue the educational process followed by the deafblind students in their own home and also to involve them in the education of their children. The aim of this encounter was also to orient families and have parents and professionals working together in order to resolve the difficulties which arise on a day to day basis, and, at the same time, to show the parents the educational programme which their children follow. The professionals gave advice to the parents about how they should behave with their children, both in the home and in order to avoid a sense of abandonment or one of over-protection which can cause irreparable damage to the children.

An effective educational programme for the deafblind students requires the collaboration and coordination of all the persons working with them; that is, parents,

teachers, instructors and carers. It is highly important that these people apply a coherent and uniform educational approach in which important information and ideas are exchanged, for these are the people who come into closest contact with the child.

## The importance of paternal attitude

Parents are the ones who are, during the holidays, with the deafblind child when he wakes up, when he gets dressed, when he eats, when he bathes and when he plays. This day-to-day routine has been followed in the school and has been perfectly assimilated by the children who have obtained the necessary practical knowledge in order to be able to perform these tasks with a certain independence. However, when school is over, there has to be a continuity on the part of the parents and the persons who surround the child, so that what they have achieved during the course of the school year is not lost. (Carmen Corcuera, the mother of Gennet, a student in one of the deafblind units of the Centro de Recursos Educativos 'Antonio Vicente Mosque' has evaluated this experience as follows: 'For me, these meetings were a marvellous experience. I have learned many things during this encounter,

including the need to have more patience and moderation when I am with Gennet. However, what I most liked was the focus on the future, because I feel that 'united we stand, divided we fall', and now we are united, parents and professionals, on behalf of a common goal.'

## Conclusions

Many parents do not really know how to take care of their deafblind child and so experience like this one, in which the professionals of the school are placed at their disposal in order to give them advice, orientation and even correct them as to the best way of treating their children, prove to be highly productive. Training talks were given to the parents on daily living skills, playtime and communication with the deafblind child. These talks ended with open discussions in which the parents expressed and shared their own experiences.

This first meeting was organised in order to provide the parents of deafblind children with direct knowledge of the programmes and with the aim of granting continuity to the work carried out with their children in the centre. In this way, the parents can, at home, put into practice the work methods which the professionals have demonstrated for them during these encounters.

## News from around the world

### South Africa

Approximately fifty deafblind children are being educated in schools for the visually handicapped. A national conference in June will address the needs of blind children and will include a full day on multiple disability including deafblindness.

### Sweden

From 1994 there will be a new law to strengthen the rights of the most severely impaired children and adults. This will be important for deafblind people and *should* result in the need for interpreters being addressed. Also for "the small and less known groups of disabled people" there will centres of special knowledge built up all over the country.

In September a project started at Mo Gard to build a group home

adapted to meet the needs of 4 deafblind young adults.

From July the government will provide deafblind people with a computer with modem and braille display or enlarged text on screen for use as text telephone and for writing. Since September the Association of the Swedish Deafblind has had its own Bulletin Board which is used by about 500 people. The government pays the telephone bills for deafblind people when they call the database.



# Making a start

Following the political changes in Czechoslovakia,  
PhDr Jan Jakes describes how developments are progressing  
for deafblind people.

I would like to start this article with a word about the dissolution of the Czechoslovak state, formerly Czechoslovakia, into two states – the Czech Republic and the Slovak Republic. All that I am going to say here concerns only the Czech Republic unless I mention otherwise.

I should like to say something about care in the past for deafblind children. The Institute in Prague-Hradcany was created for blind children in 1808. It also accepted deafblind children – we do not know exactly when, but we suppose it could have been around 1910, or 1920. There were very few of these children and their education and training was provided by nuns. The Czech version of the Lorm touch alphabet was used as a means of communication.

Following the communist coup d'état in 1948, the Hradcany Institute for blind children was nationalised and reorganised. The nuns were forced to leave the Institute, and that was the end of education for deafblind children in our republic. From this time, there were only references in literature, the memories of old people and the Czech version of the Lorm alphabet.

During the following period, no one was interested in the care of deafblind children. From time to time there were notes about deafblind individuals. Some attempts were made to find out how many deafblind people lived in Czechoslovakia, but all ended in failure. Only a few individuals were found. This gave rise to the opinion that there was only a very small number of deafblind people, so there was no need to provide care for them. Besides this, there was also a feeling that deafblind children are mentally handicapped and therefore not capable of being educated. Children and young adults who were deafblind usually ended up in homes for the mentally handicapped. Children with lesser impairments were accepted at schools for the visually or hearing impaired. Special education and rehabilitation care for deafblind people did not exist. This sad period lasted for 42 years.

The change of political regime in 1989 gave new possibilities for various civic activities. Also, the field of care for disabled people became an interest for the general public. So an opportunity was

created to start taking care of deafblind people.

What is today's situation like? There are no systems for education, upbringing, training, rehabilitation or care for deafblind children. Nor is there any practical or theoretical knowledge or experience of deafblind issues. The fields of medicine, pedagogy, psychology and sociology do not feature deafblindness. There is a lack of information on rehabilitation and compensatory aids for deafblind people. No special education or rehabilitation facilities for deafblind children, young people or adults exist. There is no specialist staff for training, educating, rehabilitating or caring for deafblind people. The state's main interest is in transforming the economy.

The tough issue of deafblindness and the urgent need to deal with this problem was recognised by a worker in the Union for the Hearing Impaired when he met a deafblind person in the Czech Republic in Spring 1991. From his initiative, an official working group to help deafblind people was created. This group contained social rehabilitation staff for hearing and visually impaired people. Their work resulted in the creation of a non-governmental and legal body LORM – the Society for the Deafblind – in November 1991. Paradoxically, once LORM had been established, the working group dissolved.

LORM, the Society for the Deafblind, is a small organisation. For the time being, there are only two full-time workers employed here, some part-time and external workers. There are also two voluntary members on the organisational committee. LORM receives the funds it needs for its activities from a small unit in the Ministry of Health in the Czech Republic. The society is active in the Czech Republic and also has a legal remit in the Slovak Republic.

To be more accurate, in the Slovak Republic the activities for the welfare of deafblind children ought to be provided within the framework of the Evangelist Church. It is preparing to inaugurate an institute for deafblind people in 1993.

Based on comparisons with similar states, we estimate that there must be 1,000 deafblind

people in the Czech Republic and approximately 1,500 – 2,000 in Czechoslovakia. Today, after nine months of screening, we know around 300 deafblind people. So, the screening continues. A big problem is diagnosis and fact finding about the situation for deafblind people. There are only a few of us to undertake such a big task. We concentrate on child diagnosis. We lack the necessary equipment to perform psychological diagnosis. We are also starting a database on deafblind people for individual rehabilitation and care purposes.

Last summer, as a first step towards helping deafblind children and their parents, we organised a rehabilitation course for families with deafblind children. Without any previous practical knowledge and with the minimum of theoretical knowledge we held an event in which the pedagogical and psychological capabilities of our staff had to be proved. They had to improvise. Despite this, the event was very well received by the parents. A similar event is being prepared for deafblind adults.

We are going to establish a rehabilitation and educational centre for deafblind people. We are endeavouring to get in touch with specialists in the training and education of future teaching staff and carers of deafblind people, as well as diagnosis. We have managed to get in touch with the Pedagogic Faculty of Palacky University in Olomouc. We're trying to get information, literature, advice and other materials on deafblindness and on deafblind people.

We are aware that a lot of work remains to be done before we manage to establish a good system for meeting the complex needs of deafblind people of all ages. We have to cope with a number of theoretical, conceptual and organisational issues. We have the following priorities:

- to establish facilities for special support and help in the education of deafblind children
- to develop individual support for deafblind adults so that they can cope with the difficulties caused by their impairment
- to develop the concept of self-help in activities for the welfare of deafblind people.



# A new start for Joshua

Joshua's story is a sad one but one which, thanks to the work going on at Kabarnet School for the Deafblind, is not necessarily hopeless. Seventeen years ago he was born with normal sight and hearing and when he was of school age he went to an ordinary primary school. When he was in standard four he inexplicably lost his hearing and immediately started learning and using sign language. Just as he was adjusting himself to a life without sound he tragically learnt that his life would be lived in darkness as well. He was gradually and irreversibly losing his sight.

Since Joshua arrived at Kabarnet in 1988, his eyesight has virtually disappeared and he has to depend on other people for mobility and orientation. But here, apart from having companions with whom he can identify and who readily come to his assistance he is learning important skills to communicate to the outside world and vocational trades that will give him a certain measure of independence in future.

The tall lanky young man whose teacher, Mrs Judy Rett, describes as intelligent has, within a very short time learnt to use hands-on sign language, is learning to use Braille and goes for vocational training every afternoon where he is taught woodwork, knitting and agriculture.

Kabarnet School for the Deafblind has completely transformed both Joshua and his family. He went there a disillusioned young man who had watched his world slowly

**Kiruri Kamau, a Kenyan journalist, recently spent some time at the Kabarnet School for the Deafblind, in Kenya. During his stay he had the opportunity to observe life at the school and the progress of its pupils. Here is his account of life for Joshua.**

disintegrate and who could not understand or be understood by those around him. His father, gnawed and made heartless by despair had brought him to the school with the intention of dumping him there.

"He came here a defeated man and declared that he was ready to donate him to anybody who wished to have him", reports Mrs Rett. However, intensive constant counselling and guidance to Joshua and his father has helped them to accept his plight and they are both working towards his rehabilitation. The older Namwaya has taken an active role in the school's affairs and is now the chairman of the parents' association. Mrs Rett who initially trained as an ordinary teacher views her work with Joshua as a challenge which, though requiring sacrifice and patience, she must surmount.

"It is not easy. It can sometimes be very frustrating when one is not understood and has to say the same thing again and again, but it is a pleasant challenge and very fulfilling," she says.

Joshua wants to be an executive

in an office in future, so he told me through Mrs Rett. But given the stage of development at which Kenya is and the amount of investment in technology needed to allow him to get there this is a very very distant possibility. However in the event of not being able to become an executive his second choice preference would be teaching multi-handicapped children.

Mr B L Lentoimaga, the headmaster of the school, says it is possible to integrate Joshua in the mainline society through a transitional programme aimed at preparing those he would work with. But he cautiously points out that an integration programme would only be possible if what he calls interveners are available.

"Training such people is a long and very expensive exercise and I don't think here in Kenya we are ready yet for such an investment", he says. He thinks the best that can be done for Joshua and others like him is to provide a sheltered workshop where he would work under close supervision and direction. Already such a workshop is under construction at the school and will be operational very soon.

Maybe time will translate Joshua's dreams into reality. But even if he does not fully realise them he will not have to live in a lonely silent and dark world. Kabarnet School has reopened the door, which fate had rudely slammed shut, of being able to interact with other people and of being and feeling useful in society.

## Fourth Canadian Conference on Deafblindness

### *Caring Enough to Let Them Grow*

Fredericton, New Brunswick  
June 3 - 5, 1993

*Caring Enough to Let Them Grow* will focus on the premise that every deafblind person has the capacity to reach their full potential. Their unique disability challenges us to provide the right kind of support and guidance that allows them to grow.

### Who should attend?

Deafblind consumers, parents, educators, social workers, service providers and people interested in services provided to deafblind people. For further information, registration and fees, contact:

Conference Coordinator, CDBRA NB, 34 Island View Drive, Fredericton, NB Canada E3C 1K8  
Tel: 1-506-452-1544

## Seminar

### Adventitiously Deafblind People Spring 1994, the Netherlands

This seminar is being held to establish a network for sharing information, ideas and experiences amongst professionals working with adventitiously deafblind people.

Workshops will be held to consider the following topics: interpreter services, networks, mental handicap, psychological aspects, elderly deafblind people and other related themes.

The seminar is restricted to 50 places, so if you would like further information, please contact

Anneke Balder, c/o Stichting Doof-Blinden,  
Professor Bronkhorstlaan 10,  
3723 MB Bilthoven, The Netherlands.  
Tel: 030 - 250604.



# The educational management of deaf pupils with Usher syndrome

Dr Wendy Lynas, at the Centre for Audiology, Education of the Deaf and Speech Pathology at the University of Manchester documents the results of extensive research into Usher syndrome in deaf schoolchildren.

## Introduction

Wendy Lynas' paper 'The Educational Management of Deaf Pupils with Usher Syndrome' reports on a survey to investigate the needs of pupils with Usher syndrome in varying educational settings which was initiated by Sense in 1987. As the study progressed it became apparent that this work needed to be put into an academic setting which could bring to it the disciplines applicable to a study of the educational management of a group of deaf

children with special educational needs because of their visual condition.

Discussions with the Centre for Audiology, Education of the Deaf and Speech Pathology at the University of Manchester and in particular with Dr Valerie Newton and Dr Wendy Lynas resulted in the department taking up research into the educational needs of pupils with Usher syndrome. This paper is an interim report based on the findings from several different types of educational settings and on many interviews with staff and pupils.

The study is not complete, pupils

under ten have not been investigated nor pupils in units and more pupils in mainstream settings need to be observed to complete the picture. However, it is hoped that this paper, which highlights some of the issues in educational managements of pupils, will stimulate further thinking on the educational needs of children with Usher syndrome and make a useful contribution to an area where there is a dearth of written material for teachers.

Mary Guest  
Head of Usher Syndrome  
(Services) Sense

It is estimated that 3-6% of the school population with congenital hearing loss have Usher syndrome (Vernon 1976): that is, associated with deafness, usually profound, is the degenerative eye condition, Retinitis Pigmentosa (RP). As RP is not at present medically curable, intervention must be directed towards alleviating the worst effects of the disability through education and management. Intervention is, however, problematic for several reasons.

First, the disabling effects of gradual loss of vision superimposed on a substantial hearing loss are immense. Second, since there is considerable individual variation in the onset and severity of the symptoms, the progression of the condition through childhood and adolescence is unpredictable. Third, the emotional trauma for both the Usher individual and his/her parents of knowledge of the condition can often lead to a denial of the problem which significantly impedes a satisfactory adjustment to the disabling effects. Finally, the relatively low incidence of the

condition and consequent geographical scattering of the Usher population means that from the point of view of diagnosis and educational intervention, knowledge and understanding of Usher syndrome is also dispersed. Professionals of all kinds – medical, educational, welfare – who are involved in serving the needs of children and young people with Usher syndrome are unlikely to have any previous experience, let alone expertise in the diagnosis and management of condition.

So, despite the fact that the symptoms of night blindness become manifest during a deaf child's primary school years and the gradual loss of peripheral vision is generally identifiable and having some effect at the very latest by early adolescence, formal diagnosis of Usher syndrome is typically late: the Sense survey 'Usher Syndrome in the School Population' found that in Britain although the age of identification ranged from 5-23 years, the majority of individuals were diagnosed between 11-18 years with the highest number reported at

age 16 years (Guest and Roper, 1988).

That diagnosis is late is a matter of serious concern: research indicates consistently that from the point of view of the emotional adjustment of the individual with Usher syndrome and his/her parents, the earlier the condition is known about the better (Vernon and Hicks, 1983). That subsequent intervention may be uncertain and experimental is likewise a matter of concern: the child or young person who is substantially deaf and whose vision is gradually deteriorating merits all the expert attention that there is. Those serving the educational needs of Usher children and young people deserve good advice and reassurance that they can make a positive contribution.

## Research in Manchester

A major aim of some research currently being undertaken at Manchester University in association with the Usher Syndrome Services of Sense (Lynas, 1991), is to increase and make more



widely available the pool of knowledge about the nature and effects of Usher syndrome. An important aspect of the work is the aggregation of information that has already accumulated in "pockets" up and down the country about practical accommodations which might ease the day-to-day living of the Usher pupil and improve access to the education that is being offered. A further aim is to throw some light on why it is that Usher syndrome is diagnosed late and whether or not it is sensible or realistic to encourage teachers of the deaf to be alert to indicators of night blindness and loss of peripheral vision amongst their deaf pupils. What follows is a preliminary report of the findings of the research which may offer some insight to educators of deaf children and at the very least should point to ways in which further research might develop.

The findings are based on qualitative research: observations of Usher pupils/students in different educational settings in England: conversations with teachers, care-staff and the Usher pupils/students themselves. So far, 15 Usher children/young people have been involved aged 10-20 years in the following settings: residential school for the deaf, day school for the deaf, comprehensive secondary school, and Tertiary College. Two of the special schools for the deaf (one day and one residential) each had five pupils with Usher syndrome.

### Letter

Thank you very much for publishing the article by V. Chulkov in *Deafblind Education* No. 9, January-June, 1992. But there are two misprints in it: page 14, 3rd para, it should be written: Figures compiled in this country in 1986 by M. Pevzner, G. Bertyn and R. Mareeva show that 30% of deafblind children are mentally retarded.

Then in Case Study: the 1st para: She is rubella handicapped has congenital cataracts, aphasia (not aphasia) ...

Best wishes

**Svetlana Vishnevskaja**  
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### Specific objectives:

- 1 to explore the reasons why formal diagnosis was generally so much later than the appearance of the early symptoms
- 2 to find out whether there are clearly identifiable behavioural indicators of RP which, if teachers were sufficiently sensitive, could lead to speedier diagnosis
- 3 to investigate and report the kinds of accommodations currently being made in schools by teachers, care-staff and peers to Usher children and young people
- 4 to consider the kinds of moral support offered to the Usher child and young person and his/her parents and to evaluate the effectiveness of the support.

It is not expected that the research would or ever could offer a blueprint for effective intervention; but, on the basis of the idea that small modifications and adaptations to the environment, both physical and social can "mean a lot", it is believed that aggregating information of possible accommodations and support might help educators in the difficult task of serving the needs of their Usher pupils.

### The problem of late detection

The research indicates a strongly felt concern amongst educators that in the case of most of the Usher pupils, diagnosis was occurring late. It was commonly the case that there was a prolonged gap between initial suspicions of visual problems on the part of teachers and formal medical confirmation of the condition. There was no single identifiable cause for this. The following reasons were variously cited as contributory factors: failure of routine school-based visual checks to test for visual fields, the problem of conducting any accurate visual tests where the individual concerned has a serious hearing problem; "bad" experiences at eye clinics/hospitals caused by difficulties of communication leading to an unwillingness on the part of the deaf children and/or their parents to attend further appointments; a long wait between "failing" a visual field screening test and securing an appointment with an eye consultant; the tendency for eye specialists not to confirm diagnosis of Usher syndrome on the first visit.

Whatever the reasons, it is clear that the service for testing the vision of deaf children is failing to be delivered effectively and is

insufficiently comprehensive to detect RP in the early stages. Given the problems of detection of RP in deaf children, it is tempting to consider the possibility of the greater involvement of teachers of the deaf and care-staff in the identification process (Jones, 1989). It is they, after all, who have a deep understanding of deafness and a close knowledge of the individual children for whom they are responsible. It could perhaps be assumed that they could distinguish behaviours attributable to deafness from those which seem to stem from some other disorder.

Our investigation confirms other evidence (Bulkaert, 1985) that there are behavioural features associated with night blindness and a narrowing of peripheral vision and that these are often noticed by teaching or care-staff. The following indicators of visual field problems were cited: above average clumsiness; frequent failure to throw and catch successfully in ball games; bumping into people; stumbling over objects at below waist level, inability to easily locate objects which fall off the desk, impaired mobility particularly in unfamiliar surroundings such as experienced on a school trip; over-cautious and tentative movement generally; difficulties for staff and other children in attracting attention. Indicators of night blindness cited were: blinking caused by an inability to see well in a relatively dark classroom after having been in sunlight, failure to read faint printing on blackboard, worksheet, OHP or VDU, switching on lights in dull conditions.

In the case of some of the pupils subsequently diagnosed with Usher syndrome teachers stated in retrospect, that they had noticed several of the symptoms before diagnosis. However, these same teachers were firm in their belief that it would be unwise for them to be given responsibility for screening the condition. The reasons given were, first, that characteristics such as clumsiness and bumping into people were not exclusive to deaf children with RP; second, and perhaps more important, were the false 'negatives', three out of the ten pupils in the two special schools, identified by the medical service as having Usher syndrome, did not arouse any suspicions at all prior to diagnosis. This was despite the fact that in these schools, staff had experience of children with Usher syndrome and were sensitive to the behavioural indicators of the condition. These pupils were believed to be either better at visual



scanning and therefore at masking their visual problems or were thought to have less severe symptoms in the early stages. This failure to identify the condition despite being attuned to typical manifestations of it led to the view in both schools that relying on teachers as screeners was a hazardous business, and that there was no substitute for regular eye checks. In both schools, therefore, all the pupils were regularly screened for visual field. Close working relationships had been established with local opticians and eye clinics and this was felt to be very important.

### Accommodations in school

It has quickly become apparent that all the schools featuring in the investigation had instituted changes to the environment in an attempt to accommodate the day-to-day needs of the Usher children and young people. This was particularly evident in each of the two special schools which were each attended by several Usher pupils.

Modifications included changes to the physical environment of the whole school, adjustments made by individual teachers in their teaching rooms and also accommodations made by other pupils both in and out of class.

Adaptations to the school and classroom environment were typically made as a consequence of discussion amongst staff and in consultation with the Usher pupils themselves. The amount of careful thought that took place in all the institutions was impressive and reflected a deep and ongoing concern to do as much as possible in order to overcome and circumvent the daily inconvenience to the deaf child or young person with poor light/dark adaptation and reduced peripheral vision. The following examples illustrate changes made to the physical environment, lighting, classroom organisation and presentation of visual materials:

- (i) White bands at the edge of all steps and stairs throughout the building.
- (ii) Lights on all day all over the school.
- (iii) Removal of any lights which were very bright or dazzling.
- (iv) Non-glare curtains, non-glare glass windows, and non-glare paint.
- (v) Replacement of school furniture which has bright, shiny surfaces with furniture with a dull, matt finish.

- (vi) Venetian blinds on classroom windows.
- (vii) Luminous plugs and a permanent blue light on in corridors in residential accommodation.
- (viii) Placement of low tables in varying parts of corridors on which were attractive lamps with low watt bulbs and plants/ornaments, ostensibly for decorative purposes. The idea was, however, to introduce into the environment a potential but small hazard in order to encourage the Usher pupils to learn to be vigilant and alert at all times.
- (ix) Provision of luminous laces for training pumps.
- (x) Attention to written material on worksheets, blackboard, whiteboard, OHP, VDU. In one school all classrooms had a whiteboard with black markers; in another there were blackboards with yellow chalk; in another most written material in classes was presented on the OHP with red markers. Differences of practice here reflected in the main, differences of opinion of the Usher pupils themselves. Other examples of helpful accommodations were: producing worksheets in bold type, avoidance of computer-type with an indistinct dot-matrix, adjustment of VDU's to ensure maximum contrast with minimum glare.
- (xi) Attention to the arrangement of classroom furniture so that chairs, desks etc. were more or less kept in place and so that objects such as bags, shoes, boxes etc. were not left lying around on the floor.
- (xii) Offering the best possible seating position. Teachers' thoughts varied about where this might be, but Usher pupils' preferences suggested that towards the back of the class with their backs to the window seemed right. This confirms research evidence which indicates that a person with restricted peripheral vision can see best at a distance of about 5-6 ft. away (Hicks, 1979).

Where adaptations to the physical environment are made as part of a thought-out "whole school" policy, there is the obvious advantage that the Usher pupil is not singled out for special attention. Yet special

attention to the detail of the physical environment seems to be so important. If Usher pupils are frequently troubled by small incidents which remind them of their visual problems, this can serve to undermine and demoralise.

### Accommodation of peers

A very useful source of support was found within the peer group of the Usher pupil. On the whole other pupils/students did not seem in any obvious way to be "aware" of a fellow pupil with a visual handicap. In fact, there seemed to be concern not to draw attention to the difficulties of a classmate. However, teachers were able to report that most of the pupils had internalised helpful ways of behaving, for example: not leaving their coats and bags on the floor, offering a guiding hand in unfamiliar and dark places; taking care to avoid being bumped into, signalling for visual contact before communicating. In one of the special schools attended by five Usher pupils there was regular class discussion about the implications of RP and this was felt to be beneficial in creating a supportive atmosphere amongst the pupils.

### Usher pupils' adaptations

In order for Usher pupils to achieve maximum independence at school or college, it is important not only for them to be in a facilitating and supportive environment, but also to make certain adaptations themselves. The research so far indicates that Usher pupils made use of strategies to accommodate their condition such as: visual scanning, maintaining a certain distance from others when interacting with them, selecting activities which exposed their visual problems less. Examples of the latter include: avoiding sports activities like badminton and tennis, which demand good hand-eye co-ordination and selecting those which do not, such as athletics and swimming.

Generally it seems important that Usher pupils acknowledge their visual problems in order to take some ownership of the task of making adjustments to the condition. The greater the degree of acknowledgement, the easier it is not only for the individual to adjust, but also for school staff to make consumer-led adaptations to the environment.

Continuous monitoring of the Usher pupil, which need not be done in any overt or obtrusive way, also seems to be an important principle. Regular and repeated in-service



training about the implications of RP serves to keep awareness and sensitivity alive. Sensitivity to the needs of individual children or young people was, however, felt to be of paramount importance. There was certainly no single profile of disabilities and needs: variations in hearing-loss, I.Q. and personality as well as difference in extent of loss of vision made each individual unique. There were also marked individual differences in ability to deal with their visual difficulties.

### Denial and parental adjustment

Impressions gained from our investigation so far are that adults participating in the education of Usher pupils are more than willing to adapt to the needs of these children and young people, and very concerned indeed to learn about strategies for helping them cope in and out of school. The scale of the problem, however, was such that feelings of helplessness were common and nowhere were these more keenly felt than when confronting the problem of helping parents of Usher children adjust to this situation. Quite understandably, parents were frequently overwhelmed with strong emotions on discovering that their deaf child had yet another major handicap and a commonly cited reaction was that of denial of the problem.

This caused concern not only for the feelings of parents but also for the fact that such denial over a long period might lead to poor adjustment on the part of the Usher child/young person. It is not easy to begin to help a child or young person in school face up to a fresh set of problems if these matters receive no mention at home. Also staff doubted the ethics of discussing the matter with a pupil without the parents knowing or consenting. Where there was denial there was no opportunity to discuss with parents ways in which practical strategies might usefully be adopted both at home and at school. Even where there was some acknowledgement on the part of parents, many staff felt "out of their depth" when dealing with parents' grief, anger, guilt, resentment etc. Several school staff pointed out that they were inexperienced in counselling and ill-equipped in the task of family support generally, believing themselves to be disadvantaged relative to their colleagues who specialise in working with young hearing impaired children and their families. Parents who could not communicate easily in English and whose expectations

of children and attitudes towards disability were not understood by teachers caused further anxiety. In the residential school the problem of communicating with parents was felt to be exacerbated by lack of frequent, close contact.

Compounding the difficulties of offering appropriate support was the fact that the prognosis of the condition is so uncertain. Even doctors cannot predict the rate of progression of vision loss, nor know whether or not the final outcome will be total or near total blindness. Hence neither teachers nor anyone else can know what it is precisely that will have to be adjusted to in the future. It is little wonder that school staff felt inadequate for the task and fearful lest they make a difficult situation worse. It is not surprising that the staff featuring in the investigation tended to concentrate on day-to-day small-scale adjustments such as arrangement of furniture and protection from glaring light, rather than confront the "big issues". It is perhaps some consolation that the literature on adjustment to Usher syndrome suggests that focusing on day-to-day difficulties and offering low-key support is probably what best serves the needs of Usher children and young people in school or college (Vernon and Hicks, 1983).

### Conclusion

It would be wrong to draw firm conclusions from a relatively small amount of research. However, the investigation so far does draw attention to some important issues. It offers insight about the problem of delay in arriving at a formal diagnosis of Usher syndrome and throws doubt on the wisdom of relying on a "teachers as screeners" policy as a way of accelerating firm diagnosis. That some teachers "had their suspicions" about some of their deaf pupils before formal diagnosis does not, however, rule them out as significant participants in the detection process. The research does support the idea that all children with sensory-neural hearing loss should be given regular eye tests of visual field. Furthermore, the research suggests that serious attention should be given to the way in which the tests are administered so that poor communication between optician/ ophthalmist/ optometrist and deaf child does not interfere with the accuracy of the results.

A pressing reason for improving the procedures for detecting RP in the deaf child population is that the incidence of Usher syndrome in Britain could well be increasing.

This is because of a greater number of consanguineous marriages in Britain largely from within the Asian population resulting in an increase of certain genetic conditions (Lumb, 1981). Congenital hearing loss is an example and the incidence of childhood deafness is greater amongst certain groups of South Asian origin than in the population generally (Basu and Jindal, 1978). It has been confirmed elsewhere, for example, in small communities in the Nordic countries and the USA, that consanguinity is associated with a greater incidence of Usher syndrome. (Boughman, Vernon and Shava, 1983). Hence it must be supposed that there could be much as yet undetected Usher syndrome within the hearing-impaired child population in Britain. What is particularly problematic is that families of S.Asian origin are amongst those who are known to be poorly served by health and welfare agencies (Ballard, 1979). Hence there is all the more reason for instituting a more reliable and thorough-going system of checking the vision of hearing-impaired children.

The amount of careful thought within the schools and services featuring in our study that has been devoted to catering for the practical day-to-day needs of deaf children with RP is most encouraging. The short courses and conferences that have been organised over the last three or four years by the Usher Syndrome Service of Sense have clearly been very useful. There is further scope for offering regular opportunities for teachers, care-staff and other relevant professionals to develop and share their knowledge of useful strategies for easing the practical adaptation of the Usher child or young person. The issue of the more subtle, ongoing effects on the ability of the deaf child with restricted field vision to receive the education offered and to develop their "unique sensory potential" (Jenson, 1976) is unclear and more detailed research is required to throw light on this matter.

The research confirms the magnitude of the problem for parents of deaf children in accepting or even being able to acknowledge the diagnosis of RP. Parents need and deserve expert support both for themselves and for their children's sake. Many of the teachers featuring in the investigation felt unequal to the task of offering appropriate support and advice, often themselves feeling emotionally overwhelmed by the diagnosis and prognosis. Colleagues with expertise



in counselling and supporting families of young deaf children could perhaps make a contribution here. Professionals would also benefit from information about the ways families can be helped to deal with "multiple" problems in the child (Cunningham and Davis, 1985). Perhaps the best source of information would come from parents of Usher children who have experienced the pain of realising that their deaf child also has RP and who have, at least to some extent, adjusted to the situation. Teachers would be greatly privileged if such parents could share with them their experiences and ideas about how they coped.

As the research continues we hope to gather more information about the ways in which potential difficulties in school can be overcome and we intend to extend the range of educational contexts that are studied. It is also intended to explore whether or not it might be possible to develop a reliable instrument for the purpose of screening RP which could be used by teachers of the deaf as a routine part of their work. We are aware of the need to develop greater insight into the counselling needs of parents of Usher children and of Usher young people themselves. In particular we shall be looking at ways of helping professionals cope with their own feelings of distress about a child with Usher syndrome and so help them in their role of supporting parents.

It is important to develop positive attitudes towards Usher syndrome. The many adults with Usher syndrome who lead fulfilled and satisfying lives is testimony to the fact that there is life after deafness with RP.

## References

Ballard, R (1979) Ethnic Minorities and the Social Services in Khan, V.S. (ed.) *Minority Families in Britain*, Macmillan 1979.

Basu, S K and Jindal, A (1978) Genetic Aspects of Usher's syndrome *Indian Paediatrics*, 1978 15/5 (429-431).

Boughman, J A, Vernon, M and Shaver, K A (1983). Usher's syndrome:

Definition and Estimate of Prevalence from two high risk populations, *Journal of Chronic Diseases*, 36, 8.

Bulkaert, P (1985) Principles of Guidance of Persons with Usher syndrome.

*Proceedings of First Meeting of the European Usher Syndrome Study Group*, April 1985. Instituut Voor Doven, St. Michelsgestel, The Netherlands.

Cunningham, C and Davis, H (1985), Working with Parents: Frameworks for Collaboration, Open University Press.

Gottlieb, D D and Allen, W (1985) Visual disorders in a selected population of hearing-impaired students. *Volta Review*, 87, 3, 165-170.

Guest, M and Roper, F (1988) Usher Syndrome in the School Population. Sense.

Hicks, W (1979), Communication Variables Associated with Hearing-Impaired/ Vision-Impaired Persons - a Pilot Study *American Jn Annals of the Deaf*, August 1979.

Jenson, P (1976) Educational Needs of Students with Progressive Loss in Hearing and Vision. Helen Keller National Center.

Jones, B (1989), Teachers as Screeners, Fifth *European Usher Syndrome Study Group*, Warwick University.

Lumb, K M (1981) Prevalence of Hearing Loss in Children of Asian Origin, Scientific Meeting of the British Association of Audiological Physicians and Community Paediatric Group, Manchester.

Lynas, W (1991) Deaf Children with Usher Syndrome. *Journal of British Association of Teachers of the Deaf*, 15, 2.

Vernon, M and Hicks, W (1983) A Group Counselling and Educational Program for Students with Usher's Syndrome, *Journal of Visual Impairment and Blindness*, February, 1983.

Vernon, M (1979) Usher Syndrome: Problems and some solutions, *Hearing and Speech Action*, 1976.

Wager, H and Whate, K (1988) Visual Defects in Children with Hearing Impairment, *Brit. Orthopt. Journal*, 45, 56.

## Help wanted for research project

Anselmo de Dominicis, a technological designer from Aprilia, Italy is working on an electronic and computerised project for developing communication in deafblind people. He would like to hear from anyone with skills in electronics, hardware and software, medical research and deafblindness who would like to collaborate with him on this project.

If you are interested, contact

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## Speech and Language Technology for Disabled Persons

May 31 - June 2, 1993

Stockholm, Sweden

The European Speech Communication Association has identified the area of Speech and Language Technology for Disabled Persons as an important area of current research interest. An ESCA Tutorial and Research Workshop is being organised in Stockholm with this focus. Contributions to the workshop should be research-orientated, or concerned with an application which can be demonstrated (live or on video).

If you are interested in submitting a paper, or attending the workshop, please contact:

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# Using a LogoWriter

The idea of using a computer to improve the education of visually impaired and deaf children is neither new nor original. Nowadays there are many different ways of doing this, and when in 1989 we started our work, encouraged by the brilliant lectures of the author of the Logo computer programme Professor Seymour Papert and Dr Carl Sperry from Massachusetts Institute of Technology, we were not sure of success. One of the Logo family, the LogoWriter computer programme which we used in our work provides wide-ranging teaching opportunities and learning facilities but at the same time it appears to demand a rather high intellectual level of the students. Nevertheless the situation in Russia, where there are not too many educational programmes translated into Russian which could help us to move step by step, made us select the LogoWriter as the basic one.

## What is LogoWriter

LogoWriter is based on Logo educational computer programmes. Logo appeared rather a long time ago and now many programmes with the same main features have been designed.

Logo is a computer programming language, ie a special set of keywords and rules which allows one to manage a computer, making it function and act in different ways. But while nearly all computer programming languages are designed to manage only the computer itself and its computations, the Logo language creates its own world where a little turtle lives on the lawn of the screen. The Logo programme provides plenty of possibilities to operate inside this microworld.

Students can move the turtle and turn it with such instructions as 'Forward', 'Right Turn' etc. And the turtle can trace (or not trace) its path lines of different colours. This allows the student to create very complicated pictures on the screen. For instance, if one wants to draw a square one needs to type into the command window the following instructions:

1. cg (clear graphics from screen)
2. pd (pen down; the instruction makes the turtle start tracing)
3. repeat 4 [fd 10 rt 90] (this instruction makes the turtle repeat four times a list of

instructions which consists of two commands: to move the turtle ten 'steps' forward and then turn right for 90 degrees).

One can see from this that the Logo language allows the student to construct complicated instructions such as repetition of command sequences.

When this language was being created, the ideology of the programming was taken from logical programming (in particular, from LISP), and this is reflected in the name 'Logo'. This conjunction of the logics and graphics under the same software shell seems to be very natural and productive because it allows students to comprehend different sophisticated logical concepts through its human-oriented graphical representation.

Other main facilities of the Logo are discussed below:

Using Logo, a student can create different shapes for the turtle, changing the picture of the turtle to a car, a flower, a cat or something else, selecting these new shapes from the built-in library or by drawing them himself.

Students have access to the computer sound generator, timer and so on. Using it they can create music, organise games and make different accessories for the Logo-programmes.

The Logo programme allows students to implement and use procedures or macro-operations easily. And all the results of their work (procedures, texts and graphics) can be stored and used later.

The LogoWriter programme we used also has a built-in simple word processor and facilities to merge texts and graphical information in an easy way.

## Our students

Our students are an experimental group of the visually impaired and deaf children of the Research Institute of Defectology residential (boarding) school. The group consists of five students listed below with diagnoses which they had in 1989 when we started our classes:

- 1 Sveta L  
14 years old, VIS OU 0.09, deaf, in the group from 1986
- 2 Lyuba B  
14 years old, VIS OU 0.3, hard of hearing, in the group from 1984

## 3 Vadim P

14 years old, VIS OU 0.1, hard of hearing, in the group from 1984

## 4 Irina G

12 years old, VIS OU 0.1, deaf, in the group from 1986

## 5 Roman V

13 years old, VIS OU 0.1, hard of hearing, in the group from 1983.

As one can see, all the students have severe hearing and visual impairments which cause different types of deprivation. Sometimes their lack of access to information leads to different psychological dysfunctions as we could see in Roman, and to some extent in Lyuba. They have especially serious problems in space perception and spoken language comprehension and that is why we used the computer in the lessons on spatial orientation.

## Why is LogoWriter useful for visually and hearing impaired children

The LogoWriter programme at the first level looks a verbal system driving the turtle. Experts usually recommend children to remain at this stage for rather a long time because it allows students to become familiar with the main peculiarities of the computer. Turtle driving becomes a game for students and provides a high level of motivation. As for our children whose space perception was severely disturbed, Sveta L. remained at this stage for a whole year and the other students also remained 'turtle drivers' for several months. But this stage is very important for children who lack access to information because it allows them to learn to move their reference point from themselves to the turtle – a very hard problem for all of them. In solving this problem the students become able to describe a way to school or bus stop verbally and understand descriptions made by other persons – experience which is really necessary for them.

After reaching more complicated aspects of the LogoWriter, we needed to return to support and improve this skill on a regular basis. Another skill which children developed extensively was the planning of their future activity. In computer terms this involved programming, and LogoWriter, like



many other programming languages, provides all the necessary tools for this. In contrast with other major languages, in Logo one can easily assess and trace one's programme because of the graphical representation of nearly every step of the computer turtle. During our classes we concentrated on these two items because of their importance in rehabilitation.

### Results and discussion

As we mentioned above, one of the main aims and results of our classes was to teach children to perceive space and its properties in a more adequate way. As we have seen, our children normally had an exact image of right and left sides when the turtle orientation did not greatly differ from their own. But if students needed to make the turtle turn right or left when it had already been oriented in a complicated manner, for instance upside down or bent, they tried to achieve this many times before they succeeded. In six months the most advanced of our students learned to construct exact instructions when they saw the turtle and after only a year they were able to produce exact instructions, without visual support, by writing a set of commands on paper.

Children trained every week for one hour, but the motivation level

was so high that when we came to making Logo-programmes or, as they called it, plans, the children liked to work even without the computer, preparing their own programmes at home.

Our experience has to be considered only as preliminary, but, nevertheless, it allows us to make some points.

The LogoWriter programme creates extremely high motivation for learning. At the same time LogoWriter helps to create a comfortable communicative situation encouraging children's information exchange. Not all the students demonstrated the same abilities in using Logo both as a drawing tool and programming means. Three of our students (Lyuba B., Vadim P and Irina G.) achieved more, and their computer classes were a great pleasure, both for the students and for the teachers. But at the same time Sveta L. was so passive that we feared we should need to stop her computer education. However, after a long period of delay, she overcame all her problems and began making progress. Roman V. developed his skills well but his psychological peculiarities did not allow him to be involved fully in a two-way information exchange with other students. All of the students learned to type and to use the word processor.

In the education of the visually and hearing impaired children the maximum individualised approach is preferable. The Logo family of programmes allowed us to select different styles and strategies for different children. Obviously, visual impairment is not ideal if you need to use a standard screen, but the screen display of LogoWriter is relatively large so visually impaired students can use it. As for teachers, they need to provide different tasks for students related to their visual ability. Hearing ability had nearly no significance because normally teachers used finger spelling and sign language.

At the moment the authors are continuing these classes with LogoWriter and plan to start classes with younger students.

### Acknowledgements

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## News from around the world

### Japan

For a few years deafblind people and others have been meeting in Tokyo and Osaka. Once a month social activities have now developed in other parts of the country.

A new association for deafblind people, Zenkoku Morosha Kyokai, has been established in Japan. Activities include consultation and information services, provision of interpreters and helpers, and communication training workshops. A bulletin in braille and print is published twice a year.

Deafblind children in Japan attend a variety of different types of schools. The National Institute of Special Education is now undertaking a national survey of deafblind children. This should be of great value in promoting deafblind education.

### Israel

The Israeli organisation of Education and Rehabilitation Workers for the Blind and Visually Impaired is now publishing a 50 page magazine 3 times a year making much relevant material from foreign publications available in Hebrew to parents and workers.

The unit for blind multi-handicapped children, Keren Or, has expanded activities to include a day care program for children aged 1-4 years. Several of these children are deafblind and motor handicapped. There is no specific training programme for working with deafblind children but staff are developing their own methods. Ideas on a suitable short training programme would be welcomed,

### Malaysia

Diana Khoo of Penang is trying to find out if there are any programmes for deafblind people in Malaysia. She has written to organisations working with deaf or blind people and to education and welfare bodies.

### Norway

In Norway, in order to counteract the medical institutional model of handicap and focus on potential and talents, congenitally deafblind people are being regarded as a cultural minority. Following this model several new group homes are being built for congenitally deafblind adults.

All adventitiously deafblind people have a right to a state funded interpreter service. The education of professional interpreters is now included in the education of interpreters for the deaf.



**Deafblind 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 deafblind children and young adults. Photographs and drawings are welcome; they will be copied and returned.

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