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The 1994 annual meeting of the IAEEDB Executive Committee was held in Bydgoszcz, Poland from the 14th to 16th April. The Polish Association for the Blind, in particular Joseph Mendrun, Elzbieta Olesziak and Zbigniew Tyepitowski, organised an excellent meeting providing all the participants with perfect arrangements for accommodation, meals and meetings. On behalf of the IAEEDB I would like to express our gratitude to them and all the other people who contributed to the success of the meeting. A special mention must be made for the wonderful burman who kept tending us night after night until the early hours of the day!

Before the Executive Committee Meeting a Symposium entitled “Behaviour and Personality Difficulties” took place. For the first time IAEEDB members had the opportunity to discuss issues which had, until then, received rather little attention. Presentations and working groups ensured a great exchange of information and much discussion about deafblind people who suffer from mental illness. It was particularly noted that the cost of services for these people is much higher than the cost of usual services for deafblind people. These services and initiatives for developing and improving them, were discussed in depth and the knowledge that was exchanged will hopefully ensure new services are created, or existing ones improved, throughout the world. Many thanks to the organising committee Kurt Vinterhoj, Paul Andreelli, Dietrich Bunek and John Hatton who prepared and led this successful symposium.

During our time in Poland the future of the IAEEDB was discussed in many formal and informal situations. In recent years the IAEEDB has developed and changed a lot; a fact illustrated in Poland by the number of delegates who attended from Central and Eastern Europe. The IAEEDB is effectively a network within which local, national and transnational organisations operate and co-operate. Recently there has been much more co-operation within and between regions, and an increase in international service development, so it is now vital for us to decide how and what the IAEEDB will do in the coming years.

The Executive Committee therefore decided to establish a Working Group to discuss the future and develop a Strategic Plan for the IAEEDB. There is a report on this on page 5.

During the meeting in Bydgoszcz I decided that I will not be seeking re-election as Chairman when we meet in Cordoba. The efficiency of the Secretariat and the fact that we meet every year ensures the continuity of IAEEDB action and I feel that the election will not affect this. If anything it will stress the fact that the IAEEDB belongs to all of us.

Having seen the number of interested people during the meeting in Bydgoszcz I have no doubt that we will not have a problem finding a new chairman to lead the organisation towards the end of the century. It has been a pleasure for me to chair the meetings and work with all of you and I will continue enjoying this role until Cordoba (1995). From then on a new colleague will have to make sure that the way our work is organised is adapted to the ever increasing number of members and with the purpose for which the IAEEDB was designed.

Jacques Souriau
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EDITORIAL
Helen Matson, after four years of being Deputy Editor of Deafblind Education and doing most of the work on top of her Sense role, is no longer involved in the publication. She continues to work for Sense but is now Assistant Director for the Sense Fundraising and Communications Department. Many many thanks to her for doing so much for Deafblind Education.

Although I was not at the last IAEDB Executive meeting in Poland - I am told I was missed!!! - I am continuing as editor of Deafblind Education. Thankfully I am now joined on the Editorial Team by Sense's new International Officer, Richard Hawkes and Sense's Project Assistant, Anna Cartwright. Their influence and hard work is demonstrated within this issue.

You will have noticed that this Deafblind Education is different. There are some changes to the design which will, hopefully, make Deafblind Education more useful and easier to read. We hope you like the alterations. However, each edition of Deafblind Education is still basically the same - news from around the world, some items of information, particularly on the IAEDB, and a couple of significant articles.

The articles are submitted by their authors or are selected from relevant conferences or seminar papers. We would very much welcome and need articles of news for the next issue. I hope to hear from you.

Enclosed with this issue is an index of the contents of the previous issues of Deafblind Education. Thanks to Anna for putting this together.

Asuncion Leyton, from Spain, has joined Richard at Sense's International Office. We are taking this opportunity of having a Spanish speaker around to produce a Spanish insertion for a limited number of issues. This will be included with copies going to Spanish and Portuguese speaking members of the IAEDB.

There have been regular discussions at IAEDB meetings about producing material in other languages and hopefully this first experiment will be successful. Producing material in Spanish, at this time, seems particularly appropriate since the IAEDB's next world conference will be in Argentina and the next European conference will be in Spain. If you are interested in this initiative, please contact Asuncion Leyton at the International Office at Sense Midlands.

Malcolm Matthews.
IAEDB Executive Meeting 1994

From the 11th to 17th April 1994 over 70 experts from the deafblind world met in the unpronounceable Polish town of Bydgoszcz for a number of meetings including the Annual Meeting of the IAEDB Executive Committee.

Preceding the Executive Committee was a meeting of the IAEDB Sub-Committee on Staff Development, a meeting of the Scientific Programme Committee for the 11th World Conference in Argentina in 1995, also a meeting for delegates from Central and Eastern Europe and a symposium entitled 'Behaviour and Personality Difficulties' (see page 18). Delegates also had the opportunity to visit the Louis Braille Blind School and a sheltered workshop for blind/visually impaired people.

Relief from the hours of intensive work was provided by a concert given by the Polish Blind Association, a visit to the Filharmonia Pomorska and Bobbi the Barman, who seemed happy to serve up the best Polish vodka until the next day's session was about to start!

The meeting for colleagues from Central and Eastern Europe was particularly successful. For the first time delegates from Albania, Bulgaria, the Czech Republic, Estonia, Hungary, Lithuania, Poland, Russia and Slovakia sat together to discuss the specific situations in their countries. Much was discussed and it is certain that there will be considerable follow-up action, especially as Sense now has an International Officer keen to develop work in that region.

It is always enjoyable to welcome new people to the 'deafblind family' and this committee meeting commenced with the following new members joining IAEDB: Olga Ilgina (Estonia), Irena Matulieni (Lithuania), Janka Sarisska (Slovakia) and Pilar Gomez (Spain).

The Executive Committee discussed many points of interest, more details of which are available from the International Office of Sense, but of particular relevance were the discussions about the future of IAEDB and the discussion about launching an international programme.

Jacques Souriaux talked about the future of IAEDB, and the issues that were discussed in Poland, in his Chairman's Message.

Last year Sense and IAEDB commissioned a report on how to develop an international programme with deafblind people in developing countries. The Executive Committee agreed the main points of this report – that there should be a programme, that the priority regions are the Third World, Central and Eastern Europe and the former Soviet Union. It was agreed that the programme should be taken forward by Sense, which will now be looking to start a number of projects and programmes in the aforementioned regions.

Before everyone departed for the end-of-week banquet, it was agreed to hold the 1995 Executive Committee Meeting in Cordoba, Argentina at the same time as the World Conference; and in 1996 we will meet in Vancouver, Canada.

The whole week was a tremendous success and everyone departed feeling positive (apart from the Scandinavians who missed the bus and had to take a taxi 200 km to the airport).

Miss the bus in Cordoba and it's a long swim home.

Richard Hawkes
International Officer, Sense, UK

Canadian Videos

The Canadian Deafblind and Rubella Association has recently produced three nine-minute videos about deafblindness. They are entitled:

1. Deafblindness: A Unique Disability
2. Independence with Intervention
3. Living in the Community

These videos were produced as part of an Awareness Campaign launched in 1993 to raise the awareness of deafblindness throughout Canada.

The videos are available from the Canadian Deafblind and Rubella Association at a nominal cost to cover reproduction and mailing.
Strategic Plan

The Executive of IAEDB has established a working party to discuss the future and develop a Strategic Plan for the IAEDB.

It was agreed that this group should consist of the Chairman, Vice-Chairman and Secretary-Treasurer. They in turn agreed the following:

1 The Strategic Plan Working Group should include those organisations actually developing international activities geared at supporting new programmes for deafblind people throughout the world. Thus Hilton-Perkins, Sense, NID and Lega del Fano del Oro were invited to join the group.

2 Tony Best, Headmaster of the Royal National Institute for the Blind, Condover Hall School in the United Kingdom should also be a member of the group and should have responsibility for co-ordinating it.

3 There should be as much consultation of all IAEDB members as possible.

The action of the Working Group will be organised in three phases:

a The initial preparation of an action plan, to be discussed during the first meeting of the group. The following topics should be included:
- aims
- method of data collection
- forums for discussion
- decision making procedure
- deadlines for the work
- individual responsibilities.

b Initial presentation of this action plan, for discussion and amendment, to the Executive Meeting in Cordoba in 1995. Delegates will be informed of all the information collected and will make decisions concerning what action will take place between the Cordoba (1995) and Vancouver (1996) Executive Meetings.

c A presentation of a proposal for the IAEDB Strategic Plan to the Executive Meeting in Vancouver in 1996. This presentation should be done so that:
- all data collected is available to the members
- proposals can be discussed and modified after discussion
- a final decision is made by the Executive after thorough discussion. The amount of time needed for this discussion will mean that it will not be possible to have a symposium at the Vancouver meeting.

In addition, as our next two Executive Meetings will take place in North and South America, it maybe necessary to organise regional events in Europe, Africa and Asia.

This will ensure that members from these regions who are not able to attend the Executive Committee Meetings are able to meet, exchange views and contribute to the future developments of the IAEDB.

Sense International Office

In March 1994 Sense (the National Deafblind and Rubella Association in the United Kingdom) appointed Richard Hawkes as its first International Officer.

There had been much discussion within Sense for a number of years about professionalising the international work. The final decision was made after it became obvious that there was a growing feeling within IAEDB that programmes for deafblind people should be developed in parts of the world where services are virtually non-existent.

The role of Sense's International Office will be:
- assisting the development of programmes for deafblind people in the third World, Central and Eastern Europe and the former Soviet Union.
- Strengthening international links between organisations throughout the world
- ensuring a co-ordinated approach to accessing international statutory funds
- raising the profile of deafblindness as a unique disability throughout the world
- developing information about services that exist in every country.

For more information about Sense's international work, or to be put on the mailing list for the Sense International Newsletter, please contact:

Richard Hawkes
International Office
Sense
4 Church Road
Edgbaston
Birmingham B14 3TD
United Kingdom
Tel ++44.21.456.1564
Tanzanian National Committee for the Deafblind would like to express their heartfelt thanks to SHIA (Swedish Handicapped International Aid Foundation) and the Swedish Deafblind Federation for sponsoring two teachers from Tanzania to attend a two-week orientation course at Kaberet School for the Deafblind in Kenya.

The two teachers (Ms Grace Muhumba and Mrs Medrin Gambo) have now started a home visiting programme in Dar es Salaam to counsel and guide parents of deafblind children. One child involved in this programme is Arafa Haji Hassan, an eleven year old girl living with her parents in the suburbs of Dar es Salaam. Arafa was not born deafblind, but at the age of four after a short severe illness, she acquired visual and hearing loss.

The programme will give exercises to children like Arafa while she is at home and plans are underway to start a unit.

For further information contact:

Ms Elly Mocha
PO Box 22408
Dar es Salaam
Tanzania
Tel: 051 49389

Since the Anne Sullivan Foundation was formed in 1989 Ireland’s primary activity has been trying to persuade the Department of Health to provide a special unit for congenitally deafblind young people.

Historically in Ireland only a minority of deafblind children have been accepted in schools for the deaf or schools for the blind, most have attended centres for the mentally handicapped. On becoming adults they have then been transferred to psychiatric hospitals for the rest of their lives.

In October 1993 the Department of Health agreed to provide the running costs of a residential home and training centre for ten young deafblind people. The Anne Sullivan Foundation will be responsible for the capital outlay for the building and the management of the centre.

Building commenced in April 1994 in the grounds of an existing home for 43 deaf people, eight of whom have also lost their sight.

In Malaysia the Multi-Handicapped Unit of St Nicholas Home in Penang is the only place providing a service for deafblind children.

The Head of the Unit, Simon Rajendran, has attended a Hilton-Perkins sponsored Diploma Course in Teaching Multi-Handicapped Children. The course, which lasted five months, took place at the Perkins School for the Blind in Boston, USA.

'Multi-Handicapped' refers to a combination of two or more disabilities, but all of the children in the unit are visually impaired. Some of them are deafblind and others have additional disabilities.

Simon Rajendran has now developed a planned programme in the Centre for eight children and has started to develop outreach programmes and assessment in the community. He is also involved in the establishment of a programme for multi-handicapped children in another centre south of Penang.
Rehabilitation and training camps for the deafblind

Paper presented at the 3rd European conference of the IAEDB, Potsdam, 1993

Jozef Mendrun is from the Association for the Welfare of the Blind, Poland.
Elzbieta Oleksiak is from the Polish Association for the Blind, Poland.
This paper is addressed to experienced professionals as well as the newcomer working with the deafblind.

Eight years ago when we began our rehabilitation programme we were very unaware of the needs of deafblind people. We began our course of activities with an acknowledged lack of experience; how were we going to communicate and what could we expect from the participants? We did not know that, depending on the timing and degree of sensory loss for a deafblind person he/she will require different forms of communication, rehabilitation and caretaking approaches.

Rehabilitation and training camps have proved a valuable means of gaining such information on the needs and capabilities of deafblind people. Through establishing close contact with the children and adults who attend these courses we have been able to appreciate their varying needs with a level of understanding previously unknown.

Camps usually last two weeks and bring together deafblind people, their companions and a team of specialists. These often total 50 people.

Companions are usually parents, in the case of children, and spouses, relatives or close acquaintances for adult participants.

The camp programme aims to provide an enjoyable time for both the deafblind person and their guide, whilst identifying the needs of the participant. We have found that the deafblind person is initially unable to assist in constructing their activity programme since they are unaware of their needs. It is one of the Camp aims to identify participant’s capabilities and requirements.

At an early stage in the camp programme we create opportunities for in depth observation and diagnosis of the participant. This answers questions on the capabilities of the deafblind person in various areas, and supplies vital information to not only the course organisers and specialists, but also to the deafblind person him/herself.

Composition of the Camp
Experience has taught us that an ideal number for a camp is twenty deafblind people. People’s age, methods of communication and their interests are considered in creating a group. This number is then split into smaller groups to promote the interaction of participants. We have found it necessary to distribute a far greater number of questionnaires to prospective participants to assemble 20 people as only 30% generally respond to the invitation.

The following criteria are considered when selecting participants for a camp:

- the degree of their visual and hearing loss
- the degree and type of any developmental disorder
- their place of residence and whether there is a possibility for medical and rehabilitation assistance at that residence
- their social and family situation (e.g., single mother/stressful family life / difficult financial situation)

Professionals who attend
To fulfil the aims of the camp programme we require a team of specialists to attend. This is usually composed of the following: psychologists, pedagogues, logopedists, a teacher of play and music, a visual training instructor, a physiotherapist, an instructor of communication, a mobility instructor, psychotherapists, doctors/physicians, an instructor of daily living skills, an activity-centred therapy instructor and the head manager.

It is important that these staff can work simultaneously with a child and his/her parents and has the personality to cope with the camp activities. They need to be flexible in their approaches, and demonstrate perseverance and enjoyment in performing the laborious and time consuming exercises whose effects, though often small, may take a long time to become apparent.

Instructors undertake tasks such as:

- direct work with the deafblind
- preparing each day’s detailed plan of action for individual participants
- writing up each lesson
- carrying out individual consultative and therapeutic talks with participants
- attending group seminars for participants /holding lectures for other staff
- participating in everyday meetings of the rehabilitation team
- elaborating on the final recommendations of the camp and passing these on to participants

Professional development
Camps create an ideal opportunity to train staff in assisting deafblind people. Staff are usually professionals working with the blind, the deaf or people with learning difficulties. They do not have experience of working with the deafblind and are often uncertain about achieving goals with the participant at the beginning of the programme. A
Camp is an excellent situation for them to gain the knowledge and skills necessary for this.

An extremely important aspect of the camps is the opportunity they provide for various professionals to work together. This is a rare event since they are usually dispersed around the country and work in isolation. Specialists are often required to resolve difficult issues on their own and can experience considerable stress as a result of this. Camps aim to elevate some of this by inviting a cross section of specialists to attend, hold discussions and jointly analyse problematic issues. This provides psychological support through knowing there are other people who can be consulted when difficult situations arise.

Content of the Rehabilitation programme
The rehabilitation programme strives to have impact through the following areas:

- Teaching various methods of communicating (e.g. palm point alphabet, Braille writing, sign language & typing)
- Improvement of vision
- Improvement of hearing and speech
- Psychological and pedagogical lessons
- Mobility and orientation training
- Physical education and physiotherapy
- Club type activities and demonstration of rehabilitation aids
- Activity centred therapy, for example, sculpture in clay and wood
- Training in daily living skills
- General medical examinations
- Interviews aimed at a detailed identification of the rehabilitative and social situation of camp participants.

Preparation for Camp activities
An important condition in carrying out a successful course camp is to have a well considered programme of evaluation and rehabilitation. This preparation involves the following:

- Creating a set of questionnaires to gain information on participants. These aim to facilitate, direct and coordinate the work of the specialists
- Translating various publications concerning deafblind people that might guide the rehabilitation work
- Providing appropriate materials for each activity and lesson.

Ongoing Rehabilitation
We are aware of the anxiety the rehabilitation camps create in some deafblind people when they consider returning to their home environment. Camps aim to develop hope for a deafblind person’s future, and it is likely that they will wonder how this can be sustained where they normally live. However, we feel that in giving the deafblind even this occasional awareness of themselves through new experiences and as a focus of interest they receive valuable encouragement.

After two weeks of a camp we gain a reasonable understanding of a deafblind person’s capabilities and needs. This knowledge must now be transferred to ensure continued assistance for the person, and be translated into an ongoing rehabilitation programme. The Camp works to achieve this through joint action projects. These create special centres of education and rehabilitation and provide assistance in homes. The information acquired on a camp enables these projects to be planned in the most effective manner.

Course aims
The main purposes of course camps are defined as

- Providing a rehabilitation and medical diagnosis for participants
- Working out individual programmes of rehabilitation for each participant
- The partial accomplishment of such programmes through running rehabilitation projects
- Familiarisation of the deafblind with hearing devices, optical and non optical devices, and supplying these as needs arise
- Familiarisation of the deafblind with other technical appliances which would assist their everyday life and professional work
- To make guides/carers of the deafblind aware of their role and methods of communication
- To make parents aware of the needs of children with both visual and hearing impairments
- Creating conditions for deafblind people to relax and get to know one another
- To train guides/interpreters or parents in the ongoing rehabilitation programme at home
- To advance the qualifications of professionals who attend the camp.

Some hints for training camps
While running a camp it may become apparent that some individuals will require additional assistance to achieve the benefits of long term rehabilitation. This may require repeated invitations to attend camps until it is possible to provide rehabilitation services in their place of residence or another centre.

The wide range of communication needs of deafblind people indicates an education programme for staff should be provided in the various methods of communication.

Camps have proved an ideal arena for developing future specialists who are skilled in working with deafblind people. To maintain and further add to this number the composition of invited specialists could be 50% previous camp staff and 50% new professionals.

We encourage the staff who participate on the courses to contribute to both the development of rehabilitation theory and practice through gaining further experience and in producing publications.

The rehabilitation programme described here comes with both our own recommendation and those of the deafblind people who have participated in them. The need for further rehabilitation and training courses for the deafblind is widely confirmed.

Jozef Mendrun
Association for the Welfare of the Blind
00-216 Warszawa ul. Koniktorska 9
Poland.

Elzbieta Oleksiak
Polish Association for the Blind
Central Board
00-216 Warszawa ul. Koniktorska 9
Poland.
We are very pleased to give you some further information about the conference. You are now able to register for the conference, and we encourage you to do so as soon as possible. Full details of the programme, workshop submission forms and application forms can be obtained from:

IAEDB Conference
Hilton-Perkins Program
Perkins School for the Blind
Watertown MASS 02172, USA

To get this information, write to the address above, telephone (USA) 617 924 3434 or fax 617 923 8076.

Call for Papers
If you would like to present a paper at the conference, you are invited to submit your proposal to the Programme Committee. All proposals must be submitted by December 1st at the latest. You are advised to apply as soon as possible as only a limited number of papers can be presented. Full instructions for the submission of proposals can be obtained from the conference office at the above address. The priority areas for workshops are:

- Staff Training
- Professional Ethics
- Use of Personal Advocates
- Behaviour
- Sexuality
- Vocational Services
- Interpreter training and services
- Communication with severely handicapped individuals
- Programmes for congenitally deafblind adults
- Transition from school to adulthood.

Starting and Developing New Programmes in Latin America
This workshop will be of interest to all participants involved in starting new programmes for deafblind children.

Participants from Argentina, Chile, Uruguay and Brazil will present an analysis of information and written materials received about programmes in Latin America. It will describe the current situation and identify what institutions need to focus on to develop successful new programmes in Latin America. There will also be a panel discussion on developing policies and plans to ensure a strong future for deafblind services.

Usher Syndrome
The programme for this group will include the following topics:

- Ways of working with children and young people in the educational setting
- Training, offering some strategies for working collaboratively across the professional disciplines.

This focus group will be of interest to people who have Usher, their families, and to all professional workers in the medical, educational and social work fields.

Families and their Concerns
Parents and relatives of deafblind people are invited to this day, as well as medical professionals and educational specialists. The morning will include topic development and question and answer sessions. During the afternoon, participants will work in discussion groups. Among the main themes for discussion are:

- The couple in privacy: their fears and guilt
- Relationships between parents and the other children in the family
- Doctors and their attitudes: parents' reactions
- The social environment: changes in family habits
- Organised struggle for common objectives: The Associations of Parents.

Adventitious Deafblindness
The purpose of this day is to make participants more aware that acquired deafblindness exists and how it is different from congenital
examining a deafblind child's behaviour

the purpose of this day is to introduce participants to principles and techniques for addressing behaviour difficulties of children with deafblindness. upon completion, participants will be able to:

- define behaviour
- examine the functions of a behaviour
- understand the basic principles of behaviour management
- understand the relationship between the management of behaviour difficulties and the ways in which deafblind children learn.

participants will be provided with resource materials and references for use in implementing the concepts and skills learned in the workshop.

details of additional focus groups, including those on early childhood and management issues for non-profit organisations, will be included in the next announcement.

registration

full details of registration are given in the programme information that can be obtained from the address given above.

to register, you simply have to send your name and full address to the conference office with your registration fee. this must be remitted by check, in us dollars, payable to 'fundacion helen-kellercordoba'. fees are:

- before 1 september 1994 ......... us$ 280
- before 15 february 1995 ......... us$ 320
- before 1 june 1995 .............. us$ 370
Personal and Sexual Development in the Deafblind Adult

Virginia Von Malachowski, Deputy Regional Director, Sense Midlands, UK

Background
Sense Midlands offers residential and educational opportunities to 63 deafblind and multisensory impaired people. The centre has been open for six years and has steadily increased its numbers over that time.

It became clear as we grew that we needed to address some fundamental issues about the personal and sexual development of the people who live here.

Amongst the issues which were challenging us we saw:

- deafblind people displaying inappropriate sexual behaviour in public
- deafblind people displaying unwelcome sexual behaviour towards other students and staff members
- staff giving mixed messages to deafblind people about what was acceptable behaviour
- staff reluctant to discuss client’s sexual behaviour because they were too embarrassed.

As an organisation, Sense was still at an early stage of developing its Adult Services so there were no ready answers about how to approach these issues. Within the wider field of special needs there had been little work done on which we could draw.

We recognised that we were failing to address the personal and sexual needs of the people who were with us but we also recognised the complexities in doing so.

We set a series of objectives for Sense Midlands:

1. Decide what would be our “approach” to personal and sexual matters with our population.
2. Make clear statements to staff/parents/sponsoring authorities about our approach.
3. Raise staff awareness about attitudes/practicalities and legal issues.
4. Give staff clear guidelines about practice.
5. Give clear guidelines about assessment of needs, programme planning and teaching materials.

There were a number of significant factors which guided our action:

- Sense Midlands was still a very “inexperienced” centre and needed to move in a considered way.
- there was very little published material to guide us.
- any teaching would likely be tactile and raise considerable complications.

What did we do?
1. A Working Party was set up 4 years ago.
2. The group began with a fact finding and research mission to explore other peoples practice.
3. The group clarified our position in relation to the Law.
4. The group formulated a Policy Statement which made clear statements about our beliefs and values.
5. We wrote an assessment document which let us clarify the areas we wanted to address for our students and gave us a tool by which we could assess their needs.
6. We wrote Operational Guidelines which formed the planning procedure for any work we would undertake with the student.
7. We offered staff training/awareness to all staff with the help of an outside “expert”.
8. We took the first step – !!

Let us look at some of those aspects in a little more detail.

The Legal Situation
The law in England turned out to be very unclear. Many of the laws were outdated and did not reflect current values. There were gaps in the legislation and in areas where we sought guidance, none existed. Many of the laws were untested in relation to special needs and it was difficult to determine how the issue of “informed consent” might be interpreted.

We managed to extract which aspects of the law did relate to our group and received guidance from national disability groups as to how to interpret certain clauses. Our purpose was to understand the limitations of the law and to ascertain the best way to work within those limitations whilst protecting staff and clients.

If we were working with people who wished to conduct sexual relationships with another then we needed to abide by the following legislation:

- Sexual Offences Act
- The Age of Consent
- The Mental Health Act.

There needed to be a number of issues borne in mind, such as how the law defined mental handicap and how it differentiated between the “normal”
population and this group of people. There were also issues around the age of consent for homosexuals although no law relates to lesbian behaviour.

No legislation helped us to define the phrase "informed consent" which was to be a crucial interpretation in relation to the laws and their application to our population.

The Policy Statement

was written in accordance with Sense's Mission Statement which states that we believe that everyone:

- is a full citizen with rights and responsibilities, entitled to dignity and respect
- has the right to information, to make choices and to fully contribute to the planning of services
- should have access to services that take full account of their individual needs.

A recognition of these rights and responsibilities in terms of personal and sexual development means that our deafblind people have the right to make an informed choice, to say no, to love and be loved, to develop a warm personal relationship and to express their feelings.

In order to enable this to happen for our students we recognise that if the teaching involves any work of an intimate or sexual nature then the planning and implementation of the teaching needs to be done in a very systematic and accountable way.

The Operational Guidelines

This planning strategy allowed for at least five people to be involved with a maximum of ten people as appropriate. It built in as many safeguards as were possible around the legal situation and importantly the strategy ensured that no one person took responsibility.

The group responsibility enabled us to act on behalf of the student in an advocating role to ensure that as far as possible we were interpreting his behaviour and allowing him to have informed choices.

The Assessment Document

provided us with a tool by which we could address a number of areas of relevance. The areas we covered were:

- Development of self
  - awareness of self
  - bodily functions
- emotions
- personal sexual behaviour

Development of relationships

- awareness of another
- friendships (non-sexual)
- sexual behaviour towards others
- sexual relationships.

Staff Training and Awareness

The staff awareness sessions preceded the launch of policy, operational guidelines and the assessment tool. We raised issues about our deafblind people and their rights but we also aired concerns about the risks and problems we might face. The sessions were very open, non-judgmental and unstructured in their aims. Staff gave the working party a clearer idea of the areas of concern and what was required to be in place in order to address their needs.

The group responsibility enabled us to act on behalf of the student in an advocating role to ensure that as far as possible we were interpreting his behaviour and allowing him to have informed choices.

The Plan in Action

Brian is twenty three years old. He has congenital Rubella syndrome and presents with partial sight, moderate hearing loss and severe learning disabilities. He has been at Sense Midlands for four years.

Sexual Behaviour

Sexual advances toward staff and other clients had been reported for a number of years prior to arrival at Sense Midlands. This had been mainly managed by the use of behaviour controlling drugs, some of which were designed to reduce his sexual drive. On arrival at Sense Midlands the drugs were steadily reduced. There were no major changes in Brian's sexual behaviour which were linked to the reductions although it was fair to say that the frequency of his approaches did fluctuate from time to time.

There was also a high frequency of aggression associated with his sexual behaviour mostly in the form of biting others.

The sexual behaviour we observed was:

- unsuccessful attempts to masturbate by rubbing himself against people, surfaces or the floor and putting his hand down his trousers and pulling at his penis.
- approaching staff of either sex and pressing himself up against them often very forcibly. He could also get very sexually excited in massage or swimming sessions and was particularly attracted to the male member of staff who ran these sessions.

- there were a few occasions when he "presented" himself to staff whilst he had an erection in such a way as could have been interpreted as requests for anal or oral sex.

- he approached both male and female students. This would often happen at night when he would rush into another bedroom and attempt to put his penis to their face or get into bed with them.

Until we ourselves were clear about what the organisation policy would be and how we might go about working with Brian then we simply attempted to minimise inappropriate behaviour by building in a number of preventative strategies and also to make it clear to him what behaviour was acceptable and what was not.

Having got to a stage where we felt that we understood the law, we had made clear statements about our own beliefs, developed some strategies which would help us assess him and safely plan an intervention for him. Then we began the programme that is currently being undertaken.

Brian's Personal Planning Group consisted of eight people chaired by the Head of the Department. It involved a range of staff who had different responsibilities and relationships with him. The parents were invited to be part of the group but declined expressing their trust in our judgement and their support in the work which we were doing.

As far as we knew Brian had never ejaculated while masturbating and we felt that his approaches to other people and also some of his aggressive behaviour was possibly associated with requests for help or expression of frustration.

We agreed that our aim was to teach Brian how to masturbate to orgasm. We felt that he did not have the motor dexterity to manipulate himself and that had probably been one of the reasons for his lack of success so far, we concluded that our approach would be to aim to teach him to use a penis vibrator.

The programme was written out in clear teaching stages and specified
when it might be necessary to touch him in order to show him what to do. The teaching sessions were to be conducted in his own bedroom by a senior member of staff who did not come in to contact with him normally. Each session was observed and recorded by another member of the planning group with the notes from the session helping us to plan the next stage but also to be confidentially retained to safeguard staff who had taken part in the teaching.

We did not start the teaching until the family and sponsoring authority had agreed to the programme details.

The teaching programme was as follows:

1. B accepts vibrator
2. B places vibrator on penis
3. B holds vibrator long enough to achieve orgasm
4. B washes self and vibrator

After only two teaching sessions it became obvious that this approach was not going to achieve a desired outcome. The problem was that Brian was far more interested in the person doing the teaching as a "sex aid" than the vibrator.

We needed giving Brian the vibrator when he was masturbating to see whether he might "discover" how to use it but he would not accept the aid and handed it back to the tutor on each occasion.

We used two sets of materials - each set consisted of a model penis and a vibrator, the teacher would demonstrate possible ways in which the penis could be touched or stimulated and would encourage Brian to copy this action. We felt sure that he had the symbolic understanding to relate this demonstration to his own body at another time.

The programme was as follows:

**Target**

Brian will turn on vibrator touch and place over model penis after this has been demonstrated by named tutor.

**Steps to target**

1. Tutor asks B to go to the bedroom.
2. Tutor helps B turn on vibrator.
3. Tutor sits on the edge of the bed with B and holds model penis on their lap.
4. Tutor takes 2nd vibrator out of box and turns it on.
5. Tutor holds model penis in one hand and touches the model with the vibrator - tutor puts vibrator over model penis.
6. Tutor gives B model penis and gestures to place it between his legs.
7. Tutor gives B his vibrator in right hand and instructs him to touch or place vibrator over model penis.
8. If necessary tutor to repeat behaviour with the second set of equipment at the same time that B is using the model and vibrator.
9. B's vibrator is left in the bedside cabinet. If he makes a sexual approach during the teaching then the session will be concluded.

So far we have done three teaching sessions, each has been no longer than 3-4 minutes in duration. Each time Brian has concentrated well and has been interested in the materials. He has brought the sessions to a close by packing up the equipment but has chosen to leave his own vibrator in his bedside cabinet which he had not been keen to do previously.

The programme will continue in the slow and considered way in which it began with a review after every two teaching sessions.

**Conclusion**

In the early stages of the work at Sense Midlands we were under the naïve impression that someone, somewhere would have the answers to all of the dilemmas and difficulties we faced. In reality it seemed that few people had faced the challenge of these issues. Our attempts have been tentative and slow but guided by a firm belief that the quality of life for the individuals who live with us would be enhanced by access to information and opportunities which would allow them to express themselves more fully.

As an organisation we have been persevering in overcoming the practice details and realistic in the goals we have set ourselves. We believe that this provides a firm and safe basis for development to continue and for the deafblind people to enjoy a more fulfilling and complete lifestyle.
The EUCO Unit

In 1993 The European Co-ordinating Unit for Staff Development in Deafblind Services – The EUCO Unit for short – was established on the initiative of the IAEDB and the ECDBS with the major idea to improve the services offered to deafblind persons through a co-ordinated European co-operation on staff development. The EUCO Unit’s network and information service is vital in this.

To benefit from The EUCO Unit’s services you must subscribe as either a corporate or a funding member.

We would like to thank warmly the 10 funding members and the 50 corporate members for their interest and confidence in this initiative. If you are not already a member, you are always welcome to join the network.

As a member of The EUCO Unit you will receive some information material:

- The first issue of the EUCO News Bulletin came out in April. The second issue will be with you in the autumn. The EUCO members – those who have subscribed to the services of The EUCO Unit – receive it automatically.

- The EUCO Unit is editing, and will distribute, an inventory of resources in deafblind work in Europe; institutions, schools, associations – all kinds of services to deafblind people (and we also welcome entries from other parts of the world!). The inventory will be up-dated yearly.

- The EUCO Unit Bibliography of books, articles and video material on deafblindness and related areas is also currently being prepared. It will contain the bibliographic information on around 2500 titles in NUD’s international library which are in English (some in German and French, as well). The bibliography will be up-dated yearly to include all new titles.

Leadership at a European Level
In co-operation with the European Council’s Youth Centre a one week workshop/seminar will be organised in 1995 to enable young deafblind people to come together for a leadership course. This idea was the result of meetings with young people during the 5th Helen Keller World Conference which took place in Italy in September last year. As the form and content take more shape, interested parties will be contacted.

Exchange between Lega del Filo d’Oro and the Centre for multisensory impaired people in Columbia
The Lega del Filo d’Oro has earmarked resources for the development of services for deafblind people in developing countries. The Institute has initiated a corporation with Centro para Limitados Visuales y Auditivos in Colombia and will start up by having 2 staff members coming to Italy for a study visit in November this year.

Two of the Projects currently in development are:

European Development Project on Communication with Congenitally Deafblind Persons
Communication is a first priority area for all deafblind people, whatever their age, level of development and social situation. They need skilled helpers to be able to communicate at the maximum of their capacity.

The aim of this project is to create a basis for improved staff development in

Kurt Vinterhøj, Principal of the EUCO Unit and Director of the Nordic Staff Centre

Clipboard

Information and co-ordination of projects to develop services for deafblind people in East and Central Europe
At the 1993 IEADB Executive Committee meeting at Perkins School for the Blind in Boston it was decided that the EUCO Unit should collect information on all development projects for deafblind people in the countries of East and Central Europe. In future it will be possible to get information on what is already done to develop deafblind services in these countries. This is to benefit from each other’s achievements and avoid duplication of efforts. It is important that the work to develop services for deafblind people becomes as effective as possible.

The need for development in the region is strong and therefore schools and organisations around the world have been requested to assist in developing services for deafblind people.
the area of communication with people who are born with deafblindness. The project focuses on the critical steps in communication development. A book and a video tape for use in staff development is the very concrete planned outcome. The focused target group for this material is staff trainers and professionals responsible for IEPs.

Ethics
In recent years professional ethics have come under the microscope, probably because of the fact that ethical behaviour is not always explicit to professional competence and training. The guidelines suggested by professional groups rarely take into consideration such issues as the right of the client for self determination, however, a positive fact is that client groups have a more decisive role in creating and delivering services, decision making and advisory roles.

In interacting with deafblind children and adults and deafblind people's families one is often confronted with ethical dilemmas, while there are practically no supporting guidelines. Now is the moment to investigate this subject in a general manner, leading to a more specific form concerning deafblind people.

For more information on the activities of The EUCO Unit, please contact:

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Until recently there was very little provision for deafblind people in Slovakia, thus depriving children and young adults of their basic right to education.

In 1992 a School for Deafblind Children was established in Cervenica in Eastern Slovakia. This partially filled the vacuum.

As this school was the first of its kind in Slovakia advice and assistance was sought from abroad. This has come from schools in Hannover, Potsdam and Bydgoszcz which have each hosted study visits for selected staff from Cervenica. The Hilton-Perkins Programme has also been very involved offering professional support and inviting a Slovakian professional to attend their Training Programme.

At the moment there are five children in the school and another three at home who will move into the school when current renovations are complete.

The educational system of the school is based on the pattern developed at the educational Centre for Deafblind Children in Hannover with educational activity divided into the following five areas:
1. Development of motor skills
2. Perception abilities
3. Daily living skills
4. Cognition, communication and language
5. Social development

Each child has their own individual programme which is developed according to their mental and physical abilities and, most importantly, to their own needs.

The underlying rule for their education is enabling every child to have access to everything possible.

Thus, after an initial diagnosis, the most suitable way of communication (signing, loom, Braille) is determined. Four out of the five children are able to receive information through signing.

Extremely detailed progress reports, in individual files and also on video, are maintained for every child. From these reports it is clear that each child has made a considerable amount of process since starting at the school.

The methodology and educational practices will be reviewed with time. It is too early at the moment to be able to evaluate these properly, but the school will adapt with time according to evaluations.

As with any new initiative, particularly in a country that has undergone deep changes, there are considerable problems to overcome:

- there is not enough money to complete the reconstruction of the school in the most appropriate way
- the staff need to participate in longer study visits to other countries
- the staff need further training in assessment and evaluation techniques.

If you are interested in assisting developments in Slovakia, or would like further information, please contact:

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Modified Sign Language for Congenitally Deafblind People

At the 3rd European IAEDB Conference in Potsdam it became obvious that many congenitally deafblind people do not have the necessary visual and motor skills to be able to use the sign language of the deaf as their means of communication. In a variety of centres work is being done to adapt the signs of the deaf to suit the needs of congenitally deafblind people. Many people have expressed a desire to cooperate in this area of work. They aim to enhance developments and avoid the same work being done in different places.

Here ANN THESTRUP and OVE VEDEL ANDERSON report on developments in Denmark.

Sign language
We have worked for 12 years with congenitally deafblind children at the department for the deafblind at Aalborgskolen, a school for deaf and hard of hearing children.

We consider sign language of the deaf a language with all the structural aspects of other languages such as syntax, grammar and vocabulary, and that sign language is considered the native language of deaf people.

Consequently we have for many years used sign language of the deaf as a basis for our communication with congenitally deafblind children, and in the training of their language skills.

The group of children that we have in mind in this study are mainly functionally deaf children with various degrees of residual vision, most of them with various additional learning and motor difficulties.

Problems exist in using a visual language in communication and language training with congenitally deafblind children.
We found that in many children the communication ability was good, but they did not learn to communicate in sign language.

Congenitally deafblind children in our department generally have a number of difficulties beyond hearing and vision impairment, for instance:
1. Delayed motor development and motor dysfunctions
2. Reduced spatial orientation
3. Reduced sequential memory.

Visual impairment causes lack of visual feedback in using sign language.
Motor dysfunctions and reduced spatial orientation make it difficult for these children to master a number of signs, for instance:
- signs which involve asymmetrical movements
- reciprocal two-handed signs.

A reduced sequential memory causes difficulties in performing signs with sequences of movements.

Modifying the signs to suit the needs of congenitally deafblind children

In the course of time many teachers and other staff members had begun modifying difficult signs on their own initiative. Some children would therefore in the course of their day meet up to 5-6 different modified signs for the same word, which would cause a lot of confusion.

We therefore felt a need for standardising the modified signs, realising that the natural changes and development of language being used among a group would not occur in the language of the congenitally deafblind because most of them do not communicate together.

Principles for modifying the signs of the deaf to signs for the congenitally deafblind
1. The number of movements in each sign should be kept to a minimum.
2. The number of motor elements should be kept to a minimum.

3. The lack of visual feedback should be replaced by a tactile/kinesthetic feedback, thus 'signing in the air' should be replaced by 'signing on the body'.
4. The initial and final positions of the sign should be on the body and must be very distinctive.
5. Signs should make use of the entire hand, rather than part of the hand or fingers only.
6. Signs involving both hands should be symmetrical rather than asymmetrical.
7. The signs should be functional: preferably iconic/natural signs, meaning signs describing the movement or action as experienced by the deafblind child, or describing a physical attribute of an item as it would be experienced by the deafblind child, therefore using a tactile rather than a visual attribute.
8. Arbitrary/symbolic signs should be avoided.

Standardising the modified signs
Since we had found a necessity for standardising the modified signs, we set up a procedure to establish:
1. which signs are difficult and therefore have to be modified
2. which signs, out of several possibilities in the sign language of the deaf would be suitable for the deafblind without changes

Using this procedure the staff from the
residential homes, the teachers and the parents co-operated in assembling a list of 362 signs to be examined. These signs were examined, resulting in 98 of them being rejected and replaced by modified signs according to the principles described previously. The rest of the signs were standardised. This meant that one sign was chosen among several possibilities in the sign language of the deaf to meet the requirements of deafblind children.

A video film and a pamphlet of the 362 signs, with special notation to mark the 98 modified signs was produced and distributed to schools, residential homes and parents, to establish the use of these signs.

**Future goals**
The idea is to use the modified signs where needed, and as long as needed in the individual case, with the purpose of gradually approaching the sign language of the deaf.

**Examples**
The following pictures show four examples of how the signs can be modified according to the mentioned guidelines.

![1a: "Cucumber" (Danish Sign Language of the Deaf)](image1)

![1b: "Cucumber" (Modified Tactile Sign)](image2)

![2a: "Banana" (Danish Sign Language of the Deaf)](image3)

![2b: "Banana" (Modified Tactile Sign)](image4)

The left column pictures named 'a' show the sign as used in the Danish Sign Language, the right column named 'b', shows the modified sign.

**References**
The photos of the modified signs are from the pamphlet ‘Davblind borh. 362 tegn’, Daveskolernes Materialaboratorium Aalborg 1988.
Behaviour and Personality Difficulties

The statement below was prepared at the IAEDB Symposium on Behaviour and Personal Difficulties. If any reader has any comments on this we would be pleased to hear from you.

Statement from the Symposium

All people have equal rights, including the right to full participation in society.

In order to obtain access to these rights deafblind people need services to meet their unique needs.

To maintain their mental health deafblind people need an environment which provides

- appropriate communication
- a feel of security
- information regarding available options
- the opportunity to expand their own strengths
- the possibility to make choices
- access to relationships

If behavioural problems occur, then deafblind people should have access to specialised services, given by a multi disciplinary team to enable a holistic approach, in their own environment, in a specialised deafblind setting or in a deafblind unit within existing psychiatric service.

A multi disciplinary approach should include a psychiatrist with specialised knowledge of deafblind people, a medical doctor, interpreting services, a social worker, and a deafblind specialist worker as well as the deafblind person themselves and their family, carer, or advocate.

Problem behaviour should be managed in a manner that is respectful and dignified and does not impinge on the rights of the individual. People should be aware that the use of drugs and adverse techniques will exacerbate the deafblind person's already severely limited ability to communicate and receive information.

Due to the high staffing needs and the requirement for specialised training for the people involved with services to deafblind people, the costs involved will be high. The provision of psychiatric services to this group of people is no exception to this.

Any psychiatric service should be seen as part of a continuum of services aimed at the prevention of any behavioural \ mental health problems. This could include specialist counselling services, family support, advocacy schemes, intervenor services, residential services, staffed by specially trained people etc.

European Organisation

In May 1994 the European Communities Deafblind Secretariat (ECDBS) became the European Deafblind Network (EDbN).

The most fundamental change is that EDbN will now be open to all European countries and not only those in the European Union (as was the case with ECDBS).

EDbN strongly believes in the involvement of deafblind people, family representatives and professionals. Each country sends one delegate from each of those categories to the Annual Meeting; three people from each are elected to the Management Committee; and the Chairperson is elected in turn from each group.

Lex Grandia, seminar speaker and Chairperson of the Management Committee of EDbN.

At the Annual Meeting in Athens Mr. Lex Grandia, a deafblind man from the Netherlands, was elected as Chairperson for the next year. Many IAEDB people will know Lex from the IAEDB Executive Committee in Poland where he kept everyone singing through many nights with his expert piano playing! It is sure that with him as Chairperson EDbN is in for an exciting, and hopefully successful, year.
The International Association for the Education of Deafblind People was founded over 30 years ago to promote the education of deafblind children and young adults throughout the world. The Association originally brought together professionals working with congenitally deafblind people. In recent years it has begun work with adventitiously deafblind people. Professionals, researchers, families, deafblind people and administrators are now involved.

The objects of the Association as established are as follows:

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

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

Membership

There are two categories of membership: individual and corporate.

Individual membership is open to anyone. An annual donation of £10 is requested. Each country can have a representative on the Executive Committee for every 10 individual members up to a maximum of three representatives.

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

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

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

☐ I wish to become an individual member of IAEDB. I enclose £10, or

☐ I wish to become a corporate member of IAEDB. I enclose £100

Our corporate representative will be ____________________________

Signed ____________________________

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