

The Special Interest group – Medical Issues (adults)
Worcester, South Africa, October 26th 2005
Viveca Schoultz

The Medical issues SIG came together for the fourth time in Worcester, South Africa in connection to the 3rd Mental Health and Deafness World Congress. The idea of the SIG was to stimulate a free discussion and share knowledge among professionals that work in a clinical, medical, psychological or socially oriented setting for the adult Deaf. The invitation to participate in the SIG was open to everybody attending the congress. The participants were invited to present a paper, a question or a case to the rest of the group.

This year the Medical issues SIG had about 30 participants from countries like South Africa, Congo, Sweden, Holland, Belgium, England, Australia, Norway, Denmark and Finland. In the group there were psychiatrists, psychologists, social workers and Sign language facilitators who worked in different clinical settings.

1. Tove G. Larsen from Centre for the Deaf in Denmark: Persons with acquired deaf-blindness. Description of their own situation and need for psychosocial support

Tove presented a Nordic longitudinal study in which 20 persons with acquired deaf-blindness from Sweden, Norway, Iceland and Denmark were interviewed six times during one year. The focus of the project was to systematically gather information about the deaf-blind person's own experiences with acquired deaf-blindness and to get an insight about the consequences of a progressive hearing and sight disability. With this study they wanted to build up new knowledge for those who work with persons that have acquired deaf-blindness and their families.

The study had an individual perspective where the deaf-blind persons daily life, personal reflections and individual ways of acting to compensate for the functional reductions were studied. The society's perspective was studied regarding how the deaf-blind persons were met by relatives, friends and local community. One focus was also the communication in the family and how the impairment affected that.

The study has just finished and six booklets will be published shortly. The booklets are: 1. Theory and methods, 2. Receiving a diagnosis, 3. Getting support, 4. Being active, 5. Getting an education and work and 6. Narratives of everyday life.

Selected extracts from the book:

- The visually impaired child is even more vulnerable in less-structured leisure situations
- It is so difficult to be isolated and so difficult to be part of a group – you have to give the youngsters some survival strategies, many refuse to speak about it, and try as hard as possible to feign nothing's wrong
- The survival strategy can last some years, but not for ever – and especially not when eyesight worsens considerably
- Many young persons with acquired deaf-blindness give up and isolate themselves or prefer a “quiet existence”

What can you do? You have to make communication and information available in their environment. Other pupils in the classroom need to understand the special needs of the pupil with acquired deaf-blindness (here often hard-of-hearing and sight impaired person). It's crucial that people around the deaf-blind person understand that people with acquired deaf-blindness need more time and attention to take in information and give feedback than their non-disabled peers can in a more or less passive manner. Independent behaviour comes when they learn that their own contribution to the decision-making matters and is valuable.

The Centre for the Deaf gives education to parents and family, they form groups of teenagers with similar problems and groups for senior citizens to enable them to exchange experiences. They give individual therapy and they have rehabilitation projects.

A DVD and the book are available free from: dbcent@dbcent.dk

2. A team from Conrad Svendsen Centre in Oslo, Norway: a case report

The team worked with a 50-year-old man with limited communication skills, violent behaviour and a lot of "acting out". The man used very few signs when he came to the unit. The work with this man therefore began with the team deciding that all behaviour, also violent, was seen as communication.

The violent behaviour was problematic for the team. Staff was off on sick leave, because of this. A course in how to react when the man was violent was organised. The team also tried to see the individual behind all his diagnoses, they tried to find out what he liked and wanted and they also tried to meet him in the moment.

In the beginning of his time at the Conrad Svendsen Centre the man was very impatient and the staff tried to meet his every need. This way of being sensible to the man's need made him more secure and the staff has noticed that violence has gone down with approximately 50 % every six months.

The team has also worked intensely to improve their own attitudes. They never said no to something the man said or did, instead of no they said for example that they did not like that way of doing things. With this attitude they found a different way to do things with him.

The man also learned some signs for example for feelings and his communication skills developed positively. However he still uses a lot of "homemade" signs. He has developed a sense of humour and there is more positive interaction between him and the staff. Earlier there was so much anxiety in dealing with the man that it was hard to see his skills. The need for medication has also changed.

The team has learned that a large staff is necessary for this kind of work. Currently there are 16 persons working with him. It is also important that the staff does not change.

3. Ditte Gaarde from Centre for the Deaf in Denmark: Public health service for the Deaf in Denmark and Danske Doves Landsforbund's support for the mental health field

A Sign language interpreter-project started in the year 2003 in Denmark and has now become permanent. During funerals, sports events etc the interpreter is free of charge. Hospitals pay for the service of interpreters.

Deaf issues are still not well known in health care settings in Denmark but a psychiatric inpatient unit for Deaf does exist. It is called Y9. At Y9 a team offers diagnostic evaluations and psychiatric treatments for all Deaf in Denmark. The unit also has an outpatient service. The team consists of: a psychiatrist, a psychologist and a psychiatric nurse, they all work part-time, and a social worker. The team also has a Deaf associate worker, part time. The associate worker's job consists of social skills training, making contacts with isolated patients, locating Deaf persons with substance abuse-problems and he also serves as a bridge between the psychiatrist and the patient. Y9 works in close relations with the Centre for the Deaf.

In the year 2004 the unit had 39 hospitalisations on 27 different patients. This means about 4 patients per week, but also sometimes 7 or none. Many of the patients were isolated, they did not know the health care system. They having great difficulties to get access to a proper service.

Ditte Gaarde also told the SIG-members about Danske Doves Landsforbund's support for the mental health work. A group has been formed for Deaf professionals working in mental health settings. The aims of the work are for example to:

- spread information in the public health field about Rubella
- spread information about mental health issues among Deaf
- create a databank for Tinnitus- and Menière-patients with information about treatment and research
- do a survey about sexual abuse in the Deaf community
- study the need for a emergency-group for Deaf
- reduce bullying in Deaf schools. Studies has shown that bullying is two to three times as common in schools for Deaf as in schools for hearing
- organise better service from psychiatrists and psychologists for the Deaf living in the countryside

4. A short discussion about aggression-issues (Ines Sleeboom-van Raaij)

It is important to find out why a person is aggressive. There are many explanations for aggression. A person can have problems in processing what is happening around him and information that he receives. He can have epilepsy or low communication-skills.

In many cases it can be very helpful to observe the patient thoroughly, what happened before the person started to be aggressive?

In some cases medication can be necessary. There are two main types of medication in this situation: 1. medication that treats a disease (for example epilepsy) and 2. medication that sedates the patients. This type of medication should only be used for short periods.

With Deaf persons that have no language skills it can be useful to use photos and other pictures to improve the communication.

5. A team from De Kersenboom in Hoeve Boschoord, Holland: a presentation and a video about their unit for multi-handicapped Deaf.

Hoeve Boschoord is a big unit with about 160 patients. The patients all have mental retardation and many have behavioural problems. Also some forensic patients lives there.

About four years ago 'de Kersenboom' was founded as a part of Hoeve Boschoord. The name 'De Kersenboom' means cherry tree in English and it is a unit for Deaf patients with 8 beds. The average time of stay at 'de Kersenboom' is 2-5 years. The unit is owned by a private institution but the government pays for the clients stay at the unit.

In 'de Kersenboom' everything is very visual. For example there is a whiteboard with photos of the staff that visually shows who is working and who is on leave. All the Deaf patients also have their weekly program on a board, easy to understand visually. The whole year with important dates, birthdays etc. is also visually shown.

The unit has different kinds of therapeutic programs, which are aiming at helping the patients to be more secure. All tasks and steps of the programs are evaluated together with staff and the patient her/himself.

6. Linda Hochstenbach-Nederpel from VIA, National Centre Mental Health and Auditive Disorders, Holland: Patients with Tinnitus and/or Hyperacusis.

Patients from all over Holland, aged between 18 – 65 years come to the centre VIA. All these patients have some degree of hearing loss. They also suffer from Tinnitus and/or Hyperacusis and they also have a psychiatric diagnosis. These patients have a lot of symptoms, for example concentration problems, sleep disorders, depression. Many also abuse alcohol or tranquilizers.

When a new patient comes to the unit he/she has an interview with the psychiatrist for a psychiatric evaluation. After that the patients receives a somatic evaluation from the general practitioner and the psychologist.

After the evaluations a treatment plan is offered to the patient in which group therapy, psychiatric treatment such as medication, individual therapy (often cognitive therapy), relaxation therapy is included. In the therapeutic program the therapists provide the patients with information about how to cope with sleeping problems, how to cope with the lost of silence, how sports can increase your blood pressure, which can make the tinnitus worse etc. The patients also get homework, for example, tasks about how to help the partner to cope with the situation.

The treatment program takes 10 weeks and the aim is to decrease the stress level for the patient. At the end of the program the therapy is evaluated. All patients evaluate their situation (with SAL 90) and level of tinnitus three times: before the start of the program, immediately after finishing the program

and three months after the program. The evaluations have shown that depression has gone down among the patients but fear has gone up.

7. Steve Powell from the charity foundation 'Sign', England: a few thoughts

England has many services for the Deaf and can therefore offer a lot of information about services for Deaf children, Deaf prisoners etc.

In England today the main goal is to improve the access for Deaf patients to basic services in health care and also how to get the services of a specialist when needed. Videophones can be one way to access these kinds of services.

8. The future of the Medical issues-SIG?

At the end of the day a "brain storming" about the future of the SIG was held. Here are some issues the group-members wished to discuss in the future:

- questions about general issues regarding the Deaf
- case-reports
- cognitive therapy and other therapy-forms that work with the Deaf
- specific support about how to help individual patients the best (for example Tinnitus-patients)
- forensic psychiatry and what is happening in that field
- limitations and boundaries to the work in the Deaf issues-field
- perspectives from other Deaf professionals
- general attitudes towards Deaf
- preventive medicine
- how to engage the clients and empower them
- how to support Deaf professionals in their work
- Sign language interpretation in mental health settings
- research issues (for example the use of written questioners among Deaf)
- how to produce visual information for clients
- bullying among Deaf children
- how to motivate Deaf clients towards work
- substance abuse among the Deaf

The members also wished more networking between countries, for example through the Internet and networking among the African countries. A new name for the SIG was also on the wishing list.