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Presentation by Ingemar Färm, EDF,
at the ECCL-conference “User Involvement”
the 21st of April 2007 in Zagreb

CHALLENGES TO THE INVOLVEMENT OF USERS IN THE PLANNING AND DELIVERY OF SERVICES

1) A SHORT HISTORIC BACKGROUND

As in most countries people with disabilities in Sweden have lived in institutions 24 hours a day, 7 days a week, year after year. And it has a very long history. During the Leprosy-epidemic in Europe in the Middle Ages the first hospitals were established. A researcher has counted them to 14.000 in Europe. When the epidemic was over many of the hospitals were transformed to asylums for poor people and people with mental illnesses.

There were some obvious reasons for this transformation: Protect the community, protect the individual and save money. Later on other reasons were added like moral, religious and political ones.

The development in Sweden can be divided into the following periods:

- The Hospital period until 1850. The religious view on people with mental illnesses as lunatics were the predominant view.
- A more scientific way of thinking and behaving in relations to people with mental illnesses became to be more and more important during the next 50 years. At the same time professionals and politicians began to talk about care. Very huge institutions were built. The new care ideology was also transformed to other groups of disabled people as those with intellectual and mobility impairments, people with tuberculosis and epilepsy, blind and deaf people etc. Institutions were built up also for those groups.
- The third period lasted until just after the Second World War. The development can be characterized as approaching the medical or biological way of treating people with different impairments. Some disability organisations started their history in the institutions as a reaction against the conditions at the institutions.
- The fourth period started during the 1960ies. It was a progressive period when also people with intellectual and mental disabilities raised their voices against the system with institutions, where you could be placed without your own consent and where there was a very authoritarian way of governing the institutions. The Association of people with Intellectual disabilities (FUB) were founded 1956 and The Association of people with Mental and Social disabilities (RSMH) were founded 1968.

Both FUB and RSMH were very active in the ideological and political debate. Around 1960 FUB

formulated the principle of normalisation and around 1970 RSMH started a campaign about tearing down all institutions for people with mental illnesses. Both organisations were supported by radical doctors, authors, politicians, media etc and the first results could be seen.

- The fifth period started around 1980 with legislation, where normalisation was the word of honour and there were decisions in the parliament to close all institutions. The peak was the Act concerning Support and Service for Persons with Certain Functional Impairments, LSS, 1993. In this legislation people with intellectual disabilities, autism and other severe disabilities got 10 specific rights. One of them is the right to live in an accommodation you have chosen yourself including special services. The most important part of the act is the ideological one. All services according to the act shall be delivered on the request or application from the individual. This means also that the applicant has the right to administer the personal assistance and most of the other rights themselves.

As my presentation at this conference on the theme “**CHALLENGES TO THE INVOLVEMENT OF USERS IN THE PLANNING AND DELIVERY OF SERVICES**” I will refer to an inspection report from one of the County Councils, Västra Götaland (Western Gothic County), in Sweden. The report is named “A place of one’s own in group accommodation”.

2) A PLACE OF ONE’S OWN IN GROUP ACCOMMODATION

The most usual form of accommodation with regard to LSS-the act is *group accommodation*. In this each member of a small group (usually 4-6 persons) has his or her own apartment but shares common facilities such as kitchen and lounge with the others. As a general rule, there is staff on duty all the time. It’s said in the background text to the act that “*services provided are to be matched to recipients’ individual needs and are to be in such form as to make them readily accessible to the persons requiring them and enhance their ability to live an independent existence*”.

Organization

Processing applications and implementing decisions

When responsibility for services for people with disabilities was transferred to the municipal councils, in many cases it was treated as an extension of the services for the elderly. Today service for disabled persons has its own organization.

The process starts with an application from the individual. In this he or she has to assess his/her needs. The local authority then examines the application for accommodation including special services, and decides whether it should be granted. The decision shall make clear what special services are to be provided. They shall also decide on the way in which the individual applicant’s own wishes have to be met. It could be a request for accommodation with shared facilities, or for accommodation in a specific district, or for accommodation to be shared with another specified person.

If the applicant does not like the accommodation he or she has been given he or she can make complaint. The uncertainty to whom you will direct your complaint has proven to be a problem.

Administration

One of the clearest tendencies the past years has been an increase in the number of units, which a unit manager is responsible for. This leads to less time for dialogue with residents, their relatives and the representatives of the disability organizations. The effect is also a more bureaucratic way of delivering services.

Contacts at local level

In the vast majority of group accommodations the residents have a particular member of the staff as contact person. The contact person usually handle residents' personal needs, pocket money and accounting to relatives or trustees, accompany them on visits to the doctor and look after contacts with relatives and other members of the staff on a daily basis.

The concept of contact persons at local level has many advantages. But, *who chooses* the contact person? In the inspection they didn't find **any** group accommodation unit, where the contact person had been chosen by the residents. He or she has been chosen by the unit manager or by the staff themselves.

If the individual has been assigned personal assistants, it is obvious that he or she has very considerable influence over the choice of person who is to provide the assistance. But why can't residents in accommodation including special services chose contact persons in the same way? When this question has come up for discussion with staff it is often said that the system must be fair. And what happens if someone is not chosen?

Overall and individual objectives

In carrying out the inspection they asked whether objectives for the accommodation and services have been formulated. The replies varied a lot. Examples are:

- **The ability to live an independent existence and live like other people**
- **Normalization**
- **Integrity and self-determination**

A problem is that the overall objectives were not always firmly rooted in the organization. When nursing staff were asked they replied they weren't aware of any overall objectives. Another problem is that objectives are not so concrete that they could be followed up.

Accommodation

Categories of accommodation

An apartment in group accommodation including special services is the individual's own home. According to the preamble to LSS, this requires special demands of the standard of accommodation. The rule is that the general regulations applicable to other accommodations should also apply to apartments in group accommodation.

Accommodation including special services may take a number of forms.

- The most used is **group accommodation**, which comprises 4-6 individual homes, which fully comply with minimum standards, within a detached villa or apartment block. They shall have access to shared facilities and staff 24 hours a day for services and care. Group accommodation units should be laid out and located as not to give the impression of an institution.
 - A second category is **sheltered accommodation**. In this case the individual apartments are often in one and the same building. The residents have access to certain basic services provided by staff and in some cases have access to shared facilities. The number of apartments should not be so large as to give the impression of an institution.
 - **Specially adapted accommodation** that is not staffed on a permanent basis is intended first and foremost for persons with more extensive impairments and who therefore require accommodation that is adapted to meet their individual needs.
 - **New 'models'** have been developed the past years. One is the **staircase model**. It consists of a number of apartments on the same staircase or in the same block of flats.
 - **Boarding homes** There are still people with intellectual disabilities living in single rooms and sharing bathrooms, lounges and kitchens with several others. That's not acceptable according to the law. An adult should have more than just a single room for his or her private use.
- There is a change today towards more of independent living. But, the inspectors noted that there is a

fear for change, not just among residents but also among their relatives. Young people who need group accommodation are not satisfied with being allocated just one bedroom to themselves and having to share everything else with others.

Location

If you want to participate in community life the accommodation must be physically integrated with the community. Sometimes buildings give the clear impression of being institutions, and be distant from other people in the district. The staff at one unit reported that physically disabled residents who lived in an accommodation in a residential area with easy access to services had become isolated. It had thus become more difficult for them to participate actively in community life. The apartments were excellent and fully complied with minimum standards, but that was not sufficient to lead to an independent existence.

Individual apartments

Small details can help to indicate that an apartment is a resident's home of his or her own. It may be as simple as a proper nameplate on the door, a private letterbox, an own telephone and a front-door key. The inspectors noted that doors are always left open and residents do not lock them when they go out.

Meeting individual needs

According to the LSS-act, persons have a right to care and security and to have their individual needs and requirements met without having constantly to adapt themselves to a group or collective.

Group accommodation units often have their own unwritten rules. These rules and routines have often come into existence in order to simplify the work of the staff. In some cases they have been barriers for individual residents to live the life they want to live. It is important to have an ongoing discussion about the rules and routines. The residents themselves and those who represent them should also have a chance to participate in the discussion.

Individual needs and requirements

Persons with intellectual or mental disabilities or autism are to a very great extent left to the staff who care for them. Therefore it's important with staff members' skills and attitudes.

The opportunity to decide for oneself about the life is important in terms of personal development and having an identity of one's own. Everything possible should accordingly be done to identify what each individual resident wants and would like.

Respect for self-determination and integrity

Just like everyone else in the community, residents in accommodation including special services must have the possibility to decide on

- the clothes they wear,
- the way they have their hair styled,
- matters of personal hygiene,
- the way in which their individual apartments are furnished,
- who they want to associate with during their leisure hours,
- whether they want to take part in joint activities,
- what food they want to eat and when,
- what time to get up and what time to go to bed, and
- how to spend their leisure time.

They must have the possibility of locking their front doors if they want to, receiving post through

their own letterboxes, being addressed in the manner they prefer.

However, the staff may sometimes find themselves in situations in which it is difficult to know how to proceed. What can staff do if an individual resident risks being seriously injured by wanting to go out without being able to cope with the traffic or by drinking a lot of alcohol, or by bringing 'unsuitable company' home and running the risk of being exploited, either sexually or financially?

Individual planning

The inspectors regard individual planning as the basis for all work in group accommodation units. The individual in question and his or her representative or trustee have to take part in the discussions on the planning.

Prerequisites to be met

• A home of one's own

Even people who are severely disabled and who have extensive need of support and service from staff must be able to have apartments of their own. It is part of the task of staff to help residents grasp the concept and sense of living in their own homes. This can be achieved by supporting persons to do things in their own homes, such as enjoying the company of friends, relatives and other residents, performing household chores, preparing and eating meals (if they wish to do so), cooking and baking, and reading the newspapers and their post (with help if required).

The inspectors have noted that apartments are not always used to the extent that might have been expected. For example, it is quite usual for all meals to be eaten together regardless of what the individual thinks about it.

Another question is if the residents can influence the layout of their apartments by choosing carpets, wallpaper, furniture etc.

• Staffing levels

It is important that group accommodation units should be sufficiently staffed to enable individual activities to take place, both inside and outside the premises. The services provided should also include cultural and leisure activities. In some cases the situation is solved by using contact persons.

• Professional skills, responsiveness and empathy and counselling

The experience of the inspectors is that the staff is very dedicated and take every step to ensure that residents are as comfortable and content as possible. However, there were examples of offensive behaviour. For example, residents have not been allowed to choose which clothing to wear, have been subjected to abuse or bad language and have even been locked in.

It is important that staff should have a good knowledge of the forms of disability, which individual residents have. In many cases there have been difficulties to recruit staff with sufficient knowledge and professional skills.

Cooperation

Cooperation at individual level

Cooperation should take place between municipal councils and individual recipients, their relatives and their trustees. It is important that theoretical words such as respect and integrity should be transformed into practical action and lead to satisfactory meetings.

Forms of cooperation with other organizations, both within a municipal council and outside it, should be based on the individual recipient's needs and wishes. The individual should not be put in a position in which he or she feels that the integrity is being infringed.

Cooperation at group accommodation level

Cooperation and exchange of experience between staffs is potentially a step towards the positive development of operations, as it helps to reduce the risk of isolation and the development of unsuitable care cultures. There is also the risk that lack of external input may also contribute to earlier forms of institutional accommodation being regarded as exemplary patterns, and that staff continue to follow out-of-date routines.

Cooperation at municipal level

LSS states that it is the duty of municipal councils to cooperate with organizations representing the interests of those disabled persons who are covered by the law. These organizations should be able to put forward proposals and express opinions, on an ongoing basis, how accommodation and services are organized and provided. The organizations concerned can contribute with valuable knowledge and experience.

The inspectors noted that representative organizations do not feel that any real cooperation is taking place. They have been presented with *faits accomplis*. It is important that representative organizations should play an active role in the planning process where the issues relate to disabled people.

Participation in the life of the community

Physical accessibility is one of the cornerstones of active participation in the life of a community. Accessibility guides constitute a useful aid.

Where group accommodation residents are concerned, participation in the life of the community is to some extent dependent on staffing levels. Many residents cannot manage to go out unaccompanied. In these cases there must be sufficient staff available to handle both the care requirements of the group as a whole and the wish of individual residents to engage in some form of external activity.

One possibility is that an individual resident looks for a contact person or companion who will enable him or her to engage in an individual activity. The quality of a resident's life can be enhanced by getting to meet people who are not members of the staff and whose only reason for being there is for the resident's sake.

Participating in the life of the community also includes being able to hear the news and general information, and being able to enjoy literature, films, TV, radio programmes etc. On the other hand, it seems to be less usual for residents to subscribe to regular dailies or weeklies. Information about books, newspapers and magazines in easy-to-read format has also been improved and become more widely disseminated.

Use of aids and appliances

In many cases the availability of good quality aids and appliances may make all the difference between dependence on others and self-determination. Aids and appliances are therefore very important. The inspectors have noted that they are not as yet seen as an obvious complement to the way activities are conducted in group accommodation units.

In most cases, the inspectors feel that the problem is lack of knowledge, both as which aids and appliances are available and how they can be used. Where the staff have been given training on aids and appliances they have begun to be interested in the possibilities they open up.

In the case of recipients who are suffering from physical disabilities, or whose sight or hearing is impaired, it is regarded as natural to use aids and appliances to simplify their day-to-day existence.

But the use of aids and appliances is not regarded as natural in the case of recipients with intellectual or mental disabilities.

Staffing and skills levels

The inspectors have found that, in most municipalities, staffing levels have been adequate. However, in some group accommodation units staffing levels have been too low as the result of cutbacks, and this has had a negative effect on residents.

The time managers can allocate to the units for which they are responsible is decreasing. As a result there is a risk that there will be insufficient time available for supervision of activities. There is also a risk that unit managers will become less aware of what is going on within individual units. Staff must have satisfactory skills levels and be thoroughly familiar with the objectives and principles applicable.

It is a cause for concern that it is becoming increasingly difficult to recruit suitable staff. One of the most serious problems that the inspectors see in the future in the context of the quality of services is the question of recruitment of staff with adequate training and satisfactory skills levels.