WHEN ALL RESIDENTIAL INSTITUTIONS ARE CLOSED: ON COMMUNITY ALTERNATIVES AND THE LIVES THEY OFFER PERSONS WITH HANDICAP

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FOREWORD

The end of the institutional tradition in Sweden, with its roots in the last century, can be seen as present legislation is demanding the closure of residential institutions. In the County of Skaraborg this has led to a project of change resulting in the closure of all residential institutions and the development of community services for persons who leave them.

As the first county without persons living in traditional residential institutions, this has been the source of interest. Therefore a follow-up project has been initiated to document and analyze present day services in the county of Skaraborg. The first results are being presented in this progress report.

To close large institutions and to develope community services for those who leave is a task where many persons in several places and functions in the county are concerned. Many of these have been involved to be able to present this report. We would like to thank all for these contributions.

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COUNTY OF SKARABORG -
ENVIRONMENT FOR A PROJECT OF CHANGE

Roine Nordén

Introduction

Welfare for persons with mental retardation in the County of Skaraborg has been the subject of a comprehensive work of change during the last six years. The County of Skaraborg is the only county in Sweden having carried out a total closure of residential institutions for persons with mental retardation. The activity today is said to be far advanced as to the fulfilment of the intentions being stipulated in the 1985 Act of Parliament, about services for these persons to be able to live a life being as independent and normal as possible, with the same rights and benefits as all other people in society.

For 10 years I have had the privilege of working with the organization for welfare for persons with mental retardation, as a director on a local as well as on a central level. During 1989-1992 I also worked as a project manager for the closure of the institutions in the County of Skaraborg.

I would like to give a presentation of the County of Skaraborg, its organization as an environment creating opportunities for the extensive changes having taken place.

The County of Skaraborg

Skaraborg is a county in the south of Sweden, situated between two lakes with approximately 280.000 inhabitants. The area of the county is approximately 8.000 km². In Skaraborg there are 17 municipalities, most of them with a size of 8.000-12.000 inhabitants. The smallest has about 6.000 and the largest one 48.000 inhabitants (Appendix A, enclosure 1a and 1b). In the county there are slightly more than 1.000 citizens receiving support accordance to the 1985 Act stipulating what sort of services to be offered.

In Skaraborg there is a long tradition as to welfare for persons with mental retardation. At this place Emanuella Carlbeck started a residential institution called Johannesberg in 1875. In those days she created a pattern of development of welfare and education for this group. Several institutions were built in the country with Johannesberg as a model. Within the institution efforts were made for total care, everything from premises for nursing and welfare efforts to units for school, leisure and a church. With these services inside the institution activities of these persons retreated more and more from the life outside the institution. Johannesberg has been the largest institution in Sweden for persons with mental retardation - there were up to 650 beds at one period.

Acts stipulating welfare services

The application to the Acts of Parliament controlling the welfare services have been imprinted by a long and often permanent care-taking of the mentally retarded. The attitudes of the public have seemed preserving and implied a support for a special organization apart from the rest of society. The views on persons with mental retardation was earlier filled with fear and prejudice. This care-taking involved a segregation from society and a control and custody of these people.

In Sweden a new Act for Welfare for persons with mental retardation was stipulated in 1985, which has meant a great deal to these persons. In this Act it is stated that all people with this handicap shall have the possibility to live in the community, irrespective of character or extent of handicap. The Act also stipulates a closure of residential institutions. It implies that welfare for these persons shall be concentrated on the development of the resources of the individual and the activity is to be based on self-determination and integrity of the person. Instead of segregation people are to receive support in order to share in the material and cultural services provided by society.

This Welfare Act is an additional Act, which means that persons with mental retardation first of all are to be assisted and supported by way of general Acts such as the Health Act and the Social Services Act to the same extent as all other citizens of society. The Welfare Act for persons with mental retardation only comes into force when the applications of other Acts are not sufficient. This Welfare Act is compelling, which means that if a person is judged to be in need of special support according to the Act, the contribution is compelling for the service provider.

The organization of the county

The responsibility since the end of the nineteenth century for the welfare of persons with mental retardation are the County Councils of the country. The County Council is the political authority that can be called "the parliament of the county". The County Council is also responsible for health- and care, mainly hospitals. Up to 1980 the activity of the County Council in Skaraborg was divided into a series of areas such as health- and care service, welfare for mentally retarded, education of nurses etc, with a central administration being the responsible authority.

In 1980 the County Council of Skaraborg decided to change the political organization. In every municipality a political board was established, as part of the organization of the County Council, being responsible for the health- and care service within the geographical boundaries of the municipality. These local boards, called board of primary care, were unique for the country. The purpose for the establishment of these was to reach an increased and more local interest. The politicians being involved in these boards should live in the municipality where they were responsible for the care in order to create an extended engagement.

Furthermore, a local, political board would entail shorter ways of determination, a more effective co-operation between a county authority and a municipality organization concerned, better contacts between staff and politicians etc. Several counties in the country later on established organizations similar to the one in Skaraborg.

As the intentions of the new Act of Welfare were to decentralize its activities and to assist and support in the local district, in the neighbourhood, the county council decided that primary care, the local organization of the county in the municipality, also should include the responsibility for the mentally retarded, starting in January 1986. The ideology of the primary care, e.g. about vicinity and normalization, used for the care of old people, was good experience before taking over services for persons with mental retardation. The achievement of the boards of primary care to find open forms of care when psychiatric institutions were closed, can be seen as parallel.

In Sweden it is unique that this activity has been organized in such a way that there is a local board of the county in every municipality, being responsible (Appendix A, enclosure 2). By this organization there were good opportunities when planning for the persons to leave the institutions. In each municipality there is a responsible person for the planning of the welfare for persons with mental retardation, with the function of being "the spider in the web" as to the welfare planning on the local level. This organizational solution with a local responsibility for offering the mentally retarded in the municipality his housing, leisure time, activities and employment, is one of the most important factors for the possibility to move from the institution within the time stated.

The development in the County of Skaraborg can be said to have changed. In the beginning there was care on a personal and voluntary basis which later became a strong, centralized and institutionalized care, now changing again to the more open kinds of support of today with a far-reaching integration in society. In connection with the change of welfare society as other parts of service organizations, have gradually increased their engagements for persons with mental retardation.

Closure of residential institutions

In Skaraborg the county council decided at the end of 1986 that three residential institutions for mentally retarded in the county, with more than 300 residents, were to close down not later than at the turn of 1991/1992. Johannesberg was the largest institution, with the county as the owner. The other two institutions were smaller and were privately owned.

Most of the residents were from the County of Skaraborg but there were also persons from other counties. The decision to close meant that all the mentally retarded living in these institutions, with the exception of 15 persons with serious behaviour disturbances at Johannesberg, were to move. Relatives to these people as well as staff working with them had objected in forcible words, therefore this group was allowed to stay in the institution until further notice, without mentioning the last date for moving. As the development progressed, however, the attitude developed by those involved and the County Council at last decided that also this group should be offered other forms of housing, not later than the turn of the year 1992/1993.

The County Council was of the opinion that all people living in these institutions were to be regarded as homeless and because of this they were to be offered good housing, outside these institutions. These were to fulfill criteria considered valid for housing in general. The persons with mental retardation should also be given the possibility of getting a job or an occupation, as well as a meaningful leisure. The intentions were, if possibly, to let the persons get jobs in different companies with tasks being adapted to them. Associations and organizations working with leisure activities were to integrate these persons with handicap into their activities. During September 1992, the closure of the institutions was accomplished according to the plans from 1986 (Appendix A, enclosure 3).

In addition to more than 300 persons living in these institutions were to be offered other housing, the decision implied that approximately 600 employees were in need of other jobs. When the decision to close was made, many employees applied for other jobs. Some employees got jobs in newly started group-homes within approximately 40-50 km from the institution, other employees were trained for jobs in health care.

During the process of closure, a continuous co-operation has been going on with unions concerned, as well as with FUB (The Association for Mentally Retarded Children Youth and Adults). FUB is the organization of interest in Sweden representing persons with mental retardation and their relatives. FUB exists on a national level, as well as on county and local levels. The co-operation has been very good, partly because the county authorities as well as the unions and FUB have taken part with "heart and soul" in the fundamental view giving aim and direction for this process of change.

Economy of institutional closure

The support being created locally has to the greatest extent been financed through redistribution of economic resources associated with the residential institutions to alternative community services. In addition to these 60 million SEK from the residential institutions, the County Council has contributed another 30 million SEK, the project thus has had access to 90 million SEK. The closure could be effected within the economic frames placed at the disposal of the project by the County Council.

A new budget technique has been important in this respect. Traditionally, the division of means has been effected in such a way that the local board, e.g. when going to start a group home for people leaving the residential institutions, applied for means for the running of this home. Such demands were then centrally treated within the county council and after a check-up, means for the start of running were obtained.

The 17 local boards made plans stating the requirements of means to be able to accomplish the move from these institutions. It appeared that the total necessity of means mentioned by the boards to effect the move from the institutions, exceeded the economic frames planned by approximately 30 million SEK, estimated on annual basis. The planning process was stopped for about half a year in order to be able to find proposals for measures to handle this move within the total economic frame for the project.

In 1989 the budget technique was changed for this planning process. Instead of applying for means for the start of e.g. a group home, the board concerned received a sum for each person who was to leave the residential institution (approximately SEK 350.000). This amount referred to everyone, irrespective of degree of handicap and kind of housing.

From the plans made by responsible, local staff together with the persons with mental retardation in the institution and their relatives, calculations were made for each year up to 1992, as to the amount calculated by the board. The plans contained information about where the person wanted to move, wishes about suitable housing and date to move etc. If, for example, five people left an institution, the local board concerned received 5 x 350.000 SEK, i.e. SEK 1.750.000, estimated on annual basis.

The local board, through this technique were at an early stage informed about the means to be expected in their planning for development for the persons with mental retardation. These amounts were included into the budget being stated annually for all the boards of the county. The local board consequently got a total budget for all their responsibilities, i.e. health- and care, dental care and welfare for mentally retarded.

This budget technique enforced several creative solutions as to the way of planning local support. From already established group homes, people moved to their own housing, still receiving some support from staff. Into a place like this in a group home, a person moved from the institution, and in this way the person received his support without any increase in costs for the board. The local board had been given means in the budget for this move amounting to SEK 350.000. These could then be used by the board for other urgent needs within the welfare for the mentally retarded.

The corresponding process was accomplished as to occupation. At day activity centres, persons with a mild retardation left, individually or in group, into local businesses. The places which became free at the day activity centres in this way were offered people with more severe handicap, leaving the institutions. By this procedure people could be received in day activity centres without an increase in costs for the board.

The closure of the residential institutions will be managed, within the means allocated to the project. About 70 people have moved from group homes into homes with support in the neighbourhood of a group home, or to private homes, during the period of 1987-1991. These 70 persons in group homes correspond to approximately 30 million SEK. Within the total budget that the local boards have received means have also been redistributed to other forms of welfare from services being judged as less important.

With the traditional budget technique, this process of change has probably not been able to realize. A strained economy can be said to have enforced alternative solutions at lower costs, solutions also being in line with a desirable development within the frame-work of normalization. However, it should be pointed out that if such a process is to be brought about, the economic conditions must not be in unreasonable proportion to the tasks stated.

The future use of the residential institutions

For the private institutions, the county has contributed towards finding alternative solutions for the future. One of the institutions has been sold to a housing company and it will be rebuilt into a day nursery. The county took responsibility for the staff at the institution and offered employment at various group homes. The other private institution changed owner and is today a private institution for psychiatric care. The staff was offered employment by the new owner. Some of the employees have been through training for their new tasks.

The county has decided that the institution of Johannesberg is to be sold. It is situated in a very nice area, centrally in a municipality in the northern part of Skaraborg. The intention is to try to establish housing, small shops, day nurseries, schools, places for sport and leisure establishments etc in the area. Waiting to be sold, the institution has been let to the immigrant authorities as a refugee reception centre.

Part of the institution is a donation from the founder, Emanuella Carlbeck, to the county council. An application has been sent to the authority concerned to bring about a change in the old decisions of donation so that the selling can be carried out. The income from this donation is to be transferred to a foundation. The proceeds from this foundation shall be used by the persons with handicap in accordance with the intentions of the original donation.

A shift of responsibility

The Social Services Act can be seen as an guarantee for the social security for all members of society. According to this an increased integration into society for persons with handicap, is to be achieved. All people, in spite of a disability, shall have the possibility of joining community and to live like others. Social authorities shall contribute to the planning of society and by this meet the requirements of housing for the handicapped.

With regard to the intentions of the Social Services Act about fundamental social security for all, the social services of the municipality will have the responsibility for the basic contribution of welfare for persons with mental retardation in the future. To test the consequences, and to get experiences for the future, when a local authority takes its basic responsibilities, the County Council of Skaraborg has agreed with two municipalities that they are to take their responsibility for this handicap group, starting in 1990.

Evaluation

The County Council of Skaraborg has decided that a continuous evaluation of the closure of these institutions is to be accomplished. The Centre for Handicap Research at the University of Uppsala has been engaged for this purpose. Continuous reports have been presented at conferences. This material has been fundamental for the proceeding development of this institutional closure. It has been important that experiences and knowledge have been documented and put to use during this process of change.

AFTER INSTITUTIONAL CLOSURE -
ON ALTERNATIVE HOUSING

Ingegerd Öhman

Decision about institutional closure

In November 1986, the County Council of Skaraborg decided to close 3 residential institutions for persons with mental retardation, within a period of five years. Therefore all persons living in these institutions were to move at the latest during the end of 1991. The County Council later modified its decision and decided that a group of 15 persons, being old and having lived for a long time at the institution of Johannesberg, would be allowed to stay there as long as they were alive. It was also decided that a group of 18 persons, with behavioural problems, would stay not later than at the end of 1992.

There were three residential institutions concerned. Johannesberg, in the municipality of Mariestad with 221 residents, was owned by the County of Skaraborg and Aspa, in the municipality of Mariestad, with 31 residents was privately owned. Skogsäter, an institution in the municipality of Skövde, had 54 residents and was also privately owned. That is 306 persons who lived in these three institutions.

The institutional closure within a period of five years has now been realized, and at the end of the year 1991, the persons remaining were those intended. The group of 18 with behavioural problems, has meanwhile been reduced to 11, as 7 persons already have moved. As to the remaining, the preparations to move are going on. Of the group of elderly, there are 13 persons left who will be two groups, receiving alternative housing in group homes. The institutions are estimated to be closed during the end of autumn 1992.

Individual planning

The County of Skaraborg includes 17 municipalities. In each of these the County Council is organizing primary care. At the time of the decision to close, the primary care districts started individual planning of community services for each person, then living in a residential institution. This planning was often made together with the social services of the municipality. This planning concerned the total life situation of the person.

As a person is registered in a municipality before going to the residential institution, the intention of the planning process was that he should have the right to go back there, when leaving the institution. When the planning of his housing was ready it appeared that different kinds of housing was needed e.g. housing of one's own, housing for old age people, housing with support and nursing home. Others were to move to a group home. There was therefore a great variation of housing. The needs of some could be met within the local social services, e.g. housing of one's own and housing for old age people.

To begin with the persons were to move to the municipality where they were registered. They had often contacts with their relatives living there and they could then contribute when the person were to move from the institution. There were also some relatives who, for different reasons, wanted their son or daughter to move to a place outside the municipality where he was registered. There were also situations when the person himself had chosen another than the municipality where he was registered.

Some who had formed friendships in the institution wanted to move together to a place, to which they didn't have any connection at all. Therefore they travelled in various parts of the county looking for a suitable place to live. These are some examples of the wishes which had to be regarded, when planning the housing outside the institution.

Various types of housing

In the **residential institution** most of services considered necessary, that is housing, daily activities and leisure, could be received inside the institutional area. It was also visited by the doctor, nurse and dentist. The pension of the persons with mental retardation was handed over to the county, while the persons had free services and some pocket-money each month. The persons could visit their relatives once every month free of charge.

In the institution of Johannesberg most of the people lived in single rooms, but some of them lived in double-rooms. The wards were generally large, up to twenty people in one ward. The day-room was shared by all. The kitchen, generally a kitchen only for serving, was handled by the staff. The residents were a group and it was difficult to meet the personal needs. In the two smaller institutions, there were fewer persons, generally eight, in a group.

Each had a room of his own. Food was cooked for all the institution in a central kitchen and from there it was transported to the different wards. Other rooms, such as hygiene-facilities, were shared by several people. The people lived their lives inside this institution, even if excursions and journeys to various places in the community, were undertaken. Activities during leisure time were located in the area of the institution. During the last years, clothes were bought directly in shops in local community, and the stocks of clothes at the institution were seldom utilized.

The person living in a **home of one's own** is assisted by staff from the local Social Services to the extent required, e.g. 1-3 times a day, once a day or a few times a week depending on the person's need for support.

The **home for old age people** is a kind of housing for elderly and has its roots in the old public assistance in Sweden. Old people, having nobody taking care, were placed together. In this house a person often has a room of 10-15 m^2 plus hygiene-facility. It is therefore a kind of institution. Staff is available day and night.

Housing with service is more up-to-date consisting of a number of private apartments of one or two rooms and a kitchen. These apartments are situated under the same roof. There is also a restaurant and other forms of service available, and staff assisting to the extent needed. Young as well as old are living in this housing with service.

Persons with mental retardation having lived in a residential institution and having requirements of considerable support, moved into **group homes** in these 17 municipalities. Because of institutional closure taking place there were demands for housing in the community for persons with a severe handicap. Therefore an extensive development took place. The new type of group homes were either detached houses or incorporated into terrace houses or block of flats.

One type of group home consists of four to five apartments, a common part as well as a room for the staff. This meant that the person moved to an apartment of his own, having spent a life in one room in the institution, sometimes shared with someone else. Most of the persons moved to apartments of this type. One type of apartment included one to two rooms and kitchen, while another had one and a half room and kitchen. The total area was 40-60 m². Each had an entrance of his own. In the county of Skaraborg 40-50 group homes have been established during the last five years.

The existing older type of group home, had a lower standard. They often consist of a room for the person while the hygiene-facilities are shared with another person. Furthermore, there are common rooms, i.e. kitchen and living-room.

A small number of group homes have been arranged just for persons with special needs and with specially trained staff, considering the specific demands of these persons. This was the case for persons with psychiatric problem or with autism as additional handicap. In connection to these group homes, daily activities are arranged and the persons have the same staff for support in housing as for his daily activities. These group homes are often situated on the outskirts of a community, but still with closeness to neighbours. Common daily activities are a lot of physical activities, growing of vegetables and the care of small animals.

A **home with support** for persons with mental retardation means that a person's apartment is in the neighbourhood of the group home. The person requires assistance to a certain extent, by the staff of the group home. In this way he feels secure as he can get contact and be assisted at any time of the day or night.

Some persons who have moved to the **nursing home** arranged by the county do not need welfare as they have considerable somatic needs and therefore they require nursing staff. From January 1992, the running of nursing homes has become the responsibility of the municipality.

Table 1. Various kinds of housing in January, 1990.

	n	%
A home of one's own	19	7,7
Living in a family	3	1,2
Housing with service	1	0,4
Home for old age people	8	3,3
Group home, old standard	40	16,3
Group home, new standard	98	39,8
Local residential institution	31	12,6
Central residential institution	34	13,8
Nursing home	3	1,2
Other forms	3	1,2
Information missing	6	2,4
Total	246	99,9

The table shows that the most common form of alternative housing is the group home, here used by 138 persons (56,1%). No less than 19 lived in a home of one's own. The home for old aged people and housing with service was used by 9 persons. Nursing homes was used for 3, and 3 persons lived with families. 65 people still lived at an institution and 3 persons lived in other forms of accommodation.

To live in a group home

The person with mental retardation, and in many cases his relatives, have taken part in the planning as to the decision of site. They have seen houses and apartments grow up. They have chosen wallpapers and colours, and they have furnished their flats before moving from the institution.

When the persons moved to their apartments, it was in the bedroom where they first of all made themselves feel at home. This was the room considered by them as their own. It has taken long time for them to make use of the rest and gradually they have accepted that all of the apartment belong to them. Some of them have breakfast in their flat while supper is eaten together with the others in the group home. Many of them have relatives paying visits now and then. The celebration of birthdays is really something to take place in the personal apartment with guests coming from afar, having the possibility of stay overnight.

In the group home there is a possibility of shopping and cooking. Friends and relatives can be invited in a homely way or to parties, and they can see each other exactly like other people do. If wanted, there is a group to join, but there is also the possibility to close one's door.

The persons get their pensions, housing and handicap allowances themselves from the post office. They pay for food, rent and other expenses like other people. The finances are of course managed with support from staff to the extent required by the individual.

Staff is not there to take care of the person with mental retardation, but to support and instruct him. The size of the staff group is decided upon considering the needs of the individuals living there. Several persons have additional handicap and need assistance during all hours, day and night, every day of the week.

Daily activities

In the residential institution most of the persons had daily activities, but there were also some not having any activities at all during daytime. These daily activities were located within the area of the institution, usually in special premises.

Today, when the residential institution is not considered a form of special service all persons with mental retardation, according to the present Act, have the right to service and support through daily activities.

Considering the interests and needs of these persons, daily activities varies a lot as to the extent as well as to the place where the activity is carried out. Every person has an individually designed week as to the activities in which he participates. Communication, health exercises, swimming, physical activity and adult education are, together with the daily work, examples showing important elements in this form of service.

In most of the primary care districts there are day activity centres for persons with mental retardation. These are often large and adjusted to the persons with handicap. Several people receive their daily activities there. In order to meet the new needs of experiences and stimulation represented by the persons with a more severe retardation coming from the institutions being closed, several day activity centres are being rebuilt.

Some of the persons participating in daily activities, do so in the local community, e.g. in private companies, in industry or engaged within local and county authorities. Together with some friends they make up a group, in most cases having a supervisor of their own. These groups can e.g. run a cafeteria, clean premises or work on farms.

Leisure activity

The leisure activity of the institution was well organized. There were special leisure time supervisors, arranging activities during weekday evenings as well as during the weekends and holidays. They were e.g. showing films, swimming, doing physical training, study groups, excursions and socializing together in a café. Most of these activities took place within the institutional grounds. The persons living in the institution also joined the monthly dancing event, taking place somewhere in the county. They got the opportunity to travel somewhere else to dance and to meet other people. This activity was very much appreciated.

But the leisure activities have changed. Staff in the group home is responsible for leisure, considering the interests and possibilities of each. The variations are many. A lot of study groups remain and some people join various associations. They ride, swim and play bowling. In some places there are premises where they meet, drink coffee etc. Many people prefer staying at home in their private apartment or they go out to meet relatives and friends. In a few places the persons in the group home have bought buses of their own, which can take them in an easy way to leisure activities. They can also make short and long journeys, e.g. for holidays.

The holidays are also planned individually considering the resources and possibilities of the individual. Some of the people join conducted tours, others go on holiday in a group, while some go to see their relatives.

But the monthly dancing remains and still makes an important meeting-point for persons with mental retardation. Once a month, dancing with live music is arranged somewhere in the county, and several go there to dance, meet each other and to have a nice time.

Health care

All with mental retardation are today entitled to health care, like other people. When there is need for it, they go to see the doctor at the health centre. If a stay in the hospital is necessary, staff from the group home will accompany, if there is need for this. As to the services from physio-therapists and speech therapists, there is a greater need than there are resources.

However, to the greatest possible extent these problems are tried to be solved, and this form of service recently has been reinforced by more physio-therapists. There is an expressed need of psychiatric resources. Therefore one psychiatrist is consultant to the district doctors, a solution satisfying to all, even if there is a wish for extended working-hours for this consultant.

Professional support from psychologist and social worker

When these persons lived in institutions, there was a psychologist and a social worker at the institution, serving the mentally retarded as well as the staff. But this form of service has also changed.

The psychologist's tasks consists e.g. of testing, staff support and conversations with the mentally retarded. The psychologist instructs groups of staff in group homes and day activity centres. Training and introduction of staff are also included in these duties. The psychologist is still a specialist resource being requested, and they have recently been reinforced to meet the increase in need.

The social worker is still needed, even if the supervisor of the group home has taken over many social tasks, earlier belonging to the social worker. Primary care has in many places begun to get interested in the social matters of the mentally retarded, and their social workers today work with matters of welfare. Therefore the profession of the social worker has changed, and today the work includes e.g. advice and staff support, conversations with persons with handicap and support to the advocates of the person.

Summary

To move to the community has become a revolutionary change for the persons with mental retardation having lived in residential institutions. Some of them have lived there for a few years but most of them have lived there for 10, 20 and up to 40 years, some even for a longer period. Some came to the institution when they started school, and since then they have lived there. Living in an institution can be compared with the state of being without housing.

As to this change in Skaraborg we have endeavoured to consider the requirements of these persons. The apartments in the group home is their private place and moving from there is accomplished only if the person himself wish to move. Earlier the "system" was the determining body, and the individuals were moved around according to the needs of the organization. Now we try to adjust staff support to the necessities, and the individual remains in his private place.

Those who have moved to group homes were all judged to need extensive support from staff, as considered during the personal planning carried out while they were living at the institution. These plans were not according to what the persons could achieve in their new group home. People turned out to have considerably higher abilities, and they were able to manage more tasks and more difficult duties, than was understood. This can perhaps be due to the fact that the persons were in a new interesting environment and that staff, who also was new, had positive expectations.

Most of those who moved from the institution to group home still lives there, but some of them have decided to get a more independent home and have moved into a home receiving support from a group home. As far as understood up to now, nobody wishes to move back to the institution!

To sum up, it can be established that considerable changes have been made during the last five years for persons with mental retardation, earlier having lived in institution. This is very positive. They have become a well-known group. When they lived in the institution they were placed in 2 of the 17 municipalities in the County of Skaraborg. Today they live in all seventeen.

Those who have moved from a group home to their own home, are being assisted through the social services of the municipality. In this way they have come closer to the authorities responsible for their welfare. The politicians and administrators of the municipalities have begun to know these citizens and to stand up for them. People in the community know them and they are a logical part of the community. They visit the post-office, the bank, shops, the pharmacy and other service establishments exactly like other citizens in the municipality.

It is however, extremely important to continue the work with the development of the competence of staff in order to realize the aims of these services, and to enable persons with mental retardation to live like other people, together with them. We are on the right track, even if we haven't yet reached the goal.

AFTER INSTITUTIONAL CLOSURE:
ALTERNATIVE DAILY ACTIVITIES

Kent Ericsson

Services for community participation

The reaction to institutional life traditionally offered persons with handicap led to demands for the same type of normal life as led by persons without handicap. These became one of the starting-points for the normalization process which can be found in services for persons with handicap in Sweden, emanating during the middle of 1940:s. The motive was that this would lead to a life outside the institution, in contact with persons without handicap, using the same services of the welfare society as they were using.

But what can be said to characterize this normal life? In terms used then, the basic idea was that these persons wanted housing, work and leisure in the local community. This formulation became one of the first in order to discuss the character of life outside the traditional institution and the types of services needed to fulfill this. It was logical that it was expressed in this way as the fifties and sixties were times when those who had possibility to live outside residential institutions were persons with a mild intellectual handicap, persons whose life was very similar to that led by persons without handicap.

This lead to services suitable for these persons. They were group homes with few staff as persons to a large degree could manage on their own. Daily activities often took place in a sheltered work-shop or, and if they did not get any work there, in places for occupation. Their leisure was spent in ordinary activities of community, often without, or with a limited, support.

As persons with a more severe handicap achieved community life during the seventies demands were made on a development of community services. Group homes with more staff were developed to give a more qualified support to persons living there. Activities in the local community, like the use of commercial and community services, leisure and social relations, demanded also an increase in the amount of support to be a reality for these persons.

At the beginning of the seventies sheltered workshops were brought out of services, to be part of employment authorities, for persons with intellectual handicap. As regards the work during daytime it was still a reality for some persons who had capabilities enough to match the demands of the sheltered workshop.

Places for daytime occupation were the only type of service for these persons. During the seventies they were developed further and were called day activity centres, built according to centrally planned specifications all over the country. There were mainly persons with a mild or a moderate form of handicap using these services, many of whom wanted to work during daytime. These day activity centres were therefore organized to a large extent with sheltered workshops as the model. A common size was 25 - 40 persons in each centre (Ericsson, 1985a, 1985b, 1987, 1992a, Ericsson & Ericsson, 1987).

Daily activities

With the day activity centre a new form of service was brought to persons with intellectual handicap. Its main function was to contribute to a more normal life for persons, giving the group home the function of being a home, located in the community in ordinary housing areas. With the day activity centre persons could receive their support during daytime, away from home, in places where persons without handicap could work during daytime.

The day activity centre also gave the daily activities the role of a separate form of service. Earlier it had been part of the traditional institution, with a role complimentary to the care that was carried out at wards. This new form of service brought new categories of staff to work with persons with intellectual handicap, mainly occupational therapists but also various professional people. A process also started to develop this service to be able to give quality support.

But problems could also be found with the day activity centre. Evaluations found that the day activity centre really became a centre! It became a place where equipment, staff and activities were localized. As services during daytime were localized to the day activity centre, they had to go there and they had to spend the main part of the day there.

As seen from a perspective where services are to contribute to the community participation of these persons, this situation, shown by these results, constitute a problem. Instead of being a platform for community participation in various forms of activities in the community, day activity centres became places where these persons stayed during most part of the day with only a limited degree of community participation (Ericsson, 1981, Heron et al, 1981).

Institutional closure

Residential institutions were established during the last century as the major form for support to persons with intellectual handicap. These institutions gave support for all, for children and for adults, for those with a mild and those with a more severe form of handicap. This institutional tradition lasted until the middle of the 1950:s when the first forms of community services were recognized.

A change of services has taken place since 1945, during the years when the welfare society has been established. Within this framework also persons with handicap got the right to use the services developed to realize the welfare society. In the beginning this was intended only for those with a mild handicap, later for all, even those with a severe form of handicap.

From the end of 1940:s a normalization process has taken place, giving persons with intellectual handicap possibility to live under more normal circumstances in society and to achieve an increase in the say over their own lives. The key to this development has been the community services being developed, group homes and daily activities, which to an increased extent have been able to give service and support to all persons with intellectual handicap.

With the Act of 1985 all persons with intellectual handicap therefore got the right to a life outside the traditional institution and a decision was taken to close all residential institutions. This work is at present one of the major tasks in services today in Sweden (Ericsson, 1992b).

Daily activities in need of development

At the residential institution every person were to have a bed on one of the wards. The work carried out there was the major task of the institution. There could be some activities during daytime, but those were of minor interest.

There are examples of wards, with occupational rooms, to which some persons could go for simple forms of occupation. There was also occupational therapy in some of the houses of the institution. But these were not meant to offer activities for all.

For those with a mild form of handicap there could be activities during daytime, as a member of the staff working with the running and upkeep of the institution. Examples of these types of work is gardening or work on the farm, work in the laundry or in the kitchen. Some could also have tasks giving care to those with a more severe form of handicap. For others, not being able to achieve this, there were various forms of traditional occupation. For the persons with the more severe forms of handicap there were no daily activities to be found.

During the 1960:s this created a reaction against lack of activities. There were demands for more activities and they were met by developing this part of the service of the institution. Sheltered workshops could be found on some of the institutions during this decade. But these were not recognized as a form of service for persons with intellectual handicap in the Act of 1967 and therefore they weren't developed further. The day activity centres of the 1970:s were instead a form of service which stimulated the development of daily activities at residential institutions.

The training-school with education for the children with severe forms of handicap established through the Act of 1967 Act was the first step to the development for activities during daytime for the most severely handicapped persons. As there were children at residential institutions during the 1960:s these schools were established there. They meant purposeful activities during daytime for those who had the right to go to school. But they also had the role of stimulating the development of daily activities for adults with a more severe handicap, those who didn't go to school. During the 1970:s there was an increase in daily activities at residential institutions.

But it was not until the Act of 1985 when daily activities were recognized as a form of service available for all. This became the starting point to find forms for daily activities which could give support to all (Ericsson, 1991a).

Daily activities for community participation

Apart from a need for an increase in degree of community participation, this form of service was faced with new demands. When residential institutions were closed, people moved from these places to services in the community. Those who once were expected to receive their support through these institutions were offered community services instead. This meant that persons with more severe forms of disability than seen earlier, were in need of services through these day activity centres. This created demands for new forms of activities, instead of those early ones, very similar to employment in the regular labour-market. As a consequence there was also an increase in need for staff to give support to persons with the more severe forms of handicap.

By tradition services to persons with intellectual handicap have been a regional matter, as the main part of services were channelled through residential institutions. The development of community services, with an increase of social and community tasks, meant an increase in the responsibility of the social services of local community. Today, in some communities local authority have taken over the responsibility from county services. With this background there are demands for services working together with local authority and the services they organize. Instead of day activity centres, who at one time could house 40 - 60 persons with handicap, there is a need for working in small groups, each with daily activities chosen according to the needs of the members in the group.

The model formulated to respond to these demands do not focus on the centre but on the activity group, that is those persons who together make up the group who will participate together in the activities during most time of the week. By choosing the activities of the week according to needs and wishes from the persons in the group, it is possible to achieve more personalized activities and therefore more personalized services. The organization for daily services will then not be the day activity centre but a set of activity groups in a local community, each one with its characteristic activities, depending on who the members are in the group (Ericsson, 1991b).

Daily activities after institutional closure

In the county of Skaraborg, institutional closure has taken place. Three residential institutions have closed and community services have been used as alternatives. Apart from a documentation of the project of change, a project for follow up has analysed some of the consequences of institutional closure (Nordén, 1992).

This is an illustration of the alternatives used for a group of persons who have left the residential institution. Their closure took place during 1986 - 1991 and 300 persons were concerned. Table 1 shows the daily activities for 246 persons.

Table 1. Daily activities of 246 persons, January 1990.

	n	%
Regular employment	4	1.6
Sheltered work	4	1.6
Community day centre, inside centre	105	42.7
Community day centre, outside centre	37	15.0
Institutional day centre (visitor)	5	2.0
Institutional day centre	47	19.1
No organized daily activity	10	4.1
Daily activity (ward)	10	4.1
Daily activity (home)	10	4.1
Old age pension	6	2.4
Else	2	0.8
No information	6	2.4
Sum	246	99.9

Regular employment together with sheltered work is not very common, 8 persons (3.2%), as these are persons who have lived at the residential institution, a place mainly for persons with a moderate or a severe form of handicap. Its is therefore not unexpected that more persons haven't received employment.

Most common is that these persons have received daily activities through community day activity centres, 142 persons (57.4%). Their daily activities take place mainly inside the centre, though for 37 persons the main part take place in groups outside the centre. There are 5 persons who live outside these institutions, but who still receive daily activities at the day activity centre of an institution. This is not uncommon when there are problems to create housing and activities in the community simultaneously. Then it is easier to organize housing before daily activities are taken care of.

All of the institutions were not closed at the time of this census, there is still a group, 47 persons (19.2%), who receive their daily activities through their institution.

"No organized daily activity" are persons without activities. Even if two categories indicate that there are activities organized through the ward of the institution, or the group home, these persons haven't got a place at a centre which is a special form of service, apart from their home, and they have therefore got services to a limited extent. In these three categories there are 30 persons, 12.3%. There are 6 persons who have chosen to live the life of old age pensioner, not using the organized daily activities offered through the day activity centre. 2 persons have other forms of activities.

Daily activities for community participation?

Procedure

During the period of closure of the three residential institutions a study was carried out to describe daily activities for those who had left. The analysis was aimed at ana analysis of whether these activities were purposeful and if they did contribute to the community participation of these persons. The study was carried out during 1990, the same year as previously has been described regarding types of daily activities as alternatives to institutional service. This year 142 persons received their daily activities through community day activity centres.

The first of two groups was randomly chosen from persons who had left these institutions and who had lived a community life for 1 year. From each of the 17 local communities in this county, 2-4 persons were chosen, depending on the size of the local community, ending up with a group of 49 persons. Two persons with handicap had declined to answer while 1 questionnaire was inadequate. The second group were 13 persons who had left the largest of these three institutions and who had lived on a ward for persons with severe handicap.

Questionnaires were administered to the relevant day activity centres and answered by the person in the staff-group who best knew the person with handicap to be part of the study (Kruse et al, 1990).

Comparison of the groups

When these two groups were compared it was found that A was older, with a mean age of 48.9 years, while group B had an average age of 31.1 years. Other differences between the groups concerned mainly their ability to communicate. In group B 69.3 % didn't have language as a means of communication, while there were only 29.2 % in group A. None was able to read in group B, while this was the case for 75 % in group A.

There were no differences as regards demand for support in everyday life between the two groups. This was also the case for problems of a somatic or a psychiatric nature. While group A had a broad variation as regards age and intelligence, group B was characterized as a younger group with a more profound intellectual disability.

Type of daily activities

The day activity centre is a form of service and should therefore be able to be described how it contributes to the life of the person taking part. But it is difficult to make such a description if one focus the day activity centre as it contains various forms of activities and as there are differences between persons using this centre.

The way chosen here is to look at each of the persons using this service and to describe each of them as regards each of his daily activities that occur during a week. An activity can then be described in various ways, e.g. its character, whether it takes place inside or outside the centre and to what extent it serves any purpose for the person.

Table 2. Type and frequency of daily activities

	Group A		Group B	
	n	%	n	%
Job	86	(32.3)	13	(19.7)
Task inside centre	17	(6.4)	6	(9.1)
Community orientation	49	(18.4)	13	(19.7)
Adult education	3	(1.1)	1	(1.5)
Habilitation	4	(1.5)	1	(1.5)
Creative activity	37	(13.9)	12	(18.2)
Personal care	10	(3.4)	5	(7.6)
Physical activity	32	(12.0)	5	(7.6)
Planning	10	(3.4)	3	(4.5)
A day at home	3	(1.1)	1	(1.5)
Else	15	(5.6)	6	(9.1)
Sum	266	(99.1)	66	(100.0)

By looking at the activities of each person and to describe and judge their value, it is possible to take a step towards a presentation of the meaning of this form of service for a person. In this study each person in these two groups is described as regards all activities that has taken place. Table 2 shows the activities taken place during a week for the 62 persons.

The activities taken place have been categorized in this way. By "job" is meant various forms of productive work and by "tasks inside centre" are meant those activities which are tasks for the maintenance of the centre. "Community orientation" are those which means participation in community life, e.g. to get experience of local community, to look around to know what goes on or just to experience community life. "Adult education" is the school oriented education for adults while "habilitation" are those activities aiming at the development of abilities of these persons. "Creative activity" are those that lead to some sort of expression through painting or music.

"Personal care" are those directly intended to take care of a person's health or well-being while "physical activity" are those which mean some sort of exercise, e.g. walking or swimming. "Planning" are those moments during the day when the persons is sitting down, himself or with his group to discuss the activities of the day or the week. "A day at home" means those days when the person according to plans, stay at home to participate in the work of his home.

There are differences in some categories of daily activities between these two groups. "Job" and "physical activity" are the ones which are less common for group B, that is those with a more profound form of handicap. The ones more common in this group are instead "task inside centre", "creative activity" and "personal care".

With the new types of needs represented by the persons with a more severe form of intellectual handicap, often with one or more additional disabilities, the character of the day activity centre changes. The new demands means that new forms of activities must take place to satisfy each person's need for support and service.

Purposeful activities?

As the day centre is a form of service it should be able to give persons possibilities to participate in purposeful activities. Each of these described in this study have been discussed to what degree it has some purpose.

This table describes the opinion of staff as to the degree they judge the value of these activities taking place. From this table it can be seen that there is a difference as regards purposeful activities. 76% of them are considered meaningful for group A while only 66% are judged in this way for group B. There are more activities considered "meaningful to a certain extent" in group B. With this as background it is clear that persons with a more severe form of handicap are likely to have less purposeful daily activities.

Table 3. To what extent do the activities have any purpose?

	Group A		Group B	
	n	%	n	%
Very meaningful	151	(75.9)	39	(66.1)
To certain extent meaningful	44	(22.1%)	17	(28.8%)
To less extent meaningful	4	(2.0%)	3	(5.1%)
Not meaningful	0	(0.0%)	0	(0.0%)
Total	199	(100.0%)	59	(100.0%)
No information	67		7	

There are three types of activities seen as purposeful in both groups. They are "job", "community orientation" and "creative activity". A category not considered purposeful in group A is "task inside centre".

Where do activities take place?

A characteristic of whether the day activity centre is able to organize its services to contribute to community participation of the person, is whether it is able to use places, environments or social situations outside the centre building as a place to carry out its activities. It is therefore of interest to see where they take place.

Table 3. Type of environment for daily activities.

	Group A		Group B	
	n	%	n	%
Inside centre, all	218	(55.2)	58	(42.3)
Inside centre, group	73	(18.5)	26	(19.0)
Outside centre, service	16	(4.1)	6	(4.4)
Outside centre, public	38	(9.6)	23	(16.8)
Else	50	(12.7)	24	(17.5)
Total	395	(100.1)	137	(100.0)
No information	7		1	

The types of places used here to categorize are "inside centre, all" which means that the activity takes place inside the day centre in a room or some other place which is used by all at the centre. "Inside centre, group" means that it takes place inside the centre but in a room or some other form of environment which is only used by the group to which the person belong.

"Outside centre, service" refers to a place outside the centre, but it is only used be the day activity centre and is therefore not a public place. "Outside centre, public" means that one uses a place or an environment which is also used by the public.

The main part of the activities take place inside the centre, for 73.7% for group A and 61.3% for group B. When they take place inside the centre it is less common for persons with a more severe handicap to use places of the centre, used by all. There are few activities taking place outside the centre, 4% in both groups, in places only used by this form of service and some more are using places also used by the public. These places are mostly used by persons from group B.

Discussion

Daily activities are critical when institutional closure is taking place. They are one of several forms of community services needed to create an alternative to institutional services and daily activities is one of them, as important as housing. In institutional services they are not separate but is a part, and a minor one. To establish alternatives to the institution, one is faced with the question of whether daily activities will play a minor part like in institutions or if they will have the role they deserve in community services?

This situation has several consequences. As the wards at the institution, with a minor role given to daily activities, there is an imbalance in these two forms of services. If this is brought out into community, there is a risk for an imbalance between housing with support and daily activities which could seriously harm community services being offered. It has also consequences for knowledge of how to organize daily activities. If there were only a limited degree of daily activities at the institution, and then only for those with a mild form of handicap, then there is a risk there will be lack of experiences, knowledge and methods for this form of community service. For the day activity centre, who is responsible for organizing daily activities will have to receive all with a handicap, they will risk a situation with a lack of methods to offer services needed.

This situation has also economic consequences as the lack of daily activities at institutions meant that there were economic resources mainly for the work carried out, or starting from, the wards. To offer daily activities as a part of community services it is necessary to increase economic resources to match this need for daily activities for all, as economic resources from the institution will not be enough.

As regards this part of the project on institutional closure it has been successful. There are alternative daily activities created for the persons who have left these three residential institutions. The main part has got daily activities! It is not expected that many will have employment, regular or sheltered, as these have to high demands, and offer too limited support, as regards persons coming from the residential institution. At the same time there are a group, though a small one, where some who haven't got services to the extent which can be expected.

The study carried out points to one of the critical aspects at institutional closure. They were once used for persons with a mild form of handicap. As daily activities are organized to satisfy needs of persons with handicap, they must vary depending on who is going to participate. Persons with a more severe handicap represents a change in needs of support and therefore the day activity centre will change its character - the structure of activities to offer will change and this form of service will change. New places, methods and staff are needed.

This need for development is further stressed by the results that illustrate that the activities of the day activity centre are seen as less meaningful for those with a more severe handicap. A further need for development is illustrated as community participation can be said to be a reality only to a limited extent. The tendency to have activities taking part outside the traditional day activity centre, is only taking place to a minor degree.

Daily activities as a form of service illustrates the situation at institutional closure. When closing the large institution, one has achieved to create alternatives. At the same time a process has started for the further development of these services as they were not expected, when they once were created, to respond to the needs of persons with a severe form of handicap. Institutional closure and development of community services are "two sides of the same coin", the coin being the need for support for a life with quality for the person with intellectual handicap.

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WHAT DO PERSONS SAY THEMSELVES?

Sirkka Gilbertsson

Background

The experiences of persons with intellectual handicap are important as regards institutional closure. They are the ones to move from institutional life to a life with a higher degree of participation in society. Therefore they have a critical role for this process of change. The extent to which they will feel satisfied with services alternative to the residential institution, will decide whether a project of institutional closure has been successful.

There are several ways to learn about the experiences and the opinions of the persons who leave the institution. Researchers can observe persons with handicap, staff can present their experiences from working in close contact with them. Parents and relatives can talk about what they see of the lives of their near relations.

Seldom are persons themselves asked about their experiences. There are of course natural reasons for this as these persons have an intellectual handicap which creates problems when communicating about their experiences. Several people are just not able, because of their disability, to talk about their experiences and feelings of living at the institution and to leave this place. It is also possible that they are not asked as one finds their information "unreliable". There is though an increase as regards the persons with intellectual handicap to present their views and experiences of services they receive.

The purpose of this study is to clarify whether institutional closure and these persons leaving the residential institution, will lead to a life with a higher degree of quality of life. The information for this comes from persons with intellectual handicap who have left the residential institution. What do they say themselves?

Interviews

The group to participate in the interview are 25 persons with intellectual handicap who have lived in some of the three residential institutions that were part of this project of institutional closure. They have moved to alternative forms of community services and have been living away from the institution for at least one year.

Their ages are between 30 and 60 years and all of them have been living in an institution for the major part of their lives. They have a mild or a moderate intellectual handicap and all of them use speech, some better than others, as their way of communication.

Persons who fulfilled the criteria to be part of the study were identified. Contact with them was made through their staff at the group home where they lived. After having given their agreement to participate, after having been informed about the purpose of the interview, they met with the person who was to carry out the interview. This lasted usually for two hours.

Method

From the concept of quality of life chosen to give the structure for the interview I have used the following parts. One area concerns "external quality of life" consisting of dimensions such as "living", "economy" and "work". A second area are "relations between persons" with such dimensions as "close relations", "friendly relations" and "family relations". The third area of quality of life chosen here is "internal psychological situations" such as "activities", "basic feelings" and "self image". Kajandi has found in his study of this concept that a person has a higher quality of life the better his external conditions in life are, and the better his human relations are and also the better his internal psychological situations are.

Procedure

These persons lived in various parts of the County of Skaraborg and the interview with a person took place in his home, where he was alone with me. It was important to create a favourable situation to be able to talk to one another. During the conversation I have taken notes of quotations during the conversation. All of the interviews started with me asking the person to describe a day in his life. An interview lasted for 1.5 to 2 hours.

After this I had a discussion with the person I had interviewed so that he would be able to correct me or having quotations taken away or even to make them more clear. What follows is an account for some quotations resulting from the interviews with these 25 persons, of course after them being translated. These are quotations from the first of the three areas being discussed.

The residence

"I have chosen this house."
"It was good that I got a house of my own."
"To be able to have my own key."
"I have my own key to the door and nobody is allowed to go in here."
"I have my own telephone and my own newspaper."
"Here I have my own lavatory and I do not have to share it with someone else".
"I have bought all the furniture myself to this apartment."
"We were able to choose our own wallpaper, isn't it nice?"
"I have got my rooms."
"I have only 800 metres to my mother."
"Here I can have guests."

In the majority of the interviews it is reflected how important it is for these persons that they have got a home of their own, which they do not have to share with someone else. The home is their own private space. As many of them expressed it when I came: "Welcome, I live here".

The use of the residence

"It's nice to be able to make my own breakfast, to eat it in peace and quiet."
"I do cook dinner, hot dogs, mashed potatoes, pizza - it tastes good."
"I clean up and smarten things up."
"In the evening I clean up, it won't do."
"I clean my own room and I do the laundry myself."
"Cleaning up that is a thing for the 'old ladies' (staff)."
"I do not cook in my kitchen, I eat in the dining room."
"I do not cook - that is done by staff."

To have one's own home means more participation in various forms of house-keeping. The quotations gives a picture that the person, not to full extent, is given the possibility to this participation from his own capacity.

The right of self-determination in the home

"I do decide a lot more myself these days."
"To decide for myself here is better, than what I was allowed to at Johannesberg."
"I can take whatever I want in my own kitchen."
"I decide myself here in my home."
"I decide who is allowed to enter here."
"I do not have to do things I do not want to do."
"I decide when to go to bed."
"I want to decide myself but my mother decides a lot."
"Staff does the shopping and decides what we shall eat."
"What clothes I shall wear is decided by staff."
"Staff takes out my clothes."
"The 'old ladies' (staff) decide when I am going to have a shower."
"Nobody asks me what I want."

The right to decide in his own home is experienced by most of these persons as something they are able to do. In many of the quotations however, it is also said that the persons do experience that staff and family are deciding a lot in their own home.

Discussion

As the physical environment is important in the home, it is even more important what possibilities these persons are given to use their home. He therefore is in need of support to be able to take charge of his home.

The person with intellectual handicap has got a need to free himself from the dependence of the work of staff. It is important that one respects their integrity and give them possibilities to influence their own lives.

The home has a basic function for the life of persons with intellectual handicap outside the institution. It is from here he / she forms the new life. It is in the home he / she should be able to feel secure, be able to be oneself and to have possibilities to decide for oneself, to relax from demands which society might have on them as citizens.

Being a home for the person with intellectual handicap the task for staff is complex and many-faceted. Staff is therefore in need of increased knowledge and guidance to be able to give the persons the type of support they need, to the right extent. It is therefore of importance that staff is aware of the needs, wishes and experiences of these persons in their new reality, created by the new membership in society.

Comment

These persons have been exposed to an extensive reform which means the closure of institutions. This part of the follow-up project is intended to illuminate what the persons say themselves. In the beginning there were certain apprehensions about the interviews. Would persons with intellectual handicap be able to express themselves? Would he / she be able to give the answer they believe that I expect from them? Would they not dare to express what they wanted to tell me?

From the material collected and from my experiences from the interviews these apprehensions were not necessary. All persons involved have more or less described their present life outside the institution. It is obvious that they feel important: "Just imagine that someone cares about what I think". Most of them are well dressed for the meeting, the coffee-table is set and one is very proud of receiving me in their own home. They show me around in their own home, proud to be able to offer me to use their lavatory: "It is mine!".

It is absolutely our duty to take care of the knowledge which is passed on to us through their experiences and what they have to tell us. What is presented here is how I experienced their new life. It is the persons with intellectual handicap who is the main person. Let us believe in them!

THE OPINION OF RELATIVES TO INSTITUTIONAL CLOSURE

Barbro Tuvesson

Information about institutional closure to relatives

Relatives to persons with intellectual handicap receive information about institutional closure. They read the papers, watch the news programs on TV and they hear staff talk about it. Then they get invited to a meeting for relatives, where representatives from the county authorities tell them that residential institutions are going to close down and that those who live there are going to move to apartments of their own, in the community where they once came from.

The persons who will move from the residential institutions have lived there for many years. They arrived there perhaps as infants, and now they are middle-aged or even older. Their relatives have once travelled the road to the institution in order to leave their child, a brother or a sister, there. The institution has had a function as a community of its own. Those who have lived there all their lives were given food and clothes, care and activities. At the residential institution one could stay until one died. For the elderly there was the home for the people of old age, for the sick there was a hospital ward and the funeral ceremony could be held in the church of the institution. Relatives have seen this and been living in the belief that their near relations would stay there until they passed away.

What do relatives think of the information they receive about institutional closure? Is it a good or a bad piece of information? Is this change to the better or to the worse? What do relatives think after the persons have left the institution? Do they have the same opinion about the new conditions of life as they did have when they first were brought the news about the closure?

Interviews with relatives

I have met with relatives to those who have left the institution, and I have asked about their attitude towards the closure of the institution. In all, I have interviewed 53 relatives, representing 36 persons who have lived at the institution. Among the relatives are 28 parents, 14 sisters and brothers while 11 persons are related in other ways. I have done one interview per person, which adds up to 36 interviews. In approximately 50 % of the interviews I have met one relative. In the rest two or three persons have participated. Most often they have been husbands and wives, but there has also been sisters and brothers together with other relatives. At the time of the interview, the person has been out of the institution for a period of one to four years.

Questions to relatives

I wanted to know what relatives thought of the information about institutional closure and I wanted them to value the new conditions of life in order to see if they had kept or if they had changed their views. My question to the relatives was: "When you got the information about the closure of the institution, what did you think?". I have then asked them to describe and value the new conditions of life, based upon their views of the home of their near relation.

Positive, negative or neutral

I have grouped the answers of relatives into three categories, positive, negative and neutral, at first regarding the information about institutional closure and then regarding the new conditions of life. The relatives have been talking openly, while answering the questions in the interview. After that I have, with help from my notes and tape recordings, formed my opinion of the comments of the relatives.

I have asked whether they are mainly negative or positive. Those having opinions in both directions, and none is stronger than the other, I have categorized as neutral. I have valued relatives at each interview, not each relative. During all interviews where two or three persons participated, they declared the same point of view, except for one. In that case, a husband and his wife differed in opinion.

The decision to categorize has sometimes been hard to make. Relatives are not distinct to the same extent, some use very strong expressions while others are more careful. When hesitating I have looked at the whole interview, to the words and expressions having been used.

The opinion of relatives to institutional closure

How did relatives get the information about coming institutional closure and what did they think? They received this message in different ways. Some got frightened and saw the coming change in a negative way. Others were glad and saw possibilities to a better life for themselves and their near relations. A third group saw both advantages and disadvantages, but neither weighed heavier than the other.

After the move, several relatives consider the new conditions of life as positive. There are still those who see both advantages and disadvantages with the change, and there are some who are negative.

In the matrix it is possible to see that the relatives on 10 of the interviews were positive to institutional closure before it happened. Those 10 are still positive after the move has taken place. The interviews where the relatives are negative in the beginning are 15. Among them, 2 still are negative after the move, 4 have become neutral and 9 have changed their minds and now have a positive attitude. Among the 11 being neutral before, 9 have become positive. One person is still neutral and one has changed from a neutral to a negative opinion. The last mentioned is the only among the 36 interviews which give a change in a negative direction. At one of the 9 interviews the

Table 1. The opinion of relatives before and after the move from the institution.

	AFTER			
BEFORE	negative	neutral	positive	SUM
Negative	2	4	9	15
Neutral	1	1	9	11
Positive	-	-	10	10
SUM	3	5	28	36

husband and his wife disagreed, the wife being neutral before and positive after. The husband was positive before as well as after. I have considered them as neutral, since the wife was hesitant while the husband was definitively positive.

Positive reactions to the first information

"I was the first to telephone and apply for him", an elderly mother said. When she got the information that the institution was to close, she telephoned and applied for a group home in her community for her son. He usually stayed with her every weekend and he was always so upset on Sunday nights when he was going back to the institution. The mother saw the opportunity to change this life. It could not be worse, she thought. There were other parents whose situation was the same. There had been upsetting fare-wells, and because of that parents had not seen their child as often as they had wanted to. To these parents the closure of the institution was a welcome change. They had nothing to loose.

"I thought it would be better for him. Freer. I never was an opponent," one brother says. One sister had a bad conscience during all the years her brother spent at the institution. When she was in her 20:s and he was 10, her parents had the ultimatum either to employ a tutor for their son or to send him to a residential school. Even today the sister is in tears when she talks about that situation. Her parents were working class people and had no possibility to employ a teacher. The brother was sent to the institution and he has been there ever since. Through this institutional closure the sister saw the opportunity to rehabilitate his life. Other relatives, also positive to the change, thought that another way of living could have developing consequences. Their near relations would get freedom and would be spared isolation.

"I will never forget," one mother tells. "A headmaster said that my son had to go to the residential school in order to learn something. That was plain speaking. It was horrible. He was only ten years of age." She had troubles throughout the years because the son didn't want to return to the institution. He had laid down in the hall and screamed. When she got the information that the institution was to be closed, she thought things would be better.

During the interviews I haven't asked the relatives about their experiences when leaving their son or daughter to the institution. Some people have talked about it anyhow. In 7 of the 36 interviews relatives have spoken about their experiences in this respect. They remember a letter they got, or information from a doctor or a headmaster. They can still present the information literally. Of those 7 who have talked about this, 5 were positive when they got the information about the closure of the institution.

Negative reactions to the first information

To some relatives the information came as a shock. They thought they had their near relations safely placed at a residential institution where they knew there was competent staff 24 hours a day. The relatives counted on them to stay there for the rest of their lives. "It was horrible," two elderly parents said. "We were totally taken by surprise, and so were the rest of the parents, at least those who said something." "The information came as if someone poured cold water over me." "How will it be?" "Will it work?" "It will never work for him to move back home again."

Many relatives feared their near relations would get less help in the future. "It won't work," two parents said, "he cannot cook for himself." Representatives for the county authorities talked about "own apartments in the home community". The relatives thought that their near relations would be sitting alone in his/her apartment, with just little or none support from staff.

This apartment would be in the home community of the relatives and their conclusion was that they were to take the full responsibility over themselves. One brother, in fearing this, said afterwards "I never thought they would spend so much money on the intellectually handicapped." He was opponent to the closure but he had also been negative to the institution. "If one is healthy moving into such a corridor, then one isn't well moving out."

Other relatives who were negative to the move said it was foolish to move a person who was rooted in an environment where he seemed to be happy. "They were so settled there. They had a church and everything, and then they would have to adjust to something new."

The relatives who were negative to the institutional closure had different reasons. Some wanted things to be the way they were, others felt worried about the new situation.

Neutral reactions to the first information

Other relatives have reacted neither positively nor negatively. They have seen both advantages and disadvantages with the move. They could be worried that their near relations wouldn't get enough support, but they didn't want to stop the development. "If it influence them in the right direction, then it is right," one mother said. "Perhaps I heaved a sigh of relief that he was going to be his own master," one sister said. "We were worried, but wanted to wait and see, we wouldn't stop," two parents said. "We didn't think so much about it, it wouldn't happen all at the same time," one sister told me. She had seen her brother being mistreated when he early in his life had stayed with different farmers. When he at last came to the institution that difficult period was over. The move from the institution to a apartment with service was not that dramatic. Two parents said "It is hard to compare an apartment with services at the residential institution. There is a bigger difference between being home and being at an institution."

From a negative or a neutral to a positive opinion

Many of those who have changed opinion, from a negative or neutral point of view to a positive one, have done this shortly after the move. When they have seen with their very own eyes that their near relations got adjusted to the new life and seemed to be happy, they changed their minds and considered the new as something positive. "We changed opinions almost at once. It was easy to see the quality in the apartments," say two parents.

Some relatives say they changed their opinion before the move, in connection to the information given, for example when shown the place where staff was to be placed, or promises made about care for the near relations. "At first I was hesitant and thought that she would end up in the middle of town, not being able to move about. Then I got to see the grounds and the drawings of the new house, and I was delighted and understood this was really something extra," one mother says. "When there was a decision made so that she was to eat in the dining-room and being cared for every day, then I thought that this would work out good," says a relative of a woman who moved into an apartment with support.

From a negative to a neutral opinion

The relatives who were negative before the move, and neutral afterwards, see that the new life contains advantages which they hadn't expected. But they also think there are some things missing. An elderly mother, living in a small place, does think it is great to have got her son back home. He lives in a group-home within 10 minutes walking distance from her. They meet several days a week, which she appreciates.

But she gets sad when she sees that her son doesn't get the care he got while he was at the institution. His clothes are not looked after properly and the staff seem to be more interested in taking him out buying new things. When the zip in his jacket had been broken for a year, the mother took it mended it.

The is enough staff, but she is disappointed in its achievements. "Nobody takes responsibility," she says. Some parents are worried about the staff's medical competence, for example dealing with epilepsy. "To the staff it is safe that we live nearby. We are more acquainted with the boy than a doctor is. It is hard for the staff to know when to call for a doctor," two parents say.

One mother who was negative before and now is neutral, describes her experiences like this: "At the institution they took care of my worries. These worries come closer now, and that is both positive and negative."

From a neutral to a negative opinion

At one interview I met relatives who saw the move as a deterioration. They are two sisters who were neutral to the move before while they afterwards are negative. Their brother has got a "diminished world" around him, they say. They mean he has less friends now, with whom he has no interchange. Besides he has made a fool of himself, both in church and on the bus, and nowadays he travels by a transport service. The outcome of all this is that he has become worried and restless, and this concerns the sisters.

Still a positive opinion

There are relatives who at 10 of the interviews were positive before the move, and still are positive afterwards. Things turned out the way they had expected, with better conditions of life. Those who had problems with the journey back to the institution had no difficulties now. Their near relations voluntarily got to his feet and walked or travelled back to his own place. Parents who had stopped bringing their son home because of this problem while he lived at the institution, after the move were visited every fortnight without problems. Relatives who had expected their near relations to get more freedom have seen this come true, and he is developing as a person. "We are most happy for his sake," one father says. "They were so isolated at the institution."

Still a negative opinion

Among the 15 who were negative at the early stage, 2 still are negative after the move. At these interviews I met relatives who were very negative and worried. One interview is about a woman in her 70:s who has moved to a home for old-age people. According to the relatives the problem is that she has come to the wrong place. "There are too few staff. She is just sitting there, and does not get activated. The staff thinks we should take part and we don't have the time." The woman has turned unruly, and staff can not always handle her. Then they telephone the relatives and ask them to come around. The opinion among the relatives before the move was that it won't work. "Any sensible man can understand that."

Other relatives also being negative, have a son who lives in his own apartment, and he is cared and nursed for by staff at home. The son receives support 5 times a day, and in spite of this he is undernourished, dirty and his place is a complete mess. He has epilepsy, and at one occasion the hospital phoned the parents. He had been taken there a few days ago. The parents had to answer for his bad hygiene. "There were stockings 'standing for themselves' and longjohns that stank. Do you understand how it feels being a mother and have to stand this when he has so many persons around him?"

The parents do not think that the support he receives at home is adequate. Many persons are with him and no one seems to take responsibility. This couple had been most worried before the move. They think the root to the problem is that he, before the move, got the information that from now on he was the one to decide for himself and his life, at the same time he wasn't properly trained to deal with daily life activities.

Still a neutral opinion

At one interview I met relatives who were neutral before as well as after the move. They don't remember what they thought when they got the information. They do remember it was their sister herself telling them that she was going to move.

They think it is good for her to have an apartment of her own and that she can be her own mistress. They don't like though that the apartment is situated in a noisy area. They are worried that she will get bad company. Then they also think that she feels lonely sometimes, which she denies.

The opinion of relatives to the reaction of staff

At 3 interviews relatives have talked about the staff's reactions over the information about the institutional closure. The relatives themselves were neutral or positive to the change. But they do remember the staff had a different point of view. "The staff tried to persuade us to go against the man responsible, they wanted us to sign a protest. I didn't think so," a mother told me. "The staff took offence. They didn't show it in front of us relatives, but they have told us afterwards," another mother says. Relatives think that staff had difficulties in accepting the decision about the closure, since they were at stake being unemployed.

Discussion

The opinion of relatives to institutional closure, is more positive than one could expect. There are relatives who are definitively positive and there are relatives to whom this change doesn't seem to be that dramatic. It seems as if they hadn't worried. And many of them who have been worried had misunderstood the idea behind the move. They were worried they had to take the responsibility themselves.

How come that relatives are positive to institutional closure? The first question is if they were positive when they got the information, or if they afterwards just said that they were? It has been years since they learned about the change. Perhaps they have the need to repress unpleasant information.

The relatives I have considered positive declare their points of view in an evident way. They remember expecting some kind of improvement. Either to get rid of something at the institution which wasn't good, or to make a profit from the new, for example to get their near relations home to their own community. Some relatives are astonished when I, after the interview, tell them that there are relatives who are negative.

The relatives who were negative to the move had in many cases formed their opinions from the wrong information. The county authorities had, eager to inform about the advantages of the change, mentioned that every person would have his/her own apartment. The term "own apartment" could in this case be understood as a place without help from trained staff. This was a sheer misunderstanding between the county authorities and the relatives.

Relatives who today are displeased probably have all the right to feel that way. They have given examples of unsatisfactory situations which are unacceptable. The basic idea ought to be that if community gives support with staff, everything should be satisfactory.

One can also ask the question of how the person himself appreciates his new life. Could it be that he is satisfied, while relatives are not?

Three relatives have told that staff had difficulties to accept the closure. This could be interpreted as if these parents transfer their own feelings on the staff. Why? Couldn't it be that staff was more dependent of the institution to remain, more than parents?

If several hundreds of jobs disappear from an area, to be spread over the county, it certainly is a threat to staff. For relatives, on the other hand, who during all the years have had to travel for many kilometres to see their near relations, not at all being satisfied with the services of the institution, closure could be a possibility.

I have when visiting staff, asked them what they think about relatives and institutional closure. The answers I get are unanimous. Staff think that relatives are negative before institutional closure and positive afterwards. As we can see from the interviews, the opinions of relatives are more varied. It is probably so that those who are negative make their voices heard. They have an interest in stopping the closure of the institution and act accordingly. The neutral relatives abide time with a certain anxiety, and the positive are hopeful. The two categories last mentioned have no reason to act in order to stop the change. A question I ask myself is if institutional closure is a harder adjustment to staff than to relatives?

Relatives talk about how it was to leave a child, a sister or a brother at an institution or in a hospital. There is no doubt that these experiences were painful. Even if they later on accepted life at the institution, it all began with this experience. When I have seen and heard relatives talk about their lives, I begin to wonder if the great separation took place when the near relations left home, and not as one could imagine, when he/she left the institution.

FACED BY CHANGE:
THE ROLE OF THE INTEREST GROUP

Anne-Marie Wendelholt

The large institution

Once upon a time, there was a large institution called Johannesberg, located in Mariestad in the County of Skaraborg. The institution was called "the cradle of all institutions" in Sweden because it was more than a hundred years old. At the most there were nearly 700 persons with intellectual handicap living there. In 1986 the County Council of Skaraborg, in accordance with legislation, decided to close down Johannesberg and two other private institutions. At that time there were 300 persons with intellectual handicap living there. Today they have all moved into group homes in the county and the institutions do not exist any longer.

I am a parent to a fifteen years old boy, severely and multiply handicapped, who during the first year of his life in 1977, spent five months at Johannesberg. The conclusion of this visit was that he was so severely neurologically handicapped that he was recommended a future in an institution as the only alternative. Despite this he moved back to his parents when he was 1 year of age, and has lived there ever since, naturally with proper help and support. Thanks to his very stubborn mother he has had the opportunity to "live like others, together with others", long before this was the aim confirmed by legislation.

This stubborn mother, being me, became very early a member of FUB, the National Association for Persons With Intellectual Handicap, locally as well as on county level. In 1987 I was offered a part-time job as an ombudsman for FUB in the County of Skaraborg. The county authorities gave contributions for this and my main task was to be the contact in the county in the project aiming at the closure of residential institutions in Skaraborg. This task lasted during 1987-1991, and I will here recapitulate some of my memories and experiences from this period.

What is FUB?

FUB, the National Association for Children, Youth and Adults with Intellectual Handicap, is an organization which takes care of the interests of persons with intellectual handicap on all levels. When it first started in the beginning of the 1950:s, it was a marked parental organization, while today it is more common that persons with intellectual handicap speak for themselves. FUB is a nationwide organization with more than 32 000 members. They are the persons with intellectual handicap, parents, relatives and other interested persons who want to support the activities of the organization.

Apart from the board of directors of FUB, there is an association in each county and also more than 160 local associations all over the country. The target is to have one local association in each community, to facilitate a close contact with those responsible and others involved.

Faced by change

My first impression of the County of Skaraborg and the care for persons with intellectual handicap struck me with conservatism, stiffness, bureaucracy and a lot of boredom. That these county authorities all of a sudden were to take this great step, the decision to close down all institutional services in the county during a period of five years, struck us like lightning! Persons with intellectual handicap were now to "live like others, together with others". They should all move to group homes, in the communities where they once came from or wherever they choose to live, and there to have their own apartment assisted by trained staff.

Shortly before this happened, we at FUB had a discussion regarding the design of group homes, based on a model suggesting that each person was supposed to be given a room of fifteen square metres, no more no less even if one was physically disabled. So we were very surprised by this total positive change!

We knew that our seventeen primary care boards were going to be in charge of the persons with intellectual handicap, and that the Board of Social Services of the County Council from now on only would have an overall function. Finally, we began to grasp the whole idea!

Reaction of the interest group

The reaction of FUB was quite weak in our county. Possibly, one of the explanations was due to the fact that the most active FUB members had their children living at home. The reaction in the local FUB association where Johannesberg was located, was very strong though. Naturally, they did not want to keep the institution, but they had a wish to keep the good institutional grounds and its surroundings even in the future. They also considered to build several group homes in the institutional grounds, because they were afraid that the group homes otherwise would become isolated.

The local FUB association arranged a meeting with people from the primary care board, the County Council, the county association of FUB and a representative from the National Board of Health and Welfare, Karl Grunewald. He was not very impressed and informed everybody that law and order was to be followed by each and everyone, even in Mariestad.

The organization for implementation

The first model for the organization to implement this change which was introduced, was very traditional with an administrative group, a team to carry out the change and a reference-group. FUB was to be part of the last group. Fortunately, as I see it now, it turned out be another model where all representatives involved became a part of this process of change.

This group was eventually given the name Social Welfare Group. Apart from the chairman and the vice chairman from the primary care board, there were representatives from the old system, that is the director and the assistant director, representatives for staff and FUB. It was at this time I received my position as ombudsman and I will now describe some of my responsibilities and experiences from this project.

Meetings with the Social Welfare Group

Sometimes I really thought that the discussions regarding the persons with intellectual handicap themselves became a minor issue. There were far too many discussions on planning for staff. What were they to do with staff that was going to be redundant when the persons had moved? But that was not the primary issue for me! I felt very clearly that me trying to influence on quality and content of services would have to wait for another time and place. It was very tough not to be able to influence there and then.

The counsellor who was responsible for the personal contact with relatives during the preparations to move, had many years of experience in the past with the social activities of FUB and was very well fit for that task. Unfortunately, I was never part of the discussions which he had with relatives. The over all floating "Secrets Act" closed all doors to me.

Today I know that ...

> * I should have been more stubborn and persuasive in making contact with relatives.
>
> * I should have had much more information material to hand out.
>
> * all journeys to the meetings of the Social Welfare Group were to be paid by the county authorities to the county branch of FUB.
>
> * the meetings with the Social Welfare Group were enormously informative and instructive.
>
> * a part time position as ombudsman is far too limited.

Counsellor to parents

Of all different information that took place, I eventually made contact with rather many relatives. I became the face of FUB and I was the person who was positive to the change. Far from all parents thought the way I did, and sometimes it was very difficult. But my experiences from the time at Johannesberg made me convinced, even though I definitely understood and respected the parent's worries about the change that was going to happen.

When I today look back and meet the great happiness among the relatives, for the change in life situation that persons with intellectual handicap have got, I can only feel joy together with them.

Training of staff

Along with the building of group homes for persons who had been living at Johannesberg, there was naturally a requirement for skilled and motivated staff. An endless number of times I have participated at staff introductions where I have informed about the FUB and our activities.

The discussions have often become infected, regarding the relocation of the people involved. Should persons with intellectual handicap really have such a large apartment? Especially the severely handicapped, do they really need their own kitchen? Even at this day some concern appears that persons with intellectual handicap should live too well! The FUB now has an enormous job ahead to inform over and over again for the purpose of changing the attitude of society.

How did it turn out?

In the County of Skaraborg we are very provincial. The fact that seventeen primary care boards would bring home "their people" from the institutions actually turned out as a competition. Maybe not officially, but definitely unofficially. If they can, we can better! Building sites were found, group homes were built and staff was trained, all in a very high speed.

All this happened despite the fact that the Social Welfare Group was discarded half-way. The reason for this is still "hidden in the dark" for me. Possibly this is one of the reasons why I never advise any other FUB person or parent to enter such a group. But I can honestly say that I never at any time felt like a "hostage" of this group.

The motto for the change was that it would lead to something better for each and everyone. I also experienced that this was the purpose for the work of the group. Many of the great thoughts and visions disappeared when the group was ended. In spite of a very dedicated and efficient staff, it will take a long time before we are back to the capacity and visions that was among us from the beginning.

FUB-GERDA

In the middle of the work with institutional closure FUB Skaraborg started the GERDA project. The county authorities gave a contribution to this project which mainly is about the influence of persons with intellectual handicap and about their possibilities to be representatives in their local community. In the project we would like to give them possibilities to answer and to guide us, because the fact is that they are living in the consequences of our decisions! We also want to maintain the knowledge and experience of being a resident at a large institution, that exists in this group.

Today FUB Skaraborg has a "Youth Counsellor" employed, with the main assignment to support the eleven GERDA-groups, with approximately seventy participators in the county.

Quality and influence in living conditions

Much too often, it turns out that the group homes mainly are places of work for staff. The residents cannot fully make use of their apartments because there is not staff enough. "Collective punishment" still exists when "one for all, and all for one" still goes on. This was probably not the thought, because the change should lead to something better.

When County Council starts "saving" on legislated services for persons with intellectual handicap it really becomes nasty. People being dismissed in other county activities, influence in a negative way. How is it possible to secure good living conditions, promised by the Act of Social Services, when staff is hired on the grounds of how many years of service, and not because of personal suitability? From this year on, the seventeen primary care boards do not exist any longer. When the county had their last re-organization they were replaced by six boards for health care services. They are also responsible for the care of persons with intellectual handicap, leading to risks with too large variation in staff and unclear staff roles.

The winds of change are passing so quickly through our society today, unfortunately, affecting the most exposed people first!

What were the consequences for the interest organization?

Very little happened to FUB, except in some communities, where a fine co-operation started with welfare authorities, just like intended in the recent Act of Social Services. I thought that this project of institutional closure was going to inspire the establishment of new local associations, but many communities are so small that this has been very difficult to accomplish. But we have at least had two new ones established during this period. An earlier very active local association has nearly fallen apart. If it depends on this move from institutions or something else is difficult to say. Some local associations have received many new members due to the fact that the persons who moved from the institutions have joined their own association at home.

The county association, however, has got a role which to a greater extent exchange and co-ordinate experiences and keep discussions alive, concerning quality of services. Furthermore, they were forced to give the ombudsman an office. This office is today very busy and answers for an extensive service. Except for the "Youth Counsellor" there is a person employed to handle the office.

In conclusion, if and when you have the opportunity to participate in such a change remember to

* tackle controversial questions immediately, otherwise you will not be able to sleep at night.

* be open with your views and experiences, as an interest organization has a great knowledge which should be used.

* question everything that seems uncertain. Ask until you have acceptable answers because you have the right to be "uncomfortable" in your group on behalf of your clients.

* try to make personal contacts with relatives, "secrecy" should be used in the right way. This must not be the reason to give you the possibility to inform about the interest organization.

* inform on all levels, not only relatives should know about the interest organization.

* unconditionally make sure that your county association and the local associations are involved in such a process. It is very easy to make this position into a "one man job"! You should at least have a group inside the interest organization where you can discuss your thoughts and impressions.

This is a very short summary and conclusion from the five years I have worked as an ombudsman. If I was to write about everything I have experienced, about people I have met, about sad and happy episodes and memories and of all the feelings of being involved in such a change, this would end up as a book.

If you would like to know more, then please contact me. Today I am chair-woman in a local association in Skaraborg and also the chair-woman for the county association of FUB in Skaraborg. So I am still very active!