COMMUNITY PARTICIPATION:
THE LIFE OF PERSONS AFTER LEAVING THE RESIDENTIAL INSTITUTION

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FOREWORD

Sweden has seen a dramatic change of services for persons with intellectual handicap during the last two decades, a shift from institutional to community services having taken place. One of the phenomena has been institutional closure, the abandonment of the residential institution as a place for the delivery of support to persons with a severe intellectual handicap.

In the County of Stockholm, the residential institution of Carlslund was closed down in 1988. A follow-up study has been carried out in order to describe the life led by these persons after they have moved. In this report a presentation is made of some of the results.

This study is based on questionnaires to group-homes and day activity centers, where staff, sometimes together with persons with handicap, have provided the answers. We would like to thank all for their participation in this study.

This report is prepared for presentation at the 1992 IASSMD Congress. As project manager it has been my task to put together the presentations from the various contributors. The report has been produced by the Department of School and Social Services of the North-West Region. My task has been a pleasure!

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Contributors to this report are a group of persons who in various ways have been associated with the closure of Carlslund during the period 1978 - 1991.

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CONTENT

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CARLSLUND - AN INSTITUTION 90 YEARS OF AGE

The founder

The residential institution of Carlslund was started at the turn of the century as a privately run asylum for 38 persons with intellectual handicap, most of whom came from the city of Stockholm. The institution started in a closed down carpenter's workshop in what is now a suburb to Stockholm, then a small township 30 kilometers from the city center. It was named after the previous owner of the workshop and was run by the owner, Maria Krantzon.

A period of expansion

On her death, after 25 years of private ownership, the institution was taken over by an association, specially started for this purpose. As the majority of the residents, which had risen to 172 by the end of the 1940:s, came from the city of Stockholm, which also had an increasing need for new placement possibilities, the City Welfare Authorities took over ownership at the end of the forties. This saw the beginning of an era of rebuilding, renovation and expansion, the objective being a modern institution for children and adults with a severe intellectual handicap, persons then called "uneducable".

The new institution was planned for wards giving care for 600 residents. Later a special school was built and a sheltered workshop for adults who had working ability. This period of expansion reflected an optimism and belief in the opportunities which could be provided through modern institutional care.

New developments

As a consequence of the incorporation of Stockholm city in the Greater Stockholm County Council in 1971, the institution became a part of a larger organization for services to persons with intellectual handicap. As other Special Services were developed, some residents moved to newly opened and more modern institutions and some others, those with a mild intellectual handicap, were given the opportunity to move to newly established integrated housing. As a consequence of these developments the number of residents in the mid-1970s was around 400, the majority being persons with a moderate or a relatively severe intellectual handicap.

Meantime services for persons with intellectual handicap had been developing rapidly. As a nation-wide debate during the early Seventies had brought to the fore the negative aspects of institutional life, several of the residential institutions for persons with intellectual handicap were severely criticized, Carlslund being one of them. Criticism came from professional groups, from staff groups in the institution and from the parent association of the institution. In many ways this criticism led to improvements of conditions but demands were still being made that more radical measures be taken to improve the life situation of the residents.

Parallel to this debate on institutional services, new developments were taking place in the area of community services. New alternatives had developed, often on an informal basis and designed for persons with a milder handicap. However, because of the positive experience gained from these developments, it was being felt that attempts should be made to make such services available even to persons with a more severe handicap.

Early alternatives

In the early Seventies, Stockholm County Council, having taken over responsibility for the these services in 1971, carried out a comprehensive survey of the needs of all known persons with intellectual handicap, for whom the county was responsible. One of the forms of service to be provided was housing with support in the community, adjusted to the needs of persons with severe intellectual handicap. These were termed group-homes. The program also included the development of day activity centers for the same group of persons.

The presentation of the results of this survey, with its consequences for county planning, coincided with the requirement that the state approval of Carlslund, by the National Board of Health and Welfare, be renewed. The Board's pronouncement in January 1975 gave a renewal for only one year pending a plan for extensive renovation and a successive reduction in numbers to a maximum of 200 residents.

This pronouncement gave the county reason to appoint a working committee whose task was to present a proposal for the future of Carlslund, in keeping with the requirements made on modern up-to-date systems of care. The suggestions made by the working committee obliged the county to invest extensively in the renovation of the institution, and at the same time provide over 150 of the residents, who would have to move in order to reduce the number to 200, with alternative services.

An alternative solution was therefore put forward, namely to let all the residents avail of the alternative community services which were being developed, and close the institution down when an alternative had been found for all.

The County Board for Social Services decided unanimously on the latter alternative, the news gave rise to much consternation when the decision was first made public in April 1976.

A planning project

A planning group was appointed, composed of four persons specially employed for the task. In addition special representatives were co-opted to participate in working groups, these persons representing parents and relatives, various staff unions, political groups and responsible administrators. The specially employed group was appointed to carry responsibility for analyzing all aspects of planning the alternative, one part covering the administrative and economic aspects of the plan, a second surveying the individual needs of each of the residents and suggesting alternative services, the third surveying staff interests and plans for alternative employment.

The planning group worked as an entity for two and a half years, having prepared a complete plan for the process of closure. During this period intensive discussions took place concerning both the nature, and the standards, of the alternatives which were to be provided, the parent representatives and their local organization playing a very active role in these discussions.

Following the final decision taken by the Board for Social Services as to which alternatives were to be offered, the functions of the special group were taken over successively by the regular administration which was responsible for its implementation.

Implementation of the plans

During the period between 1976, when the decision to close down the institution was taken, and 1988 when the last of the residents left, many other changes had taken place in these services. With such a long period to dissolve the institution, there was a lack of continuity. A parliamentary Commission had been appointed to suggest new legislation, which also came into force during this period. General and County elections had taken place several times, involving changes in the political scene. Among the administrators responsible for carrying out the decision, at both county and institutional level, many new appointments were made and responsibility changed hands.

To move from the institution was no new event for a resident. During the years many had moved to different services and for different reasons. Residents had also moved between the wards, either for personal or administrative reasons. During the first years of the period of closure the gradual reduction in the number of residents caused no sensation. Instead many felt that the gradual nature of the change prevented both staff and parents from facing realities and accepting the fact that the institution would eventually close down. This reluctance reflected the actual situation where opinion was divided as to the wiseness and suitability of closing down the institution.

In retrospect one can see that opinion changed in pace with the establishment of alternative services. When housing in the community and alternative forms of daily activities became a tangible reality both residents and their relatives, as well as staff, came to accept and appreciate the alternative system. The degree of satisfaction with the alternative offered did however vary. Partly because of the number of external changes already mentioned, but also because of practical difficulties, like slowed down and sometimes canceled building programs, originally commitments were not always possible to keep. At times this was interpreted as false, or broken, promises.

The process of moving

The process of moving from the institution was largely determined by pragmatic and practical issues. The survey had described, in detail, which alternative services were required and requested for each resident. When this service was made available, either within existing, or newly established services, the resident could move. One can say that the onus for successful closure lies in which alternatives are available. To begin with, priority was given to those residents whose move led to reductions in the number of persons on the wards, the short-term objective being to reduce the number of persons on a ward and the number of shared rooms. Another priority was to close down the older, and lower standard wards first.

In the closure plan prepared by the planning project it was suggested that the period when systematic moves would take place would be 1980-1988. It was reckoned that this time would be needed in order to plan, develop and establish the suggested alternatives. This prognosis was shown to be correct. During the first half of the period 25% of the residents moved, whereas the last 27% were first able to move during the last 15 months, 1987-1988. The institution was finally closed down in March 1988.

The re-use of the institution meant that it was sold to another authority, the Department of Immigration, to be used as a reception center for immigrants seeking political asylum.

When Maria Krantzon started Carlslund it was used for persons with handicap seeking asylum from life in the ordinary community.

A FOLLOW-UP STUDY

Community participation

The closure of Carlslund was unique as it was the first of a series of large residential institutions for adults, to close. It was of interest to find out what had happened to the persons who left Carlslund. A follow-up study was therefore carried out. It was requested by the Board of Social Services of the County of Stockholm and carried out by research psychologist Kent Ericsson at the Centre for Handicap Research at Uppsala University.

Information for the study was collected through a set of questionnaires which were distributed to staff in group homes and day activity centers where these persons had moved. The information was given by the staff, sometimes together with the person with handicap.

Community participation, a concept in the normalization process, was taken as the theoretical construct to formulate the questions. The questionnaire to the group home concentrated on a description of the type of housing, the life led by the person in this house and his activities in the local community. The questionnaire to the day activity center focused on a description of the activities in which the person was involved during day time.

During the period of 1980-1988, 300 persons were to move from Carlslund. Some of them, 26 persons, died during their stay at the institution or after they had left. The 6 persons who moved to family homes, were not part of this study. There were no answers for 2 persons, either from the group home or the day activity center. In this follow-up study the life of 266 persons is described. For 49 persons there is only information about one of the two types of services, housing or daily activities. For 33 persons there is only information about housing and for 14 there is only information about their daily activities. 2 persons have paid employment on the regular labour market and are therefore not presented in the part about daily activities.

The complete presentation of this follow-up can be found in a final report, this being a presentation of some of the basic questions that were encountered in this project. This first chapter is a short presentation of the residential institution which was closed and is written by Kent Ericsson and Patricia Ericsson. The second chapter, "Alternative services and the life they offer", is presented in several sections, each dealing with a topic. It has been compiled as comments on the results from the follow-up, written by persons who in various ways have been involved in the work of closing Carlslund, either at the residential institution or in the community services used as alternatives.

In this way Tommie Åkerström has written the section on "Housing with support", Kerstin Kylsten on "Daily activities" and Stefan Lycknert on "Daily activities for commnuity participation". Peter Brusén has written the comments on "Social networks and neighbourhood relations", Jan-Åke Ahlström on "Recreation and leisure time", Torbjörn Rosdahl on "Support of professional groups" and Ann-Mari Jönsson on "Dentistry for persons with intellectual handicap". Kent Ericsson has written chapter 3, with a comment on "Institutional closure - An idea and its realization".

Patricia Ericsson, a previous Director of Services and responsible for Carlslund during the period of closure, has collaborated with the authors in the preparation of this report and translated it from Swedish to English.

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ALTERNATIVE SERVICES AND THE LIFE THEY OFFER

HOUSING WITH SUPPORT

Background

In the residential institution it can be said that the "housing" provided consisted of a bed in a public ward! As late as the 1970:s up to 10 persons could be sharing the same ward. One can say that the person's own sphere, the area of personal integrity, was limited to the bed itself. The rest of the person's "housing situation" was comprised of collective space used by everyone else. The area where one cares for personal hygiene, that which must be the most personal and intimate aspect of life, especially when one has not even chosen those with whom one lives, was in the institution shared by 10 to 20 persons.

All meals were prepared in a large central kitchen, for all the residents, and delivered to the wards by a centrally organized distribution system. The situation was not made better by the fact that most of the day was spent on the wards, as it was not considered necessary that those living in an institution should have access to any daily activities.

It was clearly difficult to relate housing provisions and staff support to the needs of the person. This was especially noticeable regarding the level of staff support, all being considered from the same standard measure. One received the amount of support provided on the ward in which one was resident, irrespective of individual needs. This was particularly apparent at night, as the usual pattern was that all wards had staff on night duty.

After institutional closure

After the residential institution was closed and the persons had moved to housing in group homes it was seen that 30 individuals, 11 % of those living in the institution, had been receiving more staff support than they needed, undesirable passivity being one of the consequences.

The community alternative to the residential institution consisted primarily of three categories of housing, that is A: a small apartment with limited staff support, B: a group home in an apartment with extensive staff support and C: a group home in a detached house and with extensive staff support.

A: An apartment with bathroom and kitchen. Several apartments within a housing area, staff being based in a centrally located service apartment from which service is provided. Staff support when required and called.

B: Group home in an apartment where each resident has a separate room and shares a bathroom with another resident. The usual number of residents in this type of group home is 4-5 persons. All food is prepared in a commonly shared kitchen. Staff support is extensive. There are usually 2 staff constantly on duty during the day and one at night, either awake or on sleeping duty.

C: Group home in a detached house where each resident has a separate room and shares a bathroom with another resident. The usual number of residents in a group home is 4-5 persons. All food is prepared in a commonly shared kitchen. Staff support is extensive. Most usual is that 2-3 staff are always on duty during the day and one awake at night. The usual staff ratio 8-10 full time appointments providing for a group of 4-5 residents.

Of the 266 residents who moved from the residential institution of Carlslund, 30 persons, 11%, moved to alternative A, 84 persons, 32%, moved to alternative B and 105 persons, 40%, moved to alternative C. A further 14 persons, 5%, moved to other residential institutions, mostly in other parts of the country. There is no information about the present day housing situation for 33 persons, 12% of the original group. Of the 266 persons who moved from the residential institution of Carlslund at least 219 have acquired a more normal housing situation.

Comments

There are two reasons for the use of residential institutions for 14 persons. Some of these came from other parts of the country and were now moving to their "home-county" where the closure of institutions was not yet being carried out. Therefore group homes with extensive support were not used, so one was not able to present these persons with a group home as alternative service. The other reason for these 14 places in residential institutions, was that some persons were moved to a small boarding-school, now being re-used as a small residential institution.

Since the residential institution of Carlslund was closed down in 1988 the development of group homes has increased rapidly. To-day persons moving from residential institutions move to fullworthy housing, a personal apartment composed of bedroom, sitting-room, bathroom and kitchen.

To facilitate staffing this type of housing is built so that 4-5 apartments are located together in the same house, with the area for common service in the center. This increases accessibility to staff and gives opportunities for social activities. It is clear that this new type of housing with service has to a greater extent provided for the individual's right to a personal sphere, at the same time providing facilities for social and common activities.

DAILY ACTIVITIES

Background

The traditional institution was a comprehensive environment in which all the needs of persons with intellectual handicap were to be met. It provided a collective system of service in which it was difficult to recognize and to meet the special needs of each individual.

The living standard was relatively low and as late as the mid-sixties it was still considered quite an achievement when 40%, mainly those persons in the institution who had a mild handicap, were receiving some form of organized daily activities.

In 1967 an Act of Parliament for support to persons with mental retardation was passed. In the discussions prior to this legislation, the lack of daily activities and other forms of stimulation in institutions was severely criticized. Following the introduction of this Act, and with reference to this criticism, new forms of daily activities were developed and applied in institutions as well as in the community.

A specified program on the design of premises, staffing and working-methods was issued. The emphasis, however, was mainly on the provision of premises for production work, but with facilities for adult education and social activities.

This perspective changed gradually and the concept of purposeful daily activities for everyone gained in significance. The day activity center was seen not just as a building but rather as an organization where different premises, environments and social situations in the community, could be used for purposeful activities.

This approach meant that persons with intellectual handicap could, in a more tangible way, come in contact with and avail of ordinary social services. Activities in small groups were established in different businesses and public services, giving greater opportunities to meet the person's needs and wishes.

Experiences from these developments, and the changing nature of day activity centers, led to a new awareness of the need for daily activities even for persons with a severe intellectual handicap. In July 1986 an Act setting the rules for the support delivered, came into force, giving persons with intellectual handicap the right to "daily activities in day activity centers, or other forms of occupation, to those who lack employment and are not being educated".

The closure of Carlslund

The closure of the residential institution of Carlslund was a very important event in the history of services in Sweden, and was prepared for by a very thorough individual survey and a period of planning. It was the first time that it was presumed and accepted that even persons with a severe intellectual handicap could live in the community.

A variety of different housing was planned and often specially built, and persons moved when new housing had become available. One had also recognized that planning of daily activities must be given the same priority as alternative housing, when decisions are made about closing institutions.

In spite of this awareness of the necessity for parallel planning of both housing and daily activities, it was, in practice, not always possible to accomplish. The development and establishment of provisions for activities was not given the same priority thus limiting the integration of these persons into the community.

As a consequence temporary solutions had to be found which in some cases meant that a person who had moved to alternative housing could, for a period, return to the institution for his activities.

It is generally thought that this was a bad alternative as it could often be seen that those who returned to the institution during the day reacted in a very negative manner.

What happened for those who moved from Carlslund?

Between 1980 and 1988 all the residents moved from Carlslund. In the 1991 follow-up study daily activities provided for those who had moved were described by giving the amount of time spent in activities outside the home.

Of the 266 who had moved 29 were occupied outside their home up to 19 hours a week, 87 persons were occupied between 20-29 hours a week and 100 persons more than 30 hours a week. Two had obtained paid employment. No information is provided for 48 persons.

From the questionnaire to house-staff it can been seen that 10 persons, for example old age pensioners, have themselves chosen not to participate in any form of daily activity. In addition 37 persons had organized activities in their home away from their scheduled day services, "a day at home", during which they participated in the household activities of their home.

The study also shows that there is a wide variation in the type of activities available and one can presume that these relatively well correspond to the individual needs of the persons concerned. It can also be seen that the premises used have a reasonably good material standard, that personal relationships have developed and that new social relationships have been established.

One can draw the conclusion that moving from Carlslund has meant

* that daily activities outside the home has become a reality for those who asked for it,

* that the new activities developed correspond better to the individual needs of the person,

* that greater participation in the community has became possible.

Comments

Current legislation from July 1986, stipulated that the objective for the special services to which persons with intellectual handicap have a legal right, is the furtherance of a good life in participation with others. Daily activities, one of the special services to be provided, is to be meaningful for the individual and lead to a greater participation in the community. These objectives require that the daily activities provided, be varied in character and are based on the needs and wishes of the person.

As a consequence of the aim that persons with handicap should be able to live like others, and in participation with others, then daily activities should, as far as possible, be provided where persons without handicap also work or are occupied during the day.

With these objectives as a starting point activities have developed from the day activity centers of the 1970:s, which were buildings in which persons with mild or moderate intellectual handicap were kept occupied during the day with a variety of activities, to an organization of activities which take place in a variety of premises, environments and social situations in the community.

For persons with a severe intellectual handicap, often multi-handicapped persons, small units have been established, each person often having his own personal assistant to help. Activities often concentrate on providing sensory stimulation and personal contacts, making use of the local environment for as many activities as possible.

For persons with a mild intellectual handicap the objective is primarily to find employment in the ordinary labour market, alternatively to find special work situations for handicapped persons. The latter form of employment is provided by the state.

For those who are unable to avail of these forms of regular employment alternative occupations have been sought. These are often located in public or private businesses, the purpose being to provide work-training which hopefully may lead to employment. These often occur in small activity-groups, with 4-5 persons, under the leadership of an employee of the services. The business concerned is not obliged to pay any salary, the person with intellectual handicap having his pension and the staff being paid by the services.

The day activity is a special service provided by the County of Stockholm which has developed dramatically during the last 10 years. Having the individual needs of the person in focus has required that many types of activities, with varying content, have developed. In spite of this, we are only at the beginning of a process of change which, with the implementation of the 1985 Special Act, means that each person's need for daily activities be provided for in a personal and stimulating manner.

These changes also imply more participation in, and greater opportunities for establishing social relations with the local community.

DAILY ACTIVITIES FOR COMMUNITY PARTICIPATION

History

The historical development of services for persons with intellectual handicap follows a logical pattern. From large-scale to small-scale, from management based on organizational needs to organizations based on individual needs, from isolation and passivity for the individual to participation in society for the person with intellectual handicap.

This has been a development with a long-term perspective. In the asylum people were kept in custody, "nothing to give, nothing to receive", passively cared for, protected from the outside world, with few expectations put on them. The person with intellectual handicap was regarded as one lacking in intelligence, instead of being seen as a person in an early stage of development, both in personality and intellectually. The gifts of intelligence and the developmental dimensions of personality being woven into a whole, describing a developmental perspective of intellectual development.

The encounter

An encounter between the person with an intellectual handicap and one without is a meeting between two persons at different developmental levels, free from evaluation. Such an encounter creates a pattern for relating one to another in similar meetings. Persons with a primal personality organization must, in some respects, be protected from the strains of the outer world. But in spite of this these persons are constantly being subjected to some form of social interaction with their environment. The problem that arises is that persons with intellectual handicap in time "level out" in their development. The pattern of early relations remains but a tiredness sets in.

An example of this is the staff member who said about a person with intellectual handicap, who could not speak and had difficulty in walking. "It's strange but I have stopped speaking to her. I like her so much but I just can't manage to keep it up". The person with intellectual handicap is also one who gives and takes in a social relationship and a tiredness can set in, in this interaction.

But no person with an intellectual handicap is entirely handicapped - there is a handicapped and a non-handicapped aspect of the personality. High expectations on the highly functioning aspects, and understanding for the aspects which function at a lower level. Handicap is a condition which fluctuates.

Daily life in the community

Experiencing a daily life integrated into the ordinary community, circumstances favorable for developing the non-handicapped side of one's personality are given more scope.

Similarities with persons without handicap, rather than the deviations, steer relationships. The differences become less important even if an understanding of the limitations are not discarded. In an environment characterized by excessive protectiveness, and in which the deviations are emphasized, it is more likely that the person with intellectual handicap withdraws, allowing the handicapped aspects of his personality to develop and interaction with his social environment to dwindle.

An example of this is the severely intellectually handicapped man who, when eating at the day activity center had great difficulty in swallowing whereas at the local restaurant, in the company of a staff member, he had no problem in chewing and swallowing his food. Sharing the same "space" as others in society is important. Being linked to others, taking part in activities where one is part of a functional entity, participating according to one's own ability, furthers growth and inhibits regression.

To be the one to go on simple errands, to accomplish a task, to be recognized or to be greeted in a shop gives satisfaction. The feeling of being an outsider, which can be an outcome of one's handicap, can be counteracted by the actual experience of participation.

What has been done?

During the Seventies and Eighties traditional activities at the day activity center have been replaced by other types of activities, in other places, in the community. For example shops which sell products such as textiles, printed cloth or carpentry work which has been made at the day activity center. A further example is service to others, such as running cafes or lunch restaurants, where the person with intellectual handicap contributes according to his ability, from cutting up salad to serving at tables.

Other types of activities are being responsibility for coffee-making, or watering flowers, in offices, tasks for which no professional group is responsible but which is answering a need. Many more examples of this type of task can be found. "Going out" from the day activity center, carrying out tasks in other places and in other environments is the form of integration which has been most common. It has however, been thought important, and supportive, to remain in touch with one's own group and to still have the day activity center as a base.

The follow-up study

In the follow up study of persons who had moved from the residential institution the type of day activities participated in were registered. For each person all the daily activities he participated in during a week were described and categorized. One of the dimensions for analysis was where the activity took place. Did the activity take place inside the center or was it located to integrated settings outside the day activity center?

Table 1. Categories of settings where activities took place during a week for 218 persons who together participated in 1223 activities.

Category of setting:	n	%
Inside center, all	439	(35.9%)
Inside center, group	410	(33.5%)
Outside center, service	38	(3.1%)
Outside center, public	165	(13.5%)
Rest	150	(14.0%)
Total	1223	(100.1%)

Four categories of settings were used, the first one being a room at the center, used by all. The second category is a room at the center, but used only by the group that the person belongs to. The third category is a place outside the center, still part of services and only used by persons with handicap, the fourth type of setting is a place outside the center, used by the public.

This is seen as an expression of participation in the community. From this table it can be seen that only a limited number of the activities carried out by the persons with intellectual handicap (13,5%) took place outside their own special premises, in settings which were used by persons without handicap.

"**Daily Activities in Bridgetown**"

A day activity center with which I have been involved for some time has had as its goal that all the participants should have some form of activity in the ordinary community, whether it be sheltered employment or merely trying some new activity like collecting the post from the post office. All the participants, either in a group or individually, do in some way take part in the local community, for example having lunch at the local restaurant.

The group included five participants of whom three were women. Finding difficulty in labeling the type of organization where this type of activity is going on, it was merely called "Daily Activities in Bridgetown", there naming the local community in which it was taking place. Daily activities became a concept free from associations with production, results or being profitable, instead being an expression for a meaningful exchange with the local environment during working hours.

The premises from which they were operating were well suited for the task, being located in the shopping center of a small suburb. The two women members of staff had been there since it started two years earlier.

On entering the premises one came to a glass partition behind which there was a room for coffee-breaks. The furniture, in particular a modern wooden sofa, reminded one of the type of benches found in the waiting room of a railway station. It can be seen as symbolic for what was going on, "being on the way, only temporarily being here".

In practice the wait at "the station" can take over a year for some of the participants, packaging work of a simple kind going on while one is there. Three of the persons have a mild intellectual handicap while two of the women are autistic and seldom use spoken language. One woman sat most of the time staring at the wall whereas two of the men were socially active. One of the men has had a job with salary benefits for the last 6 months, returning to the day activity center one day a week. None of the women have any activity outside the day activity center. Without going into detail as to the persons concerned, or their activities, the nature of the process of development can be commented on.

As a member of staff, in daily contact with the persons with intellectual handicap, it is unavoidable that decisions being made, and the activities going on, are influenced by the persons' total situation and not only by the specific conditions around the task for which one is employed, namely the provision of daily activities.

A foothold in life

The topic which often came up for discussion concerned the men and their efforts to find a foothold in life. This could be a matter of the expectations and demands made by the staff themselves, or by others, on their performance or it could concern the difficulty the men had in seeing their own limitations. Failures have to be followed by new attempts.

For staff with an understanding and sharing of the failures and successes of others, and being responsible for upholding the objectives of their task, it is easy to acquire the role of parents to teenagers. One must dare to trust the ability of others to cope with what has been undertaken and have the insight that one cannot be everywhere at the same time.

Discussions in the staff group concerned the changes and developments of the different participants. Some were concerned with the woman who had been so passive. Her increasing ability to carry out her task of packaging, her growing maturity in relation to the staff. Being a woman amongst women, being a person others could depend on, belonging to a group, had become important things for her.

One of the autistic women had also become more of a personality, showing that she also was part of the social group. This was illustrated by an episode when talk concerned girls and boys and someone was showing off a new engagement ring. She had not shown any interest in what was going on. The next day one of the staff accidentally noticed that she had a ring on her finger!

One day a member of staff was ill, at the same time as another was on holiday. During that week one of the women, the one who is coping well with her own job, took on the task of introducing the substitute staff to her new job, thus surpassing all expectations. One began to wonder whether she should be found a new activity somewhere else.

Questions were often asked why one must look for an alternative activity for the person who seems to be happy where he is in the day activity center, and where he is master of the task he has got. It seemed as if it was easier when circumstances around one can be controlled, for example when one runs one's own café, instead of being in a strange social structure such as someone else's business.

One's own space

Having one's own "space", even in a very limited sense like having one's own place at the table, seems to strengthen ones personal integrity. This works as a protection against the outer world, marking the boundary between the inside and outside of the ego.

Perhaps it is important for staff to establish secure relations with each other and therefore it is natural that utterances which strengthen the group's identity are encouraged. Strengthening this inner identity may however take place at the expense of other outgoing relations. The person who goes to an office and waters the flowers is greeted with a welcome, but at the same time feels he is on foreign ground, the group to which he belongs, being somewhere else.

It would seem that those who leave the day activity center for some other activity do so one at a time. It is difficult to say whether this is an expression for the view that integration is something only for the most capable or whether it is a question of not having the mental energy to allow more than one at a time to take on this new role. It can even be a matter of chance or opportunity.

Some other examples

Some other examples can be taken from another day activity center at which I worked. The group, who were part of a larger complex, included five persons with severe intellectual handicap. The two staff members, both young women, expressed feelings of inadequacy, having time only to feed and care for the group. All are competing for attention, making the staff feel that individual needs can neither be seen nor met. The responsibility feels too great when the group are completely dependent on them for all their needs. This leads to a feeling of failure, collective treatment distancing staff from the needs of the individual. The groups at the day activity center seem too large so staff try to free themselves of this by seeking activities outside.

A reflection as to the interaction between persons with a very severe intellectual handicap and others, can be that it is difficult to maintain a receptive and sensitive attitude for a longer period of time. In a parent-child relationship, when the child is still at an early stage of development, the parent is compensated by seeing progress and development, the relationship changing with time. This is not the case for the person with intellectual handicap when the process of development "levels out" with time. Perhaps that was why the staff member stopped speaking to her friend, even though she liked her very much. Lacking a response, she just stopped speaking to her.

Finally, to refer back to the table. In the example from the first day activity center the man who had acquired employment was one with a mild intellectual handicap. He himself, with support from the staff, had found a place in society. This can be described as "crossing the boundary", something we all do in the process of socialization. With reference to the table one can see that this does not easily occur for everyone. Staff must actively go in and take responsibility for crossing the boundary. Perhaps the woman with the ring could, one day in the week, and with staff support, pack chocolates at the neighbouring chocolate factory.

My vision

In conclusion, one can, with the help of fantasy, have a vision of the staff member who stopped speaking to her friend, taking her with her to another place of work, perhaps where one does computer work, and having her beside her while she herself carries out another job. As secretaries sometimes have to leave one task to do something else, so she could leave her computer job when her friend needs to be cared for. She should be able to give her as much time as she needs, caring for her being the primary task, but thanks to her now has the chance to do something else, the computer job, which she perhaps had dreamed of but not been able to achieve. It is now much more fun caring for the person who could not speak, and perhaps sometimes someone else goes by who stops and speaks to them both!

SOCIAL NETWORKS AND NEIGHBOURHOOD RELATIONS

Introduction

The impact of social relations on the well-being of the individual is being emphasized more and more in social, medical and psychological research. Developing social networks involves the identification of positive social contacts, strengthening them and guaranteeing that they be maintained.

Persons with intellectual handicap have moved from institutions to integrated housing in residential areas. In some cases there have been negative reactions and protests. Preventing, and coping with such reactions is an important issue. An increasing awareness of this aspect of the job has led to the development of working methods directed towards social issues, the result being a new and greatly changed staff-role.

Relating social network methods to the services for persons with intellectual handicap builds on the assumption that application of this approach, in an integrated housing set-up, can give a deeper and richer content to life and thereby enhance the quality of life for residents with intellectual handicap. The social and psychological objectives which are sought to be attained through integration can thereby be made more concrete.

Studies of social contacts between persons with intellectual handicap and their neighbours have shown that social interaction is dependent on the amount of everyday contact that occurs. If there are no natural occasions for contact then social contacts do not develop. Physical integration is a basic requirement but is not, in itself, a guarantee for spontaneous contacts.

However, advantage is not always taken of better opportunities for social contact and relations with others. The major hinder seems to be the attitude staff have towards the value of social interaction for persons with intellectual handicap.

Apart from practical obstacles in recreational activities, like physical accessibility, costs, applicability of activities etc, even social and psychological obstacles play a very important part. Even when good opportunities arise the person with intellectual handi-cap is often hindered by lack of a friend or his own hesitance, not daring.

The pre-requisites for social contacts in housing are not only dependent on who one is, but also on what one does. Others must regard the person with handicap as a neighbour and not define the situation as a public service. Having one's name on the door, having one's own letterbox, participating in local activities are some of the ways for facilitating this process.

Moving from the institution and social contacts

In the follow-up study for those persons who moved from the residential institution of Carlslund contacts with neighbours and other social relations with relatives and friends were studied.

Table 2. The nature of the relationships to persons in the neighbourhood.

	n	%
Characterized by conflicts and problems	10	(3.8%)
Characterized as neutral	202	(75.9%)
Characterized as positive	16	(6.0%)
No information	38	(14.3%)
Total	266	(100.0%)

For greater majority the move to integrated housing has led to relationships with persons in the neighbourhood which can be described as neutral or positive (81.9%). For a small group (3.8%) problems have arisen.

These results are very similar to those found in other studies which have shown that between 80-90% of the social contacts are described as neutral or positive. Negative reactions have also been found to diminish relatively quickly. In general one finds an attitude of acceptance from neighbours in spite of the fact that problems do occur.

Another aspect concerns the social network and contacts with family and friends. In the Carlslund follow-up this aspect was looked at and the frequency with which different categories of guests were received was studied.

Table 3. Type and frequency of social contacts.

	Frequency of contact:			
Type of contact:	None	Year	Month / Week	Total
Parent	53	62	54	169
Sibling	79	109	11	199
Other relative	148	58	6	212
Guardian	41	97	37	175
Social contact	29	27	34	90
Important friend	6	33	12	51

The results show that very few have a friend at all. Only 12 persons of the total 266 meet a personal friend once a month or more. In other words 254 persons (95.5%) have no continuous or regular relationship with a friend. This indicates an extensive degree of isolation which can only partly be compensated for by family and staff.

It is not only the physical environment which contributes to defects in emotional development, motor ability and communication, but even a defective social environment. It has been clearly shown that institutional life severely inhibits personal development and thereby implying that community services are better in this respect.

It is however simplifying the issue to maintain that integration and housing in smaller unites automatically improves the situation. The pre-requisites may increase dramatically but whether the individual experiences a change in the total quality of life depends on the attitudes and working methods of the staff.

Isolation and loneliness can occur just as well in an integrated residence as in the institution. This analysis concerns the ways in which integrated housing should contribute to the individual's need of a changed social environment.

How to work with social networks and the neighbourhood

Development of a stimulating social environment and social relationships is dependent on many factors. The staff are the generating factor who determine whether the given conditions are used to give a deeper dimension to the lives of persons with handicap.

- The neighbourhood: How reactions, relationships and attitudes from persons in the environment provide possibilities for developing permanent social relations in the local community.
- Influence: How the interests, choices and needs when expressed by the individual himself, contribute to their being seen and regarded as persons with personal needs and possibilities.
- Housing: How the character of the house, and its physical location contribute to whether the resident can function as a social individual.
- Recreation: How external and out-going activities, and opportunities to avail of them, provide the essential means for acquiring social contacts.

Negative reactions from neighbours are often a reality and are often different in character.

I. At the beginning they can be caused by feeling that the authorities have made one-sided decisions leaving few opportunities for local residents to influence the outcome. Such reactions are directed towards a public authority and not towards the persons with handicap themselves.

II. Similar reactions can come later being caused by anxiety and lack of knowledge prior to concrete experience of what the new housing will mean for the neighbourhood.

III. After residents have moved in, reactions can be caused by real problems for example unfamiliar noise and sounds, transport, service etc. After a time such reactions often fade away and the persons with handicap be fully accepted and regarded as ordinary neighbours.

IV. It can happen that negative reactions develop towards staff, neighbours considering that they are not effective, sunbathing and drinking coffee when they should be working. Neighbours can in this way express their desire that persons with handicap are living a good life.

To attain good relations with neighbours, and thereby prevent negative reactions, both staff and the persons with handicap must make themselves visible in the neighbourhood. It is important that every opportunity for everyday contact be made use of so that they can get to know each other.

To have a socially active aspect in one's work contributes to the development of the person's social network. The staff should support ways of creating a social network and help it to grow and survive. Such a network builds on the relationships between people, a relation which has a mutual function. Being alone is thought to be strong but in reality a strong social network is a basis for the security everyone needs.

Maintaining a social network is best done by keeping traditions and helping the person with intellectual handicap to an awareness of their own background and history. Knowledge about one's family and relatives, friends and other significant persons can be used to strengthen a social network. In everyday life social contacts are encouraged and staff provide support to keep in touch with people in the person's surroundings.

One way for staff to work for building a social network is to ask relevant questions like

* How can we achieve a more socially oriented work?
* Are there friends somewhere else?
* What friends were there before moving here?
* What special interests does the person have?
* What would be a good holiday, seen from his personal interests?
* What consequences does this have for our way of working?
* How do we celebrate the holidays, birthdays etc?
* How we help to arrange new contacts?
* How can we strengthen and improve existing contacts?
* What character are the social contacts with the family?
* Who is alone and who does have social contacts?
* Are there friends during daytime whom we do not know about?

Interest for working more socially has to be increased. It concerns questions on personal development and recreational activities. Methods of work which stimulate relevant social issues in the everyday life of the person with handicap have to be developed. The risk for isolation and loneliness exists even in integrated housing.

RECREATION AND LEISURE TIME

Background

The structure and organization of life for persons with intellectual handicap living in the traditional residential institution was based on the idea of creating an alternative and segregated community for the residents. The living quarters dominated whereas daily activities and recreational facilities and interests were considered less important. Some recreational activities did take place but were within the framework of the collective pattern of life of the residential home.

Most common were different forms of entertainment, for example film shows, musical entertainment, theater and dances. The residents participated more or less according to the personal interest the staff showed for the activities being arranged. Neither cultural nor recreational activities were chosen or planned on the basis of the residents' needs or preferences. These activities took place mainly within the institutional setting even if excursions, in smaller groups, did occur to animal parks and other such attractions.

Towards the end of the 1960:s adult education groups introduced their activities to the institution, offering the residents hobby and recreational activities, arranged in the form of "study groups". These types of activities had previously only been arranged for non-handicapped persons. The organization responsible for that had, however, begun to adapt their organization even for persons with handicap and now realized that these could even be made available to those living within the institution. It was soon found that this type of activity could, with certain adjustments, be organized in order to provide regular daily activities for the residents.

No serious attempt to evaluate the quality of the recreational and cultural activities provided was made during this period of institutional care. Staff awareness and knowledge increased considerably following the 1967 Act. In staff discussions concepts like normalization and integration were beginning to have significance and impact on the activities of the institution. Staff sought opportunities for social training through activities in the community outside the institution. At this time it became noticeable that attitudes were changing, both in the community and within the institution.

The establishment of the special school within the institution in 1968 created possibilities to prepare and train pupils for a more active leisure time. When the decision on the closure of the residential home was made staff were prepared and positively inclined towards the idea of change. An awareness of the importance for persons with handicap having a stimulating leisure time gradually gathered in momentum during the 1970:s and 1980:s.

Many staff thought that moving from the institution to a "normal" housing situation would, in a simple way, even solve the question of integration in society, normalization of life and of leisure time. It has been shown however that this is a process which takes time and requires both knowledge and awareness from the staff involved.

When the institution had been closed and the residents had moved, better prerequisites for an active leisure time were made available. The opportunities in society were many and varied, but not always entirely adapted to the needs of persons with intellectual handicap. Various interest groups, the county and local authorities, began to establish "special" leisure-time activities provided for persons with intellectual handicap. Training of staff in these matters increased in order to enable them to develop more satisfactory recreational activities.

Results from the follow-up study

In the study of the 266 persons who moved from the residential institution their leisure-time and recreational activities are described as in the table below.

Table 4. Type and frequency, (none, 1-3 times and more than 4 times) of leisure activities during the year of 1990. Percentage in brackets.

	None	1-3	4-	Total
Café	7 (3.1)	21 (9.3)	198 (87.6)	226
Dancing	66 (32.8)	59 (29.4)	76 (37.8)	201
Music	70 (36.3)	84 (43.5)	39 (20.2)	193
Cinema	116 (58.6)	55 (27.8)	27 (13.7)	198
Museum	122 (61.9)	61 (31.0)	14 (7.2)	197
Theater	126 (66.3)	58 (30.5)	6 (3.1)	190
Sport	159 (85.9)	24 (13.0)	2 (1.1)	185
Religious service	163 (86.7)	16 (8.5)	9 (4.8)	188

A clear trend is seen, namely that persons with intellectual handicap increasingly participate in the leisure-time activities provided in the community for non-handicapped persons. For those who previously lived in the residential home this implies a considerable change which is considered to be beneficial for those concerned.

Comments

Since the closure of the institution the provision of leisure-time activities has increased considerably. One no longer speaks of organized recreational facilities but instead see a distinction between three areas of leisure, as for the non-handicapped population. "Organized activities", such as clubs and societies are based on common interests and activities, "private duties" like caring for one's home, garden, personal belongings etc. and "free time", just doing what one feels like for example watching television, playing records, visiting a friend, or going for a bike-ride. To feel satisfaction with one's situation there needs to be a balance between the different aspects of one's leisure-time.

SUPPORT OF PROFESSIONAL GROUPS

Background

The persons who lived in the residential institution were provided with the support they required within the framework of the institution. This could include hairdresser, chiropodist, medical support from doctor and nurse, postal services etc. The Act of 1985 stipulated, amongst others things, the right to a home of one's own. It also recommended that all institutions be dissolved by 1997.

The basis for this position was the principle of normalization and the aim of integration of persons with intellectual handicap in ordinary community. One of the implications of the normalization principle is that the normal life lived by non-handicapped citizens, be made accessible to those with handicap. Integration implies, amongst other things, that persons with handicap have a right to live in a home of their own, in the community, along with other citizens.

The staff of the institution and the relatives of the residents, expressed much anxiety about the future care of persons with handicap. They questioned who, and how well, the interests of the residents would be looked after when they had moved. An example was the anxiety felt for the needs of persons with diabetes, whether they would receive the necessary foot-care. Who in the future, would guarantee that they were given appointments? Questions like these were given much attention and caused much worry, during long periods.

Results from follow-up

In table 5 the results of the follow-up study from 1991 are presented. The current situation for the 266 persons who had moved was investigated. The answers have shown that the situation for these persons has improved. There were few where the individual's need of service was not being met. To-day it is just as natural for a person with intellectual handicap to go to the hairdresser, to the health-clinic or the district nurse, as for any other citizen.

Since 1986 service to the community has been provided partly through local open-care Health Centers, providing both medical and psychiatric service, and partly through the ordinary hospital services, as previously. The most important of the generic services is, however, the local social service responsibility for providing recreational facilities, escort services, home-helps and other social and personal assistance.

Table 5. Four types of professional support as regards who delivers this service and how the needs are being met.

	Chiropodist	Social-worker	Psychologist	Physiotherapist
No need of support	23	144	155	155
In need of support, but receives none	2	1	8	26
Service delivered from within special service	28	94	44	56
Other public service	-	3	30	6
Private service	129	-	3	2
Someone else	68	-	-	-
No information	16	24	26	21
Total	266	266	266	266

The most usual form of service was however provided from the district office of the services for persons with intellectual handicap. In the county of Stockholm with a population of 1.5 million, there are at present 18 such district offices, each having a habilitation team for children and one for adults. The team for children provides services for all handicapped children, whereas the adult team is limited to providing services for persons with intellectual handicap.

This study was concerned only with the services provided by the team for adults. Such a team usually has part-time access to an employment and a recreational advisor, whereas the standard team for adults is made up of professional groups as physiotherapists, social workers, psychologists and speech therapists.

The team is led by an administrator, assisted by secretarial staff. These professional groups have, in addition to their basic training, further qualifications in the field of habilitation and handicap. It is considered of utmost importance that this special competence be maintained and developed.

The service they provide can be summarized as follows:

Physiotherapist: Assessment of the condition and needs of the person, treatment and ordination of required technical aids.

Social worker: Advise and information in all social questions assessment and recommendation on the total need for special services and recruitment of personal advocates. Advisory and supportive contact with persons with intellectual handicap, their relatives and staff. Co-ordination of services from other authorities, in particular the regular social services.

Psychologist: Assessment of individual levels of intellectual handicap, need of support and the right to special services. Information on the nature and consequences of intellectual handicap, for the individual and his social environment. Therapeutic contact with the person with intellectual handicap and his family. Consultant and advisory support to staff concerning the person with intellectual handicap.

Speech therapist: Diagnosis and treatment of adult persons with intellectual handicap regarding disturbances in voice and speech delivery as well as eating and drinking difficulties. Presentation and training of alternative systems of communication.

The tasks of the habilitation team for adults cover various functions and services for persons with intellectual handicap, their families, within a given geographical area. These can be described in the following way.

A: Support and treatment

Various forms of support and treatment are provided by the different professional groups as long as their provision is not the responsibility of another authority. The purpose is that these services be made easily available and be provided by professionals with special competence.

Adult persons with intellectual handicap, and their spokesmen, require various forms of support. This can be a question of finding the right source of help among the services provided by society, or having someone to turn to for advice and support. All the staff on the team, from their own professional angle, have responsibility for this type of support.

Persons with intellectual handicap often need support to widen their social network. They run a particular risk of becoming isolated and restricted to their homes. A task for the habilitation team is to access the individual's need of a personal advocate, recruitment of suitable persons for the task and the administration of their appointment.

Individual treatment programs for persons with intellectual handicap by different professionals in the team, is also an important aspect of the service provided. The individual's specific need is of course the basis on which a treatment is recommended, but consultation with the family and responsible staff groups is essential for the team member.

Group support and treatment is another way of providing service. There can be many advantages from working in a group, partly that different professionals can work together with a group, providing more diversified support, but also that adults with a handicap can benefit from meeting and receiving support from others with a similar handicap.

B: Co-ordination of services

Information as to which services are available for persons with handicap, and where in society they are provided, is a task for which all members of the district team are responsible for coordinating in the interests of the person and his family.

It is also the task of the team to maintain up-to-date information on the current and coming needs of the population for which they are responsible. This basic data is required not only for the internal planning of the team but even for coordinating the services of other authorities, for example local social services and the health services.

The district teams co-operate very closely with the local social services in matters concerning persons with handicap. Staff from the services for persons with intellectual handicap are often given the role of representing the person with handicap in negotiating or making claims to require service. This can be in matters of shared responsibility or unclear legislation as to the rights of the person.

It is therefore the responsibility of the district team to keep the public in general, and in particular other service authorities, well informed as to the needs, and legal rights of persons with intellectual handicap.

As legislation in this field is extensive covering the Act for support to persons with intellectual handicap, the Social Services Act, the Health and Medical Care Act and the Administrative Procedures Act. This requires a good knowledge of current legislation and the interpretations of courts on the implementation of various services.

DENTISTRY FOR PERSONS WITH INTELLECTUAL HANDICAP

The follow-up study

With the closure of the residential institution, the special dental clinic at the institution was also closed down. In the follow-up study carried out it was therefore of interest to find out how this service was provided and to what extent the dental needs of these persons were being met after having moved. The conclusion has been that the persons who have moved are having their needs met in a satisfactory manner.

Table 6. The need for dental care and how these needs are being met.

	n %
No need for dental care	14 (5,7%)
In need of dental care, but receives none	0 (0,0%)
Needs met at dental clinic for persons with intellectual handicap	115 (46,7%)
Needs met at dental clinic for persons with special dental needs	41 (16,7%)
Needs met at district dental service	68 (27,6%)
Needs met by private dentist	8 (3,3%)
Total	246 (100.0%)
No information	20

The conclusion drawn is that the majority had access to the dental care they needed, mostly from dental clinics for persons with special needs. These are part of the public dental service, termed hospital dentistry, and are complementary to the ordinary public dental services which are run at district level. As with all other citizens availing of these services, persons with intellectual handicap are registered and therefore called regularly for check-ups and treatment.

Dentistry for persons with intellectual handicap

All children and youth up to the age of 19 years, have a right to free dental care and treatment. The same right to free service applies even to adults who have an intellectual handicap.

According to the Dental Health Act of 1985 dental care should be available to all through the Public Dental Health service. This right is equally applicable to persons with intellectual handicap as to all other citizens. The person with handicap is also free to chose between attending a private dentist, the district dental service or the hospital clinic. Hospital dentistry is however only available on referral.

In Stockholm county approx. 5.200 persons are registered as having an intellectual handicap. No study has been made as to where they receive dental care or treatment. It is however generally presumed that the majority avail of the public dental services rather than private dentists. Persons with less severe handicap are treated by the district services whereas those with more severe intellectual handicap or those with additional handicap are referred to the hospital clinics.

Has it always been like this?

The perspective on persons with handicap has changed through the times. The official view of persons with handicap, as expressed in legislation, has also changed. One can see a process of changing views, from "custodial concealment" to "treatment", later to "normalization and integration" and finally to "participation and equality".

Institutions in Sweden are therefore being closed down and replaced by integrated services. The person with intellectual handicap, as for everyone else, is given access to the ordinary social services, which even includes dental care.

The dental services have also gone through a process of change. In the Fifties and Sixties dental care was dominated by an emphasis on "restoration", caries and pyorrhoea still being a widespread problem. In the training of dentists the technical and odontological aspects of dentistry was also emphasized. In particular, persons with intellectual handicap generally had a poor standard of mouth hygiene, pyorrhoea, bacteria coating, caries and bad breath being common. This added an additional burden to their being handicapped.

An awareness of the need for preventive care gradually developed. The public dental service began information services e.g. at Child Welfare clinics. Mouth hygiene was taken up in schools and patients were informed about the relationship between diet and dental status. As a consequence dental health has now reached a high standard in Sweden to-day. This has had positive consequences for persons with intellectual handicap, even if much still remains to be done.

Why do persons with intellectual handicap have special dental problems?

There are reasons why persons with intellectual handicap often have more dental problems than others, for example

* poor physical perception
* difficulty in carrying out dental care
* bite anomalies
* breathing through the mouth
* eating habits
* side-effects of medication
* fear of dental care and treatment

Some persons with intellectual handicap, for example persons with Down's syndrome, encounter additional risks for pyorrhoea and need special attention to maintain normal mouth hygiene.

With this being the situation it is not surprising that the dental services, concentrating on the technical aspects of dental care, were unable to adapt to the needs of these patients. They were having to treat persons who could not sit still and who did not even request dental care! Staff within the services for the handicapped also lacked knowledge on the care of the mouth. This often resulted in drastic dental treatment at a late stage, under anaesthetic, in order to eliminate the worst problems.

Gradually the idea of dental services being concerned about the patients total situation gained support. An interest for "causal dentistry" developed. So called hospital dentistry and special clinics were established. These are now part of the ordinary public dental service.

Hospital dentistry

Specialist dentistry is based on a system of referral from the local district dental care service, being a complementary and supportive service for persons with special needs. The service is available for long-term hospital patients, persons with intellectual handicap with special dental needs, the mentally ill, geriatric patients and others who may need special dental treatment. The various types of handicap which may make it necessary to have special treatment are persons with cerebral palsy, epilepsy, rheumatism or persons with infectious diseases.

In the county of Stockholm, with a population of 1,5 million, there are at present 40 hospital dentists, 15 dental hygienists and 70 dental nurses. Hospital dental clinics are equipped with lifts for bed-ridden and wheel-chair patients, mobile dental equipment, vacuum cushions for support, special lighting equipment etc.

The objectives of public dental services

The objectives set for the public dental service in Stockholm is formulated as "the right treatment for the right patient at the lowest cost for the patient and society". This entails adequate therapy planning where many aspects must be taken into consideration. For persons with intellectual handicap these can include

* medical assessment
* odontological assessment
* physical status of the patient
* attitude of the patient
* staff views on the dental needs of the patient
* view expressed by relatives of the patient

The objectives in the dental care of persons with intellectual handicap is to attain an maximum level of dental health in relation to the person's basic condition. A patient may for example be given far-reaching treatment to improve mouth hygiene instead of being provided with dentures as may have been requested by relatives. Another objective is of course immediate relief from suffering or acute pain, in such cases some form of sedation being used if necessary. Anesthetics are however, according to policy, only used in exceptional cases this being considered demanding for the individual as well as being costly for society.

Prophylactic and informative services

The basis for the dental services is regular prophylactic and informative service to all concerned in order to achieve good oral hygiene. This is particularly the case for persons with severe intellectual handicap. Mouth hygiene must be cared for in the home, thus putting particular responsibility on the staff who provide for the needs of the person with handicap.

An investigation at the department of child dentistry in Luleå showed that persons with handicap are in greater need of assistance in the care of their teeth. This is partially due to the intellectual handicap itself, but even because of motor difficulties. A greater occurrence of bacteria coating, tartar and inflamed gums was found among handicap persons who were alone responsible for the care of their teeth.

One reason given for poor oral hygiene among persons with intellectual handicap is other peoples fear of infringing on their integrity by enforcing dental care, for example, brushing a persons teeth against their wishes. This gives rise to many ethical issues as to where the line is to be drawn between respecting the will of the individual and consideration for their well-being.

A study in Jönköping showed that 6 of 8 staff considered that the person with handicap was capable of coping with their mouth hygiene themselves. The dental staff considered these estimates to be overrated and found that persons with intellectual handicap had a poor standard of oral hygiene and an unnecessarily high rate of pyorrhoea. Such conditions in turn gives rise to other difficulties such as speech impairments, eating difficulties, emotional disturbances and even poor social adjustment in society.

The hesitancy of staff can also be caused by lack of knowledge about oral hygiene, dental care and the difference between healthy and unhealthy state of the teeth. Studies have shown that staff consider that they have received too little education about these matters during their official training. An attempt to remedy this has been made in Stockholm county by way of a project (1989-1991) supported by both the Board of Social Services and the Board of Dentistry. In a special education program carried out in the North-West Region of the county of Stockholm, staff in group homes were trained, both in theory and practice, in how to achieve and maintain good oral hygiene among persons with a severe intellectual handicap. The results have shown that the dental health of the persons with handicap has improved and the need for dental treatment been reduced.

Two models of dental care

These experiences from the dental care of persons with intellectual handicap can be summarized by contrasting two models of dental care. One model lays the emphasis on treating the effects of poor oral hygiene, here termed "effective dentistry" whereas the other approach, or model, examines the causes of poor oral hygiene, emphasizing preventive measures and termed "causal dentistry".

"Effective dentistry" aims at repairing damage already caused, requiring technical skills and focusing on the teeth alone. "Causal dentistry", on the other hand, takes into consideration the person's total life, housing conditions, mental state, support systems etc. The focus is placed on the mouth as a whole and its general state of well-being. Dental care becomes therefore an issue for all persons concerned in supporting the person with handicap, from both social and dental services, the individual's needs being the common factor.

The "causal dentistry" approach is gaining ground, as more emphasis is for example being put on dentistry for persons with handicap in the training of dental staff. This is a necessary development as persons with handicap are to a much greater extent living an ordinary life, integrated in the community, so their needs must be met by the regular dental health service.

These thoughts and developments can be summarized in the words of Wren: "The patient's general welfare must be placed first, his mouth second and his dentition third".

3

INSTITUTIONAL CLOSURE - AN IDEA AND ITS REALIZATION

A normalization process

When services for persons with intellectual handicap were created during the last century, residential institutions of various kinds were established. This pattern of institutional support remained intact until the middle of the 1950:s. The first steps away from these institutions were taken during the 1940:s and have gradually continued since then.

The normalization principle formulated in 1945 can be seen as a starting-point for this socio-political change. It represents an idea that persons with intellectual handicap also should have the right to normal patterns of life, outside the residential institution. In this way non-institutional objectives were brought into a system of care previously dominated by this long institutional tradition. What has happened since can therefore be seen as a normalization process, a change towards more normal conditions for persons with intellectual handicap.

This process of change can be seen at various levels. At an individual level, for the person with intellectual handicap, development has meant a switch from an institutional life to an increased participation in the life of the community where the person lives, together with persons without handicap. This community participation has also effected others. For relatives this has meant that the son or daughter no longer has to be visited at a residential institution, but in a house in the local community. Neighbours, and those providing services locally, come in contact with these persons to an increasing extent, maybe for the first time.

At an organizational level changes have occurred in the types of service provided. A development of services has taken place which contributes to the community participation of these persons. An example is education, now being provided in the community school which is attended mainly by children without handicap. New forms of services have also been developed for adults enabling them to be in places and environments where other adults spend their time. Group homes have made it possible to provide housing in ordinary housing areas, and daily activities are now organized so that activities for these persons can take place in the same place as for persons without handicap.

At the same time, the forms of care and support which were a hindrance for the community participation of these persons, have been closed down. Some examples are special hospitals, childrens' homes and boarding schools. Even some forms of community service, which do not contribute adequately to community participation, have gone through a process of change, for example day activity centers (Ericsson, 1991).

A change on a cultural level, regarded as part of the normalization process, concerns the way society perceives persons with intellectual handicap, and how their support is to be provided. The institutional tradition, with two types of establishments, the school institution and the asylum, reflected two ways of regarding these persons and consequently two types of social roles attributed to them. Those with a mild handicap who were considered "educable" were provided with schooling and were seen as "pupils". Those with a more severe handicap, who were referred to asylums and residential homes, the "uneducable", were seen as "patients" in need of care.

A competence perspective sums up the relation between these persons and the task of education and care, the emphasis being put on the need to increase the competence of these persons either through education or care. The function of these institutions thus being the provision of these very special activities.

A citizen perspective, on the other hand, is related to the normalization process and to forms of community services. Its origins are to be found in the motives for this socio-political change, it being considered a civic right to avail of the services provided by the welfare society. It is this role of "citizen" which epitomizes the perception of persons with intellectual handicap. As a full-worthy citizen he has the right to participate in community life and his and his family's desire for such a life becomes the starting point for the type of support offered (Ericsson, 1986, 1992a, 1992c, Ericsson & Ericsson, 1989).

Institutional closure

A contribution to the development of this normalization process has come from the legislation, a series of Acts of Parliament stipulating the types of services to be offered by society. During this 50-year period community services have gradually been developed, furthered by these Acts. The first directives about community services can be found in the act of 1954. They were to be made available for persons with a mild handicap, persons termed "educable". The right to schooling, in the institution as well as in the community, for children earlier thought "uneducable", came first in the 1967 Act.

The 1985 Act gave directives about services for a life outside the institution, the right to lead "the normal life", even for persons with a more severe handicap, those who previously were termed "uneducable" and therefore provided with residential institution as the only alternative. It was not therefore until 1985 that all persons with intellectual handicap received the right to a life in the community.

Parallel to the development of community services, institutional services are gradually disappearing. Institutional schooling and institutional care for children have been the first to close. A series of residential institutions for adults with a severe handicap, which had become a requirement in the 1954 Act, were therefore built during a 20-year period from the middle of the 1950:s. The right to a non-institutional life became a right in the 1985 Act, this being also the start for institutional closure of this series of residential institutions.

When institutional closure is regarded from the framework of the normalization principle it displays a complex process of change taking place at different dimensions.

At a societal level institutional closure implies a changed view towards persons with intellectual handicap and their right to participation in the community, the various laws having gradually recognized these persons right to a life outside the institution. In accordance, it has also been stipulated which services should be provided in order to further participation in the community through the provision of housing and daily activities. Institutional closure becomes a natural consequence when seen against the background of everyone's right to a life in the community. Such institutions are no longer justified when new objectives have been introduced into the social services.

Institutional closure at an organizational level, expressed as an aspect of the process of normalization, focuses on the fact that those living in the institution must move. In order to make this possible, services must be available which meet the persons' need for service and support, in the form of housing, daily activities and other professional services required after they move. If the service they require is not already available then it has to be developed. The key to institutional closure lies therefore in the development of the alternative services which replace the institution.

As well as accomplishing the task of moving, opportunities for employment of staff is also part of the process. Administrative and financial matters have also to be dealt with. And finally, new uses for the institution, its buildings and grounds, have to be found.

As the public, both neighbours and persons in service functions, come to meet those who have previously spent their lives in institutions, new questions arise about them and their needs. In the task of developing new methods in the services replacing the institution, one needs to be aware of the different societal roles on which the two forms of service are based. During the process of closure it is therefore necessary that work goes on changing attitudes towards persons with intellectual handicap.

The closure of institutions means, at an individual level, that the life of the person is going to change. He/she leaves the life being led at the institution in order to establish a life outside. The person must have access to a home and to a meaningful life during the day. In addition the person needs a life in the locality, not just commercial and social services, but even cultural and leisure-time activities as well as recreation. Social relations with relatives, as well as with friends and acquaintances, need also to be developed, based on the terms made possible by the move.

To make this possible the person must be offered housing with the support and service which his needs require. Daily activities outside the home, must also be arranged. In addition one needs to establish relations to the local social and health services in order to guarantee that the person's general needs be met as well as his special needs.

The person who moves breaks up from relationships with other persons with handicap, from staff and even from buildings where one has once lived. It is not necessarily so that these have been positive experiences, or that they have left positive memories. However, one needs to be sensitive about the way in which the person leaves the institution and the life he lived there.

Being given a role which allows for more self-determination, and the possibility of having influence over one's own life, also requires that the person develops his ability to express his needs and wishes. This means that the person must have access to persons who can speak on his behalf on those occasions when he can realize his right to influence his situation.

In order for a person to be able to move it is necessary that one develops personal services. This requires good knowledge of the person's individual needs and wishes. These can be formulated by the staff who know the person well, by his relatives and by the spokesman who has the right to speak on his behalf. In accordance with how well, and when, these needs and wishes can be met the person will be able to move and thereafter the closure of the institution will become a reality (Ericsson, 1992b).

On the closure of Carlslund

Institutional closure is not in itself a new phenomena. Residential institutions have been closed down before. Early on, when institutional closure took place, they were replaced with a new institution but is doubtful whether this can be called institutional closure. It is first when one started leaving special residential schools and replacing them with schooling within the ordinary school, that one can start talking about institutional closure. The same goes for residential institutions for children, which were replaced either by support to families, so that the child could live at home, or by small group-homes.

In order to cope with the large need for places in this type of institution, a series of residential institutions were built all over Sweden, starting in the middle of the fifties, ending 20 years later. These were residential institutions for children and adults with a severe intellectual handicap, persons earlier called "uneducable" and therefore thought to be in need of the residential institution. The original Carlslund was extended and modernized as the first institution in this series. It was therefore natural that Carlslund was also the first of the series to be closed.

The closure of this type of residential institution has continued and is still going on, the aim being to close all residential institutions for persons with intellectual handicap. Today, there are still some institutions left, but all with a limited number of persons living there.

This background has influenced the character of the closure of Carlslund. The decision to close was very consciously taken by those responsible for the institution, the Board of Social Services, in the County of Stockholm. The leadership of the organization were during the initial stage, very determined that a closure should take place.

Relatives to the persons living at Carlslund were however, very worried during this initial stage. They later developed into a group of relatives who became constructive critics of the process of change, contributing greatly to the betterment of the quality of the closure. The dominating reaction in other groups, throughout the process of change, was one of hesitancy, often negative, and sometimes even hostile.

Characteristic for this institutional closure was that it was a process of change, starting with the decision to close, the objective being the creation of community services as an alternative for all. During the planning stage more specific descriptions of housing and daily activities were to be compiled, creating models and alternatives for each of the persons who was going to move.

This task of collecting relevant experiences, and developing knowledge about how the closure was to take place, can in a true sense be seen as a process. With very general and distant goals to work for, the more precise details as to how the closure would take place developed as work went on. In consequence, there was a lack of experience and knowledge during the early phase so limited information could be given about the outcome.

The job of institutional closure can therefore be seen as the task of developing community services for persons with a mild, as well as a severe intellectual handicap, housing and daily activities, and offering them to each person who is going to move from the residential institution. When evaluating this institutional closure, the criteria chosen have their background in this model for community services (Enarsson et al, 1981, Ericsson, 1992).

Evaluation

The follow-up study carried out shows some aspects of the life of the persons who moved from Carlslund. In an earlier chapter information has been given about some of the more important parts. As this presentation is limited, this is a limited evaluation. Its perspective is seeing institutional closure as a part of the normalization process having taken place in Sweden since the 1940:s.

The closure has meant that these persons, who lived in the institution, have now got housing and a home outside this traditional institution, and have attained a higher living-standard than previously. This is the case for the majority of the group. There is however a small group for whom the closure meant that they moved to a small residential institution.

The great difference between institutional life and life in the community, is that these persons participate in daily activities outside the house. This was something which was offered to only a few at the institution but it is a logical and natural part of community services. This is also a service available for all, even if some have chosen to stay at home during the day.

The quality of these activities is however still open to discussion. There are staff to give them support, but there is still a need to develop activities suited for the persons who once lived at the traditional institution. An illustration of this is that the persons from the residential institution, who are most in need of purposeful activities outside the large day activity center, seldom get an opportunity to participate in activities outside the center. This gives reason to point to the need for development of this form of support.

Services from professional groups, here chiropodist, social worker, psychologist and physiotherapist, are met with a high degree of satisfaction, even if there are some who would like to have more of this category of service. The expressed need for an increase concerns mainly support from the physiotherapist. All are satisfied as regards the services from the dentist.

It can be said that the results show a high degree of satisfaction regarding housing, daily activities and services from professional groups, these having been available as alternatives. At the same time these services can still be developed. Housing can be better and there are examples of people moving yet another time to places found even more suitable. Daily activities can also be developed, this closure bringing about only the starting-point for this. And as seen concerning the support from professional groups, some persons not yet satisfied, thus leaving room for development of these services.

Relations between these persons and their neighbourhood as described here points to the fact that there are no great conflicts around them. Instead this relationship can be characterized as neutral. As there also are some for whom the relationship is negative, there is of course need for improvement. But what can be expected? Is a neutral relationship acceptable or is a positive relationship something to strive for?

Looking at the social contacts of these persons one finds that these are limited. Some people have no contact with relatives and for those who have, yearly visits are most common, meeting each other every month or week being less common. This leaves room for a development of relationships to parents, brothers and sisters and other relatives.

The guardian, having the right to represent the person with handicap in judicial matters, and "the social contact", being someone who should contribute to the development of social activities, are two persons from whom persons with handicap can expect to have service. This situation can therefore be seen as inadequate. There are still persons who haven't got these relationships, and those who have, meet very seldom.

One could expect that the person with handicap who has just left the residential institution has a friend who is important to him. But when staff are faced with this question very few mention that this is the case.

Some leisure activities considered traditional could be expected to take place during a year. The results show that there is a variation between different activities, with visits to the café being most common. Going dancing and attending musical entertainment occured rather frequently, but even so one third did not participate. Visits to the cinema, museums and the theater were less frequent, with two thirds not participating during the year. Sporting events and religious services were not very commonly attended, 85 % not participating.

One cannot expect that everyone should participate in all activities. On the other hand one could expect that more of these leisure activities should take place.

These are results for the entire group, the 266 persons who moved. There is of course a variation between persons within the group, some having lead a life which seems more positive than that which the information shows, it being based on averages for the group. Analogous, there are persons who lead a life below this average. However, from discussions with staff the general attitude is that these persons are living a better life after having left the institution, much better than was expected.

It is not surprising that there is a need for further development. Institutional closure can here be seen as one step taken by the person, towards establishing his life outside the institution. Against this background there are many experiences he has still not had, and several abilities which the person is still lacking. Leaving the residential institution is however only the beginning of a life in the community.

Some contributing factors

Institutional closure is here seen as a process of change, aiming at a more normal way of life for the persons with handicap and a more normal relation to society. With this process-oriented view, the result is not something which can be decided upon in the beginning, but is something which is developed during the actual process of change. Thereby the end result is influenced by what persons and groups concerned contribute to the process. The consequences are the sum of all relevant activities, whether they are positive contributions, neutral or indifferent reactions, or a negative or even obstructionist attitude. Some factors which have been relevant in this case are here commented upon.

The decision to close the institution was taken by the responsible Board, made up of representatives from 5 political parties. Their unanimous decision clarified their intentions and was of fundamental importance for the task to be carried out. The determination of senior management to carry out the task was, especially during the initial stage of the project, of immense importance for fair treatment in the organization, particularly in discussions on financial matters.

The initial worry and hesitation felt by relatives, was an indication of their interest for a good future for their sons and daughters. They were soon represented by a competent and concerned group of relatives who pressed all concerned to work with the ambition to bring about change and create alternative services which would offer a life with quality to the persons with handicap. Their attention and questioning directed towards responsible politicians was of significant importance for the outcome.

Many expected that the staff of the institution which was to be closed would be antagonistic towards the decision on closure. This expectation cannot be said to be the case. Naturally, they were not enthusiastic and overjoyed over the fact that the institution was to close down. At the same time they were aware of the poor conditions which existed and wanted services with a better quality for the persons with handicap, with whom many had strong attachments. Their lack of antagonism can be said to have been an important contribution to the closure of Carlslund.

One factor facilitating this change from institutional to community services, was knowledge about where the person was going to live after having left the institution. When relatives and staff were informed about the house where the person was going to live, the more concrete view of the alternative to the institution enabled them to participate with less anxiety, and in a more constructive manner, in the process of change which was going on.

But during the planning phase it was difficult to provide knowledge about the alternatives, the main task still being the development of the alternative housing and daily activities which were to be offered. This lack of information was not helped by the fact that this was the first time a residential institution for adults was closed down and being replaced entirely by community services. There were few relevant services, in the County of Stockholm or elsewhere, which could be shown to relatives and staff. As long as knowledge about the alternatives was lacking it was difficult to accept the decision about the closure and to participate constructively in the process of change.

The change of services was not only something which concerned the residential institution but also the alternative services which were to replace the institution. They were also faced with the need to change, previously having mainly provided services only for persons with a mild or a moderate handicap. People coming from the residential institution had a more severe handicap which meant that community services had to cope with new demands, to be able to meet the needs of a new group of persons.

This meant that those working in group-homes and in daily activities, and the professional groups in the district teams, had to develop their methods and ways of working to suit these persons. Even for them institutional closure meant a complicated process of change. This was seen, for example, at the day activity centers, units which originally were established for those with a mild handicap and therefore had developed a tradition of working with the needs of these people. They were now challenged with the task of offering purposeful activities even for those with a severe handicap.

Experiences of institutional closure

Institutional closure is, of course, a dramatic issue as the lives of persons with handicap, their relatives and the staff will change. It concerns also change, maybe even destruction, of old buildings. There will also be an increased need for housing, daily activities and services from society. Basically this is a political process of change, which needs to be carefully handled by skilled politicians.

Because of the dominating role of the residential institution, it is easy to concentrate on the reactions at the institution being closed, in particular from staff and relatives. Instead one needs to define the process, and to identify its basic components.

Closure concerns primarily the lives of the persons living there, thus being an individual process of change. The main task is to establish a life outside the institution for each person with intellectual handicap living there, the focus therefore being on these persons and their move to a new life.

As a consequence, the support needed by each person in his new life is also focused. When there are services which can give adequate support for a person, he can move. And as several persons, all at the institution, need to move there is a need for services for all. The key to institutional closure lies therefore in the creation of services, alternative to those offered at the institution. The development of these can therefore be seen as the major task during this process of change. Instead of closure, this is the task in need of extensive development!

With a frame of reference for institutional closure which gives an important role to the development of alternative services, one sees that institutional closure is a task for those responsible for these alternative services, for their development and their administration. This then becomes a broad process where all, those at the institution and those outside, have responsibility for contributing to its success.

The need for a broad perspective on this process of change is further stressed by the fact that parents, siblings and relatives are concerned. Even they move from the institution, their pattern of life also changing. For example, previous weekly visits to the residential institution being replaced by seeing the person concerned in a new house, with new persons with handicap where he lives, in a new community with a new staff-group.

If these aspects of this new life are seen as satisfying, giving a better life than before, the move from the institution will of course be regarded with pleasure. If this is not the case, the alternative life being worse than that lived at the institution, there will be regrets. During the period of change, up until relatives have seen the person in his new life, it is natural that there be times of worry and anxiety. This is something to which those responsible for carrying out the institutional closure must be responsive.

When regarding institutional closure as an organizational task it is easy to see it merely as a change of houses. Of equal, or perhaps greater importance, is leaving the perspective that considers the person to be in need of the services of the residential institution.

As institutional closure has its roots in the normalization process, this change is also associated with the development of the role of the person with intellectual handicap as a citizen, with the right to lead the normal life in the community. One aspect of institutional closure is therefore the development of a view of the person, and the support he needs, as one with a right to the normal life and the normal services that are in the community in which he lives. This requires the development of a perspective which recognizes that the support he needs can be satisfied without the residential institution.

With this view institutional closure becomes a process of change which focuses on the development of adequate support for persons with a severe intellectual handicap in order to live outside the traditional institution.

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