

**COMMUNITY BASED SERVICES:
ON THE CONTRIBUTION OF SUPPORT THROUGH
HOUSING AND DAILY ACTIVITIES**

**HOUSING AND A HOME IN THE COMMUNITY
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**PURPOSEFUL DAILY ACTIVITIES
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COMMUNITY PARTICIPATION

Entirely new goals for services to people with an intellectual handicap were formulated as a consequence of the socio-political development which began during the forties, when the creation of a welfare society became a task for many countries.

The role of the person with a handicap within the welfare society was widely discussed as part of the socio-political debate which was taking place. Were persons with a handicap also to have access to the new social services which were to be developed in order to guarantee the welfare of citizens?

The position taken in Sweden at that time was that persons with a handicap, at least with a mild handicap, should have access to the social services of the welfare society. The principle which was formulated to express this new socio-political concept was called the normalization principle.

This led to the formulation of new goals for the services provided for persons with a handicap. A radically new answer was given concerning one of the basic questions, the type of life being offered to people with handicap. Previously it had been considered quite adequate that they were referred to an institutional life. Instead, the normal life, led by non-handicapped citizens, was now presented as the ideal life to be offered to a person with intellectual handicap.

With this as background, the concept of "community participation" was formulated to express the goal for social services provided for persons with intellectual handicap. They should be offered the possibility to participate in the ordinary society and there live a life as normal as possible.

This also had sweeping consequences for the type of services to be developed for people with handicap. As previously established institutional patterns of care were not intended to provide a life in the ordinary community, new types of services had to be developed.

In this way work began on the development of community services, with the aim to offer support and service in the community, where the person with handicap intends to participate. The following process towards increased community participation has meant that people with intellectual handicap have been able to leave institutional care and instead live their lives amongst non-handicapped citizens (Ericsson, K. 1986, Ericsson, K. 1987b).

Such a process is however extensive and complex and must therefore always be carried out with the well-being of the person concerned as the decisive criteria. Consideration must be given to both the person's disability as well as the social processes in the environment where he lives. At the same time services must be carried out in a manner which leads to increased welfare.

As community services should be provided to give possibilities for the person with handicap to experience the same way of life as his relatives, friends or other persons in his age-group, the life of a person will depend on what is considered to be a normal life for them. This means that the characteristics of the desirable pattern of life developed for the person with handicap will depend on what is considered normal in the cultural and social environment to which he belongs.

In the current debate in Sweden as to the meaning of normal life some features are apparent as characteristic. Firstly, a person with handicap should have a home of his own and be able to live there in privacy. For children and youth this should take place in their own biological family, or if this is not possible, another family should be found. Adults should have their own housing, personally or together with a small group.

In another place apart from this dwelling, the person should have access to daily activities of some sort. For younger children this can be the nursery or play school, for older children and youth it is regular schooling.

For adults daily activities should be productive work, as part of the normal or sheltered labour market, with the right to an employment which provides payment for the task carried out. For the adult person with handicap who cannot acquire such employment, but who is in need of support and service during the day, purposeful daily activities with support should be provided.

The normal life is also characterized by the participation in the community outside the home and the place where the daily activities take place. The commercial and social services which a person needs for his existence, should be found here. Leisure-time activities and cultural experiences should also be available. It is also here that a person establishes social relations with relatives and friends.

These characteristics illustrate in physical terms the normal pattern of life which should be led by the person with handicap. Other features can be found to illustrate a more qualitative character of life to provide a more complete picture of the normal life.

To lead a life of dignity it is essential to the person with intellectual handicap that he is able to influence his everyday life and the type of services provided.

Another feature of a qualitative character is found in the relationships established between the person with handicap and those around him, that is to say to friends and family, to staff and to the general public. Is the mentally retarded person treated with the same respect as non-handicapped people or is he ridiculed and devalued in these social relationships? Is he respected for the full-worthy citizen he is (Ericsson, K. 1987a)?

There probably never will be, or even never should be, a general or one-sided description of the meaning of the normal life. Views and interpretations of this concept will vary depending on time and place, together with the cultural and social environment in which it is being described. But in spite of this one must on all occasions have a valid idea of what is meant by the normal life. At the same time one must be prepared to review and develop current descriptions.

A HOME FOR PRIVATE LIFE AND SOCIAL RECOGNITION

The establishment of a group-home with service for some persons must primarily be seen as the creation of conditions for a permanent life for them in

that home. It is not just a placement to provide housing and leisure, but also the base from which each person relates to his family, relatives and friends.

A home is also the place in which one's personal needs are met and where it should be possible to live a private life, without it being questioned. It is within the home that a person has a permanent, secure and stable place, protected from observation and demands from the outside world.

To allow the residence to become a home must be one of the main goals when support and service is provided for the person with intellectual handicap. It is in his home where the person must be able to have his private sphere as well as experiencing his home as a secure and stable place, where one is accepted in spite of one's deviant behaviour.

But the individual is not just a private person in his home. He is also a citizen in the community where he lives. In order to get food, private belongings or access to social and medical care the person must, for example, make use of local commercial and community services.

It is also outside the home that most leisure activities take place, in the evenings or at week-ends. Visits to relatives and friends in their homes requires that one leaves one's own home and moves in the local community. Participation in local organizations involves the individual in a life outside the home. This gives the home the function of being a platform from which he can participate in the life of the local community.

THE GROUP-HOME

What type of services are required in order to facilitate the participation of persons with intellectual handicap in the community? If the ambition is that they should be able to live the same type of life as non-handicapped, and together with them, then the services must be established within the ordinary community.

Houses and residential areas where the public live, should also be the place where persons with handicap live, with support and service according to their needs. In working areas of a community it should be possible to establish places for daily activities, which provide adequate support for persons with an intellectual handicap (Ericsson, K. 1987c).

In areas of a district where the public have access to community and commercial services and where they spend their leisure-time, it should be possible to provide also the support and service required by people with handicap if they wish to spend their lives there (Ericsson, K. 1982).

How is a house planned and designed in order to enable a person with handicap to live in an ordinary residential area in the community? There are obviously many types of housing and the ordinary private home is one example. A single person, or a couple, with handicap can live in this way so long as they receive the support and service they need, either from persons or staff who come from outside.

The group-home is another example of housing where support and service is provided. Characteristic for this is that a small group of persons with handicap live together. The size of the group can of course vary, but as soon as they are three, they constitute a group. It is of primary importance that the group is small so that personal relationships can develop between those who live together.

PERSONS WITH HANDICAP IN NEED OF HOUSING

What form of housing with support being developed and offered, will depend on which persons are in need of housing outside the institution.

The various laws, which have regulated the nature of services to be provided, have determined which groups of persons with intellectual handicap that should have access to a life outside the institution. During the 1950:s it was only persons with a milder handicap who were given an opportunity to live there.

As it gradually became possible for children and youth with a severe handicap to grow up within the family, a new need arose to provide housing for them when they became adult. At the same time another change has taken place leading to an increasing number of persons with severe handicap leaving institutions.

There has therefore been a gradual change which has meant that persons with a severe handicap have also gained access to a life outside the institution. As a consequence a need has arisen to develop housing even for these persons.

Different forms of housing with support can be illustrated from developments which have taken place in Stockholm. The first type of home outside the institution was often that an adult person was placed in a family where the man and wife were responsible for providing the support needed. The person was boarded in the family.

The next step was that the family were replaced by employed staff. A staff group was given responsibility for providing service to a group of persons with handicap, who lived together in the same home. A group-home of this type was usually a large apartment in a block of apartments. The persons with handicap lived there whereas staff only came there during their hours of duty.

It was soon found that some of them could move to a nearby apartment without staff regularly on duty, where they could live alone or with a friend. They still had contact with the original staff group who could provide support through occasional visits.

In this way the first group-home was developed. It consisted often of 3 - 5 apartments within the same residential area. Persons with handicap lived there either on their own or with one or more friends. Up to 10 persons could live within such a group. A staff group, based in one of the apartments provided service to all. As these persons only had a mild handicap it was not necessary to have round-the-clock service. Dependent on the needs, staff were on duty only part-time.

As the need arose to provide housing for persons with more a severe intellectual handicap it became necessary to develop another type of group-home. This is more of a collective unit providing a closer relationship between staff and those who live there. For a group of 5 residents there is a staff-group who is responsible for round-the-clock service in the home, and for recreation in the neighbourhood. This type of group-home requires more space so they are often located to large apartments or to detached housing.

As this type of housing has developed a greater degree of co-operation has come about between different group-homes. When new homes are started today it is common that there are several in the same housing area. In a large city like Stockholm it is not unusual to have 3 - 5 such group-homes as a cluster

within the same residential area, and that homes of different types can be within the same cluster. Which types they are will depend on the varying needs of the residents.

If services are arranged so that the cluster of group-homes are located to the same residential area, cooperation can occur between the single units. The persons with handicap from the different group-homes can meet for common activities. Also staff can meet for shared training and exchange of experiences in their working methods. It is also possible to make use of situations when cooperation can take place about sharing tasks both within and outside these group-homes.

If the formation and development of a group-home is related to the needs of those for whom it is intended, then housing outside the institution can be provided for many. Whether the model with housing and service outside the institution is possible for everyone is a question being tested during the process of institutional closure.

LOCALIZATION OF HOUSING

If a general description is to be given as to the type of housing for persons with handicap, then one can say that the housing of non-handicapped persons in the community also should be the housing for persons with handicap. A group-home can therefore be situated in different types of residential areas.

Sometimes it is suitable with apartment buildings where one, or even two apartments, can be converted into an apartment which offers support and service. Naturally, even separate villas, or other housing typical of the area, can be used.

At the same time one must respect and recognize that a person can have a functional handicap which may make it difficult to live in traditional housing. The ordinary house must therefore be adjusted, either physically, for example to facilitate the use of a wheelchair, or socially, in order to create positive relationships to the neighbourhood.

An important factor which influences how satisfactory a dwelling is for the persons living there, is the nature of the neighbourhood in which it is located. Both physical and social factors contribute to whether it can be a secure home for those who live there.

There must also be a suitable degree of service in the local neighbourhood to be able to do one's shopping for example, and to use medical services and transport. These are particularly important factors to be considered when a locality is being chosen.

If a cluster of group-homes as is being built in houses or apartments in the same neighbourhood it has consequences for localization. The units of such a cluster should not be placed too close together if the residents with handicap are to be given a chance of establishing natural relationships within the housing area.

STAFF

Because of their handicap these people need support from staff. The type of support provided varies depending on the needs of the group. For some their needs can be very extensive, for others much less so. This means that the number of staff in one group-home can be relatively small, whereas another

home can have a relatively large number of staff. In the same way one group may only need staff during a limited time of the day whereas another may need staff both day and night.

That the residence should be a home for those living there, has its consequences, not least for the staff who are to provide required support and service. The fact that one is working in someone else's home requires respect and consideration for the integrity of the person living there.

An important requirement is that staff-groups have suitable methods for conveying the service and support provided to those in the group-home. If tradition is lacking as to how one works with small groups then there is an immense task ahead in order to develop adequate working methods.

If staff are to give the support and service which people with intellectual handicap need, they will also be working outside their home. They must also have knowledge about how one best can avail of the services which are provided locally. Then it is necessary that staff have a good knowledge of life in the local community.

In order to meet questions and reactions which the person with handicap meets in community, staff must be able to inform and even influence the attitudes of people in order to develop the social environment which the person with handicap is to utilize (Ericsson, K. et al 1987).

ESTABLISHING GROUP-HOMES

Establishing a group-home for persons with an intellectual handicap implies initiating a social process, starting with the needs of the persons with handicap who requires a home, also taking into consideration the conditions and characteristics of the neighbourhood where these persons are going to become residents.

At the same time there are however difficulties associated with the establishment and development of group-homes. One depends on the fact that this is a collective type of dwelling, with a group of persons who is going to have a common home. This fact requires a sensitivity to social relationships in forming the group. At a later stage it also becomes an important task to find ways of supporting the group to develop relationships that encourage collective life.

THE VALLENTUNA PROJECT

The purpose of the project which is shortly presented here, was to give a group of 26 mentally retarded persons from special subnormality hospitals access to a life with adequate support under more normal conditions, provided within the framework of the ordinary society.

The group involved are mildly or moderately retarded, with additional social or mental disturbances, these being the cause for admission to the special hospital. They are consequently a group in need of very qualified care, whether they live in the hospital or if they receive the services they need within the ordinary society.

In order to enable this group to live within the normal community, it was necessary to create alternative services. The project to achieve this was located to a Stockholm suburb, where a series of houses and a day activity centre is

utilized. There is also administrative staff, including a socialworker and a psychologist.

The first stage of the project was the acquisition of three houses in a newly built housing-area. These were within a cul-de-sac with 22 terrace houses, but the three were not adjacent. As each person has his own bedroom, three can live in each house, therefore nine persons live in the same area.

As none of this group is physically handicapped, no adjustments needed to be made to the houses, which are two-storey. Because of their additional social and mental handicaps their main problem was the need for support in form of qualified staff. Attached to each house is a special staff-group who are always on duty, which means having special night staff. Their training qualifications being chosen according to the needs of the residents.

The demands made on a person in order to live in such an area, are too great to enable all persons from the special hospital to live under such conditions. Close proximity to neighbours is one type of hinder, two-storey houses another, so other types of housing were necessary as well.

The second stage of the project was therefore to develop a villa type of housing, a one-storey house in its own grounds, adjusted to the needs of the handicapped persons who were to live there. The purpose of locating the house to its own grounds is to avoid proximity to neighbours and the conflicts with can arise because of their often deviant or disturbing behaviour.

Two such villas were built on nearby land and close to another housing-area with apartment flats. Each villa with its own garden and entrance, houses five persons. This group of ten persons have more severe problems of mental and social character. Each house has also a staff-group with 24 hour service. The hygiene-facilities are such that even those who are severely physically disabled or in wheel-chair can live there.

To be able to work with small groups within the villa, the house is built at a right angle, at one end bedrooms and bathroom facilities for two persons and for three persons at the other end. The kitchen, living-rooms and staff room is in the center.

In order to provide a fully community-based alternative for even more disturbed persons from the special hospitals for whom neither terrace house or villa was adequate, it was necessary to find housing conditions which allow for their pattern of behaviour. This required a greater distance to the immediate neighbourhood in order to avoid conflicts.

To achieve this an older house in its own grounds was acquired, where these persons could move freely without disturbing neighbours, who live about 100 yards from the entrance. The main house provides accommodation for five persons, and in a smaller cottage two additional persons. Even these houses have a separate staff-group.

From the original group of three terrace houses, one person moved to an apartment flat in a nearby housing-area and receives staff support from those attached to the project.

HOUSING AS PART OF THE INTEGRATED ORGANISATION

Residential services for mentally retarded persons have been illustrated by this account of a particular project. But it is important to remember that housing is

only one part of the total integrated organisation of services. Of equal importance to enable a retarded person to live in the community, is the existence of places for daily activity where the individual can spend his time during week-days.

The day activity center consists of a series of small groups of retarded persons with staff support, who work either in special day activity center premises or other places in the local community. Staff responsible for daily activities are not the same as those who work in the mentally retarded person's home, the purpose being to develop different staff roles for those working in these two different service forms.

In order to develop a more normal life for retarded persons in the ordinary society, it is necessary that medical, psychological and social services are accessible. In the project accounted for here, a psychologist and social-worker are full-time employed and a psychiatric consultant attached.

The project also has access to services from a mental retardation team with medical, psychological and social staff. Their task is to guarantee that all retarded persons in a specific district have access to adequate support in these respects. This is achieved either by their own contributions or by using the ordinary medical, psychological and social services of the community.

COMMENTS

The project described here started in 1977. The experience gained so far is that it is possible to create living conditions in the ordinary community even for retarded persons with so complicated and extensive problems that they have been subjected to special hospital care for a greater part of their lives.

Experiences also show that a life in the ordinary community, can be achieved by making use of normal housing built for non-handicapped persons, if necessary adjustments are made.

Another important experience is that in a group of 25 retarded persons many different needs arise and must be met with different types of housing and support. In this project four types of housing have been used, namely an apartment flat, terrace houses, specially designed villas and an older house in its own grounds.

Even if the service provided in the houses has not been described in detail, the conclusion is that service offered in a house must be related to the personal needs of those who live there. The material equipment, hygienic and bathroom facilities, the number of staff and their dutyhours are some examples of adjustments to be made. Housing for retarded persons must be planned according to personal and specific needs, not as anonymous service units.

FURTHER EXPERIENCES

To establish a group-home and there give possibilities for persons to develop their own home provides many new and positive experiences. One finds completely new ways to develop a personal life and these can be used to gain further positive experiences (Kebbon, L. et al 1981).

Results from evaluation studies of community services show some of these consequences (Heron, A. et al 1981). The results from a study of the first two years in a group-home for both mildly and severely handicapped persons show some characteristic consequences (Thorsell, M. Ericsson, K. Brusén, P.

1987). They can be summarized that those concerned have been able to experience a more normal life.

In the home there is of course a kitchen where the person can take part in preparing food. Apart from gaining new knowledge the person also enjoys new experiences, for example that of new smells and tastes.

Being able personally to influence one's home by choosing furniture and decorations means that one not only has somewhere to live but one has even been able to develop a personal home, a place where he, with varying degrees of support and service from staff, can develop the type of life he considers desirable. "To have a home" emerged as an important category which expressed the results of the study.

There is always the risk that this type of result is regarded as trivial. But if a person has previously only experienced institutional life, with food from a central canteen instead of one's own kitchen, with life in a large ward or in common dormitories, then these experiences are extremely important. This new pattern of life provides opportunities for further personal development.

From the study the expression "a person has personal relationships" also emerged, implying that relationships to others had changed character. A mutual respect had developed in relation to staff and between the persons living there.

An increased respect for the integrity of the person does not however, clearly lead to a situation free from problems. The expression "daring to say no" is also a result which illustrates part of the process which leads to personal development. Passive handling in anonymous groups, with limited scope for expressing one's own will is replaced by small groups where the personal touch and the chance to express needs and interests is greater.

In the study this process towards a more clearly defined personal identity has been characterized in the expression "becoming a person". This is the expression which has emerged most clearly in the study.

At the same time there are however difficulties associated with the establishment and development of group-homes. One depends on the fact that this is a collective type of dwelling, with a group of persons who is going to have a common home. This fact requires a sensitivity to social relationships in forming the group. At a later stage it also becomes an important task to find ways of supporting the group to develop relationships that encourage collective life.

An important requirement is that staff-groups have suitable methods for conveying the service and support provided to those in the group-home. If tradition is lacking as to how one works with small groups in the local community then there is an immense task ahead in order to develop adequate working methods.

Another task also demanding is how to meet and communicate with residents in the neighbourhood. The risk that a lack of understanding from the general public for the need of the persons with handicap to be allowed to live in the ordinary community, can lead to an ungenerous attitude in the local community. This requires knowledge of the staff as to how one should work with the problem of social change.

Working for the realization of group-homes can in a short term perspective be thought to give rise to increasing economic demands. This is however a relative problem. To what extent group-homes lead to rising costs depends entirely on the quality of services in the alternative, provided on the ward of the traditional institution.

If institutional care is characterized by the financial profits made possible by large-scale rational care then it is hardly possible to make the same gains in a form of service based on small units whose purpose is to meet personal needs and wishes. But in a long term perspective, when personal potential for development has been taken into account, it is not certain that these financial differences will remain.

HOUSING AS SEEN FROM TWO PERSPECTIVES

The model for housing for persons with an intellectual handicap which has been illustrated here is a consequence of the socio-political policy on services for handicapped implied by the normalization principle. But another point of view can be taken in which the group-home is given a very different function. In an analysis by Ericsson and Ericsson (1981) a comparison was made between two perspectives on housing for persons with handicap.

In the model alternative to the one presented here, the aim is to establish a series of group-homes and institutions related to each other with regard to the amount of support provided in each unit. The person with handicap is then expected to move between these different units depending on the amount of support he is currently in need of. If he becomes more independent, then he is expected to move to a place providing less support. If on the other hand his need of support increases, then he should move to a place which can give more support.

In this model the ideal is thought to be fulfilled when the person no longer is in need of support and therefore can move to a private place where none is provided. This, however is achieved not until the person with handicap has lived in a series of group-homes and institutions, each of which has offered a decreasing amount of support.

From this perspective the function of the group-home is thought primarily to be that of training the ability of persons to live in and care for a home. The group-home becomes in this way only a link in the chain of housing from the traditional institution to the private home.

A parallel can be found in this perspective on housing to the way of using wards in the traditional institution. There it was at one time thought right that training should be provided in order to increase the independence of the individual so that he eventually could leave the institution for a private home in the community. The idea that a person after systematic training should be able to move from ward to ward, each with a decreasing amount of support, is by some being perpetuated in community services in the concept of the group-home.

These two different perspectives on housing for persons with an intellectual handicap can clearly be characterized by the different positions taken on four critical questions. The basic question concerns the very function of a dwelling. Is it to provide a home for a certain person or is it intended as a training unit?

If it is to be regarded as a home then the person with an intellectual handicap must have the right to remain living there and not be forced to move for

example for administrative reasons. If on the other hand a dwelling is regarded as a training unit it is natural that the individual is expected to move as soon as a certain level of competence has been achieved. From this latter perspective it is not considered natural that a person has a right to remain in residence until he himself chooses to move.

Another decisive question between these different perspectives is whether the dwelling has been planned personally or anonymously. Personal planning implies that the first step is the identification of the person and the group which is going to live together, followed by the specification of their particular needs, as a basis for establishing the home. Anonymous planning on the other hand leads to the establishment of a dwelling without any prior knowledge of who is going to live there. The personal needs of the future residents does not in any way influence the planning of the dwelling provided.

If one regards a dwelling as being a personal home it is natural that one at an early stage decides who is to live there and make it possible for them to participate in the development of their future home. If the dwelling is only to be a training unit then there is no reason to identify the future residents, as many different people, with varying needs, are going to pass through the unit during coming years.

A third question illustrating differences between these two models, concerns how one views the way in which support and service is provided to persons whose needs are changing. This can occur either as a crisis with the need for support suddenly is increased, or as a result of personal development when the need for support and service diminish.

A situation like this can be dealt with by changing the type or amount of service provided in the home, by bringing more service there or taking service away from the home. Another alternative is to move the person concerned between homes with different levels of support. He will then have to move to another unit with more or less resources, depending on whether the needs of the person have increased or decreased.

Also this situation is related to the two different perspectives on housing. On the one hand, where the dwelling is considered to be one's home it is natural that the person remains living there and that within the same environment the support and service provided, changes according to his needs. If the dwelling provided is regarded as a training unit it is natural that the individual be moved to another unit with other resources.

A fourth question concerns the extent to which demands can be made on the person to change and develop. What right have relatives, staff or even the public to demand or expect that the person's competence or ability should increase? Or is it not until when the person himself, or his spokesman, expresses a desire or need for more training that this should be offered?

This question is particularly relevant when it concerns the two different perspectives on housing for persons with an intellectual handicap. The model that advocates the dwelling as a training unit leads to a situation when the individual, by moving between different units, is constantly being subjected to new environments and new demands which he must live up to.

In order to live in a certain home and neighbourhood the person must be able to master the demands that are there made on him. The competence he has gained in one setting is not necessarily that which is required of him in the new home or environment. After moving, the person is forced to learn new

accomplishments in order to establish a new way of life in the new home. Consequently a model based on moving between different places, the person is in the situation of always being faced with new demands and the need for new learning in order to cope with new situations.

If however one instead takes the viewpoint that the dwelling provided is the person's home, where he has a right to remain, then the demand for constantly increasing competence is not made. Knowledge and ability acquired in the first setting can instead develop and be made use of as the person now can remain permanently in this environment.

This difference between these two perspectives on the function of housing is very important for the person. The home is the very base in one's life and is therefore a requisite for the type of life one will be able to experience, and thus even for the quality of life to be enjoyed.

A fundamental question must be whether the person, when provided with a dwelling, has got a home or not? Does one regard the home as a place characterized by the personal touch of the inhabitant, a place in which one can live until one chooses to move and thus being a secure and stable place for the person? If one instead regards the dwelling as a training unit, part of an ongoing training programme arranged for the person, then he cannot be considered to have a home and should instead be regarded as homeless.

DISCUSSION

An important socio-political change has taken place regarding the type of societal support provided for persons with intellectual handicap. Instead of institutional services, which have had a long tradition in this field, community services have been developed in order to make it possible for these persons to experience the normal life.

One of the most important of these community services is housing. The model formulated for housing has, as its starting point, the basic conception expressed in the socio-political policy that persons with intellectual handicap be regarded as worthy citizens. One finds however, another view of the role of the dwelling. It has also been given the function of being a training unit. As a consequence of that view the person is required to move from home to home in order to train certain skills.

As the type of services provided determines the experiences of the individual, and thus his well-being, it is essential that a decision is made regarding the role of the dwelling for persons with handicap so that it can contribute to enabling them to live a good life.

This fact illustrates that a change from institutional to community services is not just a question of establishing new services and allowing people to move. The process of change is more complex and even shows, as has been illustrated here, that attitudes towards the person's role in society are significant for the function given to different services. It can only be seen as remarkable that this question is still being debated.

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PURPOSEFUL DAILY ACTIVITIES

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HOUSING AND DAILY ACTIVITIES

The view of society on persons with intellectual handicap has changed radically in recent decades. Separation from community was previously advocated as desirable whereas the goals now accepted imply that the person has a right to a life in the community where persons without handicap lead their life.

These persons are of course in need of support and service if they are to be enabled to experience the normal life. Institutional services do not have the type of structure which makes it possible for them to contribute to the realization of community participation for a person with intellectual handicap.

Community services have instead been developed which contribute to making it possible for the person to live the same sort of life as persons without a handicap. With that as the goal they must be provided in such a way that they are available where the individual wishes to participate in the community (Ericsson, K. 1986, Ericsson, K. 1987b).

Characteristic for the normal life is the need of the person for housing and an employment. Housing should provide the person with a home of his own or for his family. Through employment the person participates in the productive process of society and thereby receives a salary which gives him the financial opportunity to develop the type of life he finds desirable for himself and his family (Ericsson, K. 1987a).

When one chooses the normal life as the ideal pattern of life for a person with intellectual handicap, it is natural that he then has access to both housing and employment. This requires services which make a life like this possible. Housing, with support and service, either as a private home or as a group-home, is one type of provision.

Access to productive and paid employment is also a goal, but one which is difficult to achieve for a person with handicap. If a person cannot receive employment but is in need of support during daytime then these needs should be met through the services provided.

What type of service can provide for these needs during daytime? If it is to be part of community services it should be able to provide activities in those areas of community, or as near as possible to them, where persons without a handicap are working. To provide these services, the type of activities offered must be purposeful, that is to say there should be a choice of activities to avail of and the terms on which they are offered should be related to the needs and wishes of those who are to make use of them.

For a person in need of services 24 hours a day to be able to live as normal a life as possible, one should be able to provide services mainly in terms of a dwelling and daily activities. But these two forms of services are not of the

same character. They are different with complementary functions in relation to the needs of the person.

Whereas the purpose of services which provide a dwelling should make available to the person a home for private life and social recognition in a neighbourhood daily activities should contribute to the experience of an active life during the day in as close proximity as possible to work of persons without a handicap (Ericsson, P. Ericsson, K. 1987).

The task of this service can therefore be said to be to provide the person with intellectual handicap with purposeful daily activities during the five working-days of the week.

EVALUATION OF DAY ACTIVITY CENTRES

The consequence of the change from institutional to community services in Sweden, was that the day activity centre became the form of service responsible for seeing that the adult person with intellectual handicap, who has no productive employment on the regular labour market, receives the service he is in need of.

The first step in the development of these day activity centres originated, though to a modest extent, in the forties and fifties. During the sixties they increased in number. During these years they were run very much on a voluntary basis whereas their establishment during the seventies was taken over by the organisation formally responsible for providing services to persons with intellectual handicap. During this decade the number greatly increased and to-day they are established in most parts of the country.

An evaluation project carried out during the seventies examined the services which had been established during the same decade. An analyses of day activity centres was therefore made in order to clarify whether their form and content were in fact adequate in relation to the function they were to fill within community services (Kebbon, L. et al 1981, Heron, A. et al 1981).

The starting point for the study concerning day activity centres was the official policy document published to state how they were to be developed. It was issued by the official state authorities responsible and contained suggestions on the type of building, sort of activities, working methods and staffing. It also suggested a variation of centres depending on the size of group to receive their services. In this publication the term day activity centre was defined as a premise equipped and adjusted so that persons with intellectual handicap could be kept occupied with varying activities during the day.

As a summarizing comment on the results of this study one can say that the day activity centres became day activity centres! The centres which had been developed both in form and content greatly resembled the models suggested in the original policy document.

The centres and types of activities described in the study illustrate that day activity centres during the seventies were premises where primarily persons with a mild or a moderate intellectual handicap were occupied during the day. The buildings were purpose-built and were therefore adjusted so that persons with a handicap easily could have access to them. There was also a wide variety of activities with which these persons could be occupied.

From several points of view these day activity centres can be regarded positively. Many persons with intellectual handicap, who for example

previously were unoccupied in their parents' home, now gained access to an active daily life. These centres also became important as new methods could be developed on how to create an active life for persons with an intellectual handicap.

The evaluation study had the purpose of analysing the extent to which this type of service contributed to the realization of goals in the socio-political policy expressed in the concept of normalization. The expression "community participation" was therefore chosen and taken as a starting point to describe the extent to which activities of the day activity centre contributed to community participation for those receiving these services (Ericsson, K. 1987b).

With this perspective on day activity centres one could expect to find that a substantial number of activities took place in the local community outside the centre premises. The study showed however that activities to a very limited extent contributed towards the person's chances of experiencing an increased participation in community life. Specifically, this was illustrated by the fact that most of the activities in which the individual participated, took part on the day activity centre premises.

The persons to a very limited extent left these premises in order to take part in other activities in the community. The type of premises and activities provided were limited to what could be done within the centre building and not to what was available in other local environments or places of work where persons without a handicap spend their working hours (Heron, A. et al 1981).

One can explain this situation when one sees that the aims and goals for this type of service were not very precisely formulated in the original policy document. Much room was left for individual interpretation of the goals for services. This led inevitably to a wide variation in the type of day activity centre developed.

In the absence of specifically stated goals many regarded the sheltered workshop and productive work in industry type of buildings as a model. Many day activity centres were therefore also characterised as places of production.

A MODEL: DAILY ACTIVITIES FOR COMMUNITY PARTICIPATION

Once it was established that this type of service only to a very limited extent has contributed to the realisation of community participation of persons with intellectual handicap, then the need becomes clear to develop a model to achieve the aims of these services.

This model is the result of an analysis of requirements for community services where the concept of community participation has a significant role, as an expression for the goal of these services. It has therefore a theoretical background. A fruitful exchange of ideas and experiences with a few day activity centres, especially that run by Persson (1982) who has developed a day activity centre in a small Swedish town along lines similar to those advocated by the model, has meant that some parts can be found in practice. Other aspects are being tried while organising daily services in the local community of Lidingö (Ericsson, K. 1982 Ericsson, K. Nilsson, I. 1987).

PURPOSEFUL DAILY ACTIVITIES

The expression "purposeful daily activities" summarizes what should be achieved in this service-form, responsible for providing persons with inte-

Intellectual handicap with adequate support and service during the day. The main point of this expression is to establish that the individual, like persons in ordinary employment, should have access to daily activities five days a week. In a general formulation it is not possible to point out in detail the types of activities which can be provided. With this type of service there is a great deal of freedom and variations can be extensive.

The statement that these daily activities should be purposeful expresses the basic intention with these services, namely that the person, by means of support and service, be able now and in the future to experience a positive life. Daily activities for a person with an intellectual handicap should not be planned in a haphazard manner. The person's needs and wishes must be the basis for the choice of activities which will occupy him during the week.

Another consequence of this aim for these services is that they also must contribute to the overall and basic goal for services. Together with other services, primarily housing but even other community services, daily activities contribute to making it possible for the individual, according to his abilities, to experience the normal life which is experienced by persons without a handicap.

One way of achieving this is the creation of personal environments where one can live as near to and with as much participation as possible in the ordinary community, at the same time under secure and stable circumstances. The creation of personal environments where daily activities can take place is therefore the main task for a service of this kind.

THE ACTIVITY GROUP

The core in this model for purposeful daily activities to persons with intellectual handicap, is the activity group. This is a group with persons occupied together during the week, together with staff required.

To say anything about the size of the activity group, expressed in numbers, is not possible as this depends on a series of circumstances, for example the type and degree of handicap of group members and the type of activities they are engaged in. It is important that the group is small so that members can learn to know each other and feel a common interest in their tasks.

If something general should be said about the type of activities which are possible and desirable one must recognize that this service leaves room for a wide freedom of choice. The activities which are provided is however dependent on what is considered to be purposeful for the single person and the group as a whole.

One can however point out some categories of activities. Activities which lead directly to personal development is one group. This consists for example of training programmes, adult education or therapeutic programmes from social, psychological or medical staff.

Another category of activities are those which increase the chances of the person to acquire paid employment. This is motivated by the fact that those receiving these services are adult persons who should be given the opportunity to experience the normal life. It is therefore desirable that they in the long run acquire productive paid employment. As this takes place on the ordinary labour market it cannot be provided within these services specially organised for persons with intellectual handicap.

Services however, can contribute to employment by providing activities which increase the person's chances of acquiring productive work. An important task is therefore to find the type of work which also is found on the local labour market so that the person, at a later date, may be able to carry out the same task as employed.

Another type of activity has a social content and is directed towards persons outside the services. In order to gain access to personal environments, activities and resources in the community it is important that time is given to informing those concerned about intellectual handicap and the type of services provided for persons with such a handicap. This is a task not just for staff, but something that persons themselves can take part in. One example is working as an informant in schools, to local authorities or with exhibitions in order to influence local opinion.

The type of activities a person and a group is working with, will finally depend on the needs and wishes of the persons in the group together with the resources, tasks and other persons available and responsible for assisting the activity group.

Which environments can be used by the activity group? The traditional environment is that which the day activity centre itself offers, that is specially built premises where all activity groups are located. If however one regards community participation as something to strive for then one should avail of all types of working environments in the area where the person resides. It is these environments, where non-handicapped people work, that are presumptive environments for activity groups.

However, it is not just one personal environment that a group needs. They need to have access to several. Which ones depends on which activities the group, or the individual members are occupied with. In this way one group can avail of several different environments during the working week.

It is also desirable that the activity group can experience a certain degree of independence in relation to the service organisation of which they are a part. Independence is necessary if activities are to be developed which suit both the group and the particular environment they are making use of. This desire for independence does not necessarily mean that one must refrain from cooperating with other activity groups. Instead it is often that two or more groups can work together for example around a project to inform about the services provided.

Staff are of course a basic requirement to give the support needed in an activity group. The type of staff employed, in terms of professional experience and qualifications, will depend on the activities within the group. A supervisor who is responsible for seeing that the group carries out the planned activities is however necessary.

The extent of staff support will of course vary between groups and depends on the need for support and service within each group. If it is dominated by persons in need of less support the need for staff will be limited. On the other hand if the persons in a group need a lot of support, the need for staff increases.

ESTABLISHING THE ACTIVITY GROUP

The creation of an activity group includes at least four stages. The first is to decide which persons are to be included, to describe their needs and desired

daily activity, the environment in which it is to be carried out and the staff support needed.

A second stage is to decide the extent to which it is possible to respect these needs and wishes. This stage consists of finding the specific activities, environments and adequate staff support. If it is not possible to satisfy the person's needs and wishes as originally described, it can of course be necessary to reconsider which of their needs can be fulfilled.

The third stage involves a decision as to which purposeful daily activities, which environments and what staff support is to be utilized in order to provide the services needed by the group. The fourth and final stage is the actual realisation of the activity group. This involves starting to work on the development of the activities one is going to work with and seeing that the desired environments are made available and accessible. Adjusting these personal environments, physically and socially, requires a lot of work at an early stage. Staff also need new work methods in order to carry out their tasks.

GROUPS IN THE LOCAL COMMUNITY

The activity group, as it has been described here, is the nucleus of this form of service. It is here that the most intense work is carried out to provide the person with intellectual handicap with a week of purposeful activities. To achieve this it is often necessary to cooperate in the use made of various persons, activities and resources lying outside the group. There are therefore common tasks and points of interest for the different activity groups to be found within the same local community.

This cooperation can take place concerning the persons involved and their activities. One example of this is adult education. This can take place on one day of the week, in a group of persons coming from different activity groups. Cooperation between groups can also take place in the use made of persons with expert knowledge, for example a music therapist, who normally is not employed by the organisation responsible for this service.

It is also necessary that the different services availed of by the various groups be coordinated for example, the means of transport used to and from the activity group. Establishing a new group for those who recently have gained access to the services requires that one makes use of the knowledge that experienced staff have acquired. Cooperation between groups is therefore natural. If activity groups are spread to different areas in a community then one gains more knowledge about which environments are available, that is to say where persons with intellectual handicap can be expected to be welcome.

When one sees these different tasks common to several activity groups, then one realizes that this type of service does not consist of one group but rather of a series of activity groups spread to various places of the community.

The number of groups within an area can of course vary depending on the extent to which services are needed. The need for coordination can also vary depending on the character of the community for example the involvement of the local labour market. Within the organisation of activity groups one must, for every situation, decide which methods of cooperation should be developed in order to achieve purposeful activities not only within the small group but even in the common interest of the total organisation.

DISCUSSION

An account has been given of an evaluation of the services responsible for providing daily activities for persons with intellectual handicap. When it was found that an important aspect of community services was lacking, their contribution to the participation in the community of the person, an alternative model for these services was formulated.

As the starting point was the person's right to participate in community life, the emphasis of the model formulated was on the importance of the small activity group, and allowed the organisational structure to consist of a series of activity groups. The model has a general character and can thus be applied in different environments and cultures. Under different circumstances the model can be realized in varying ways.

One has thus found that at least two models can be formulated for this important aspect of community services. The process of change from institutional to community services is therefore not just a question of establishing new services but even involves decisions on important questions of policy.

As with the services responsible for providing housing for persons with intellectual handicap, one is forced to accept that different models can be formulated without consideration being given to whether they contribute or not to the realization of accepted goals. This choice need not necessarily be made only on theoretical grounds but also in order to increase the possibility of contributing to the well-being of the person with handicap.

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