KEY ISSUES IN THE PROCESS TOWARDS COMMUNITY PARTICIPATION

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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. As a research psyhologist one theme of my work has been the study of the closure of Carlslund, a residential institution north of Stockholm.

Most of this work has of course been presented in Swedish, but some of it has been brought over to English, e.g. to be presented at international conferences. It has been found desirable to put this English material together. As they are articles presented over a period of time, this explains why the same theme can be found in several articles, but with different angels and at various stages of development.

The work behind these articles have been financed not only by the County of Stockholm and its Social Services, but also from research funds and the personal contributions from the authors. As some of this material has been presented internationally, it has meant some travelling and therefore some costs. Several sources have made this international participation possible. I would like to thank all who have contributed economically to the realization of these presentations.

During this work I have had the pleasure to work with several persons who in various ways have been involved in these projects. It has been very stimulating, and great fun, to work together with all of you! Thank you all for your contributions!

A key person for this work is psychologist Patricia Ericsson as she has done the translations of these presentations. I am very grateful for her contributions!

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Kent Ericsson

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Contributors to this report are a group of professional people who in various ways have been associated with the closure of the residential home of Carlslund and the development of its community based alternatives, in the County of Stockholm, Sweden, during the period 1978 - 1991.

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KEY ISSUES IN THE PROCESS
TOWARDS COMMUNITY PARTICIPATION

Kent Ericsson

SERVICES UNDERGOING CHANGE

From institutional to integrated services

If ongoing change is to be meaningful for persons with intellectual handicap who are leaving institutional life for a more normal life in the community, it is important that it bears positive consequences for those concerned. It is therefore important to understand the nature of the institutional problem and necessary to clarify which goals are to be fulfilled. A historical analysis explains the societal function of institutions and a socio-political analysis clarifies intentions behind development now taking place.

Every society has a way of providing support to persons with intellectual handicap. In Sweden, the foundation of the present day organization of services was grounded during the later half of the 19th century within the framework of the restructuring of society which was then taking place. Because of the changed role of the family a greater degree of responsibility was placed on society to provide support to these persons, and as a consequence it was compelled to develope and supply forms of care and service. The task fell upon the county councils who already were responsible for providing health services.

What type of services did this organization provide? When it was established institutions were created. These were mainly located to the countryside, and provided for groups much larger than the family unit, but even so not so large. The first system of services offered was therefore a form of institutional care. The institutional structure then established still exists, and until the mid-fifties was relatively unchanged (Söder 1978).

During the 20 year period from the 1950's most institutions have been rebuilt and modernized. During the same period institutions increased in size. The largest provided for 500 persons.

Since the 1950's the introduction of integrated services has gradually taken place. The first step was taken in the 1954 Act stipulating that the "educable" child's education should be provided in local schools so that children could remain in their family home. It also prescribed that adults be given the opportunity to live in a family, their own or another, instead of institutions, and that they be occupied in premises near their home and outside of institutions. In this way the prerequisites were laid down for these persons to live a more normal life.

In the 1967 Law a further step was taken away from institutional care, when children with a severe intellectual handicap, previously termed "uneducable", received the right to education and care in the home, their own or that of another. It was however first by way of the 1985 Law that adult persons with a severe handicap received the right to demand services which made it possible to experience "the normal life" outside an institution.

This development however only concerns the content of the legislation. Its function is merely to stipulate the intentions and regulations on which the support of society to this group of persons should be based. The laws prescribe, for example to the county councils who provide services, what type of support is to be provided. It is first when the council has made its own decisions on the realization of the goals prescribed in the law that it is actually possible to offer services to the individual. The quality of that which is provided determines the life the individual will experience.

The main challenge to-day is to develope services which enable persons with severe intellectual handicap to "live like others together with others", the goal as expressed in this Law. As the new type of services develope, institutional care must disappear as it lacks the basic requirements necessary to realize the type of life to-day expressed as desirable (Ericsson 1986, 1987d).

A socio-political change

The idea behind this transition from institutional to integrated services can first be found in the debate on the nature of the welfare society and the role of the handicapped. It began at the end of the thirties and was concerned with the question of how a society should be formed which could guarantee its citizens good living standard and welfare. As a means to achieving this an expansion and modernization of social services was recommended.

At the same time the question was raised as to how social services in a welfare society should be developed for persons with handicap. Should the institutions, based on a 19th century philanthropic tradition, continue to be responsible for the support of society to handicapped persons, or should they be given the right to avail of the provisions of the welfare society?

The latter choice, to let a modern social service bear responsibility for persons with handicap was termed "the normalization principle" by the public committee which in 1945 suggested which measures should be taken to ensure a better life for persons with handicap.

However, a distinction was made between persons with a handicap who were "partially ablebodied" and those who were "incapable of work". It was only the former group, persons with a mild handicap, who were recognized as having a right to avail of the resources of the welfare society, whereas the others were referred to continued institutional care.

In this changed official position the implications of a new socio-political view were expressed. The reason for setting up the committee, and the task given to it, was to find ways of providing a better life for these persons. The position of the committee claimed, first and foremost, that instead of institutional life these persons should be given the opportunity to experience "the normal life", i.e. the life lead by persons without handicap.

Another official view was that the resources and amenities of the welfare society should be used to provide support and service to these persons. The type of assistance developed for persons without handicap should also be available for those with a handicap. To accomplish this these persons needed to be given the right to claim similar resources. The organizations responsible for implementing the welfare society, must as a consequence, carry out the changes necessary if the services were to meet the demands made by persons with handicap.

There is also a third point in the official view which concerns this social political change. How persons with handicap are regarded is also expressed in the motivation of the committee. It is a question of human rights for persons with handicap to be able to avail of the welfare service, and that these rights are basic to the democratic ideal (Ericsson 1987a, 1987c).

The institutional problem

In the socio-political analysis one can also find an expression of the institutional problem. The three points which characterize this socio-political position are met in a completely different way within the institutional model.

It was, for example, not "the normal life" that was made available but an institutional life, which was motivated in various ways. During the 19th century it was considered right to protect those with handicap from a society in the process of change and industrialization, whereas institutional life during later decades, the twenties and thirties, was motivated by the need to protect society from these persons.

The social role ascribed these persons has also varied during different epochs. However, there are two roles which were paramount during the 1950's, when the present day institutional structure was established. While "educable" persons were given the role of "pupils", those regarded as "uneducable" were given the role of "patient", both consistent with institutional care. There were boarding schools for the first group and residential homes for the others.

With the institutional model attention was only paid to those with intellectual handicap who were at the institution and no responsibility taken for those outside. In this respect the institutions were not part of the modern social services which had developed within the welfare society. Thus one can see that the third standpoint, stating that all services should be available to all members of the public, was not fulfilled as these institutions were not a part of the welfare service system (Ericsson 1984).

The problem of "the two worlds of service"

Persons with intellectual handicap are in need of support and service in order to experience "a good life" in society. They need people around them who can give them the support they need to live in a home, have a daily occupation and to participate in the community.

The character of the services, because of this dependent relationship, influences the sort of life the person can live. Where society decides to locate its services, there the person with handicap must reside. In the buildings provided, the individual must live.

The quality of the services determines the quality of life the person can experience. Stimulating services can provide the requirements for a rich life whereas simple and limiting conditions can lead to a more meager existence for the person. Services located where the public lives provides a setting for community participation whereas services set apart creates a hinder for such a life.

As the persons's pattern of life is an expression of the environment in which he lives, and of the quality of life he experiences, the type of services influence not only his daily life but even his own personal development. The services a society provides have therefore extensive consequences for the life he lives and for the personal development he can experience.

The present situation is characterized by the fact that two types of service exists, the institutional and the integrated. They are different in character, with different background, goals and structure and with different methods of work.

In addition, integrated services are officially considered as desirable whereas institutional forms are to be closed down. As a consequence they provide two entirely different life-environments for persons with handicap. For the person the type of service he receives has significance for the quality of life and personal development.

The organization that provides both types of service at the same time is thus faced with the task of providing services whose goals, purposes and methods are contradictory. This is a source of conflict at both organizational and individual level.

This problem has been termed the "two worlds of services" in order to illustrate that qualitatively different services bear consequences for the person availing of them. In this problem there is also a theoretical basis for the developments presently going on within the services (Ericson 1985, Ericsson et al 1985).

A PROCESS OF CHANGE IN THREE RESPECTS

What sort of life, what type of services?

With this perspective one can identify three critical areas in the ongoing process of change. The first concerns the question of what sort of life a person with intellectual handicap has a chance of living. This question is important at a time of change as the answer determines the choice and type of services that will be provided. The changing serviceorganization is in itself a second problem area. The third is the development of the societal role ascribed to the person with intellectual handicap, which also is part of the process of change.

The person's participation in community life

In an organization of services with these goals a central question on which one must be clear is the implication of societal participation for a person with intellectual handicap. It may seem trivial to claim this as a goal for services. However, the difficulty lies in the fact that this is a group of persons where many have a very complicated functional hinder, whose special needs and wishes must be met as well as their general need to live the same sort of life as those without handicap.

In this attempt to realize a life in places and environments where others live and reside, one must also guarantee that the person's special needs also be met. The conditions the individual will ultimately experience will be a balance between special and general needs and wishes.

If services are to contribute to providing a satisfying life for the person a basic requirement is a good knowledge of him and the sort of life he wishes to live. There must also exist a general view as to the meaning of "the normal life" if a development of social services is to take place.
As a consequence the person with an intellectual handicap, and his spokesman, as well as the organization providing services, must have a clear understanding of the implications of the participation in community life of the person with handicap.

A personal answer can be expressed by the individual himself, or by his spokesman, and contain a concrete description depending on the situation concerned. A general answer must however contain a description which covers and characterizes the entire concept.

An example of a general description of this concept is Nirje's (1969) formulation of the "normalization principle", where his eight points characterize the "patterns and conditions of everyday life" which should be available for persons with intellectual handicap. Another way of expressing the same idea, more briefly and generally but clear and distinct in its purpose, is the goal expressed in the 1985 Law in Sweden (SFS 1985). The term used "to live like others, together with others" expresses the overall purpose of the services.

A full-worthy citizen

The expression used by the committee, "the normalization of living conditions", was motivated by the view that this sort of life was a right one had as a citizen and in this discussion can be related to the other question of the role society ascribes to persons with handicap.

There are various analysis which illustrate that the societal role ascribed to persons with intellectual handicap has varied in different periods. For example, these persons have been regarded as "patients", as "inhuman" or as "persons undergoing development" and that these roles are associated with certain types of organization which provide services. By describing the societal role ascribed this group and the type of organization which provides services, one gets an impression of the conditions under which they are living (Wolfensberger 1969).

This aspect of the socio-political concept implies that one takes a stand for the societal role which expresses that persons with intellectual handicap are fullworthy citizens.

The intention is that previous roles, for example of "pupil" or "patient" should be replaced by the view that these persons be regarded as citizens. In this way an older philanthropic and patriarchal view can be discarded. Instead the individual and his needs can be perceived on the same terms as the citizen without a handicap. He is, for example, also in need of housing, work and leisure activities and wants to acquire a good economy and quality of life. But he is also a person who wishes to have satisfactory medical, psychological and social conditions.

In order to guarantee adequate measures for his health and welfare the person must have access to the same services as other citizens. He must be able to avail of health services and receive the same psychological stimulation and care as is offered others. Similarly, measures of society to guarantee good housing, work and leisure activities to the public must also be available to those with handicap. Everyone should have access to these services, irrespective of type or grade of intellect.

The pursuit of these objectives can be expressed in terms of a change of perspective. One must see the individual and his needs in another perspective than previously. It is a social perspective which is now emphasized.

The change of services

Special services is the way of society of providing support to those in need. The nature of these services does not depend on random choice but on the basic conditions and terms provided. Many of these have an international range, for example knowledge about the problem of intellectual handicap. Other conditions can be more local, for example bound to current legislation in a country. What is commented upon here is related to present-day services in Sweden.

The socio-political change which took place, and which is termed "the normalization principle", is an example of such basic conditions. When one has taken the standpoint that these persons have a right to demand to live "the normal life" then this position must be taken into consideration when services are developed.

Those who to-day can claim the right to live such a life are all persons with intellectual handicap. On this point a change has taken place, as one previously discriminated between persons with a mild or a severe handicap when it concerned their possibility of participating in society. There is therefore a demanding need for development.

The societal role, which regards these persons as fullworthy citizens, is a further reason which contributes to demands being made on these services. As a consequence of this view these persons should be able to influence the type of service provided. It is not just the question of the right to demand services but also to have a legal right to appeal over the services provided.

An extensive development of services is therefore necessary. Some existing services can be developed in order to meet new requirements, but even completely new services are in need of development. Part of the present process of change should include both research and developmental work in order to achieve new services.

Naturally one can present an extensive number of solutions. Evaluation of these can contribute to the finding of solutions to these problems. "Services for community participation" is one model which has been formulated with the ambition of pointing to some important aspects of the services which are related to the new requirements (Ericsson 1987b).

One consequence of these conditions is the closure of institutions, as their very nature create a hinder for the formation of modern services. Such a task can be felt to be dramatic and create uncertainty. There are many who are effected by a complex process like this and can express anxiety for ongoing change. And many interests are involved. Is it not however so that the decision taken should be based on the consequences a change could have for the persons who have an intellectual handicap? Even on this point there is a need to develope new ways of closing institutions so that the consequences are best for those concerned.

Knowledge is important if services are to lead to a good life for those for whom services are being provided. During such a decisive and intensive period of change as that which is taking place now it is important to know what conditions influence the process. The task does not take place irrespective of the conditions and society in which it is occurring. Knowledge of these contribute to influencing the ongoing process.

"SERVICES FOR COMMUNITY PARTICIPATION" - A SERVICE MODEL

The model

As an example of which types of new solutions are needed in the process of change some aspects of a service model are presented, which has have taken these basic requirements as its starting point. The critical factor in this service model is the relation between the life expressed as desirable by a person with intellectual handicap and services which have to be developed to fulfill the person's wishes. The model is based on the idea that individual needs are the basis for a service system.

This is particularly important in a service system where all persons with handicap, irrespective of type or grade, have a right to participate in community life, even those with a very severe handicap. In such situations there is a great need to find personal solutions.

The basis for the model, the implications of the concept "community participation" are summarized in short. These factors have been found critical in the experiences won during the changing process when both those with a mild and those with a severe intellectual handicap have moved from institutional to integrated services.

The community participation of the person

A house and a home can be seen as the basis for a good life. It is in the home that a person, either by himself or with his family, people he has chosen to live with, that he has his security. It is here he has a chance to relax and to retire from the demands of society, both at work and in his leisure-time. It is here he has his private life and here he can have time for himself without the insight of others.

In order to be a home those who live there must be able to put their own personal touch to things. Acquire furniture and fittings according to their own wishes and taste.

A home can be acquired either by purchase or renting. It can be for one or more families. It can be in an apartment block, in a terrace or a separate villa, localized to different places in a neighbourhood, near the center or on the outskirts or even in the countryside. In order to acquire a house the individual must choose between the alternatives available at the time when he wants to move.

An employment influences the life of the adult. Then he has a place of work where is employed and where he can, for remuneration take part in the production of goods and services. This has also social significance as it is here he meets and during the greater part of the week lives with his work-mates.

There is also a need to participate in activities in the community, outside the home or work-place. In order to purchase what one needs or to receive community services, the individual must make use of shops and avail of services.

It may be necessary that during the day one needs to make use of some community services, for example, visit a hairdresser, a welfare center or go to a dentist, i.e. the type of service that is available during the day.

In the community there are also recreational facilities in which one can participate. It is also then one can belong to organizations, not just for pleasure or recreation but even with the purpose of influencing opinion in social matters. Social contacts one has with family, friends and acquaintances also take place during free time.

The quality of the life of the person, at home, during leisure but also in working life, depend on the material standard available to him. If access to financial resources allow there is a good chance of living a stimulating life.

The respect with which a person is met is also an expression of the quality of the life. How far he can influence his situation and express his own personal view as to how he wishes to live, in his home, at work or in the community at large, illustrates the degree of self-determination.

In addition the question arises as to whether the wishes of the person are respected by those in a position to influence the sort of life he lives. Freedom from these type of restrictions determines the degree of integrity and self-determination under which the individual is living.

Services for community participation of the person

The daily life of the individual can, during a day, consist of experiencing various places, environments and social situations made available to him within a certain vicinity. All environments within a given area are naturally not accessible for everyone, irrespective of whether they have a handicap or not. There are regulations and routines, more or less official, which can prohibit accessibility. For a person with handicap it can be their functional incapacity which sets these limitations.

However, of the accessible environments there are those which are made use of by the handicapped person. The extent and character of those that are accessible, and are made use of, is decisive for how the person's day will be formed. Consequentially one can see that it is possible to arrange the way a day can be spent and thus widen the experiences made available to the person.

One way of achieving this is by providing the support and service necessary to make these environments accessible. Housing, places of employment and recreational environments can all be adapted and thus made accessible for persons with handicap.

To increase the number of environments accessible for persons with a severe handicap additional demands must be made so that their adjustment be personal that is, related to the needs of just that person. The development of "personal life environments" thus becomes the main task for service organizations.

The development of personal life environments is not only a task related to the personal wish for accessibility to certain environments. It is also necessary to give those on whom the person with handicap is dependent insight into the wishes, and abilities, of the person who wants accessibility. The formation and development of life environments is therefore a question of both physical and social adjustment.

Against this background the first step in a model for "services for community participation" implies acquiring a knowledge of the life a person with handicap wants to live, either direct from him or his spokesman. It is also necessary to attain knowledge about his capacity to live that life.

The next step is to create "personal life environments" so that the person has access to a series of places, environments and social situations which are made available just for him.

The third step is to create conditions so that these "personal life environments" are actually made use of so that the individual can experience what was originally intended. The criteria for which "personal life environments" that are made accessible, and the extent to which they are made use of, can be found in the needs and wish-es expressed about a desirable life concerning housing and employment, commercial and social service and leisure and recreation.

COMMENTS

Previous analyses have shown that ongoing socio-political change has its origins in the period of the establishment of the "welfare society". At that time the question was poised as to whether persons with handicap also should have access to the welfare society. The answer came in the form of the "normalization principle" which said that persons with handicap had a right to avail of the care and social services which were being developed for the general public.

Through an analysis of this socio-political idea one finds that it contains three aspects. The right to live with "the normal life" as a model and the right to avail of the services of the welfare society are two of these. The third motive, often unrecognized, is that it was originally considered a democratic right for a fullworthy citizen to have these experiences.

These have later been taken as a starting point to describe ongoing change. One consequence is that one finds that within all three areas change needs to take place. One is the individual, concerning the person with a handicap and the daily life he experiences. Even others in his environment are effected. Another consequence is organizational and concerns the services of which he is in need. The third is societal and concerns the role ascribed to this group.

One can here find a formulation of both the goal for integrated services and an expression of the institutional problem. It can be said that these lead to two important consequences. One of these is that it is not enough for persons with intellectual handicap to merely move from institutional to integrated services. Obviously alternative services in the form of housing and day activities in a physical sense are necessary but it also requires that these are used and that participation in the community does occur. This demands that services are based on the recognition of these persons' role as citizens. New services are necessary if the move is to be carried out, but a changed perspective for the task is also necessary.

Another consequence is exemplified in the model "services for community participation". Here the original formulations of the basic standpoint are taken to describe some points in a service model.

Presuming that it is the choice and type of services that make it possible to create a certain situation for these persons then it is necessary to seek personal alternative solutions. On the question as to what should be provided the answer is found in the person's, or his spokesman's, expression of the type of life he wishes to live. The connection between these wishes and the services provided is found in the concept "personal life environment", which is the answer of the service organization to contribute to a good life for just that person.

HOUSING AND A HOME IN THE COMMUNITY

Patricia Ericsson Kent Ericsson

COMMUNITY PARTICIPATION

New goals

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 1986, Ericsson 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 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.

THE GROUP-HOME

Housing with support

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 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 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 to-day 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 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 became 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.

EXPERIENCES

Evaluation of group-homes

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 et al 1981).

Results from evaluation studies of community services show some of these consequences (Heron 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, Ericsson and Brusén 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.

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 ones 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 ones own home and moves in the local community. Participation in local organizations also 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.

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 per-son 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 persons'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 program 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.

A FOLLOW-UP STUDY OF PERSONS LEAVING THE INSTITUTION

Peter Brusén, Kent Ericsson, Maj Thorsell

Purpose and background of the study

There is a great need for additional and documental knowledge concerning what happens to persons who have moved from institutions, perhaps above all in the case of persons with severe intellectual handicap. What has been undertaken in this study is a survey of the process of change at a personal level. The experience gained can be taken as representative for the potential implications for persons with intellectual handicap when they leave an institution.

The purpose of this study is to describe the way in which everyday patterns and living conditions change when intellectually handicapped persons leave an institution. The strategy of a follow-up study made it possible to observe the process of change, from the time of moving from the institution up until the persons concerned had established a regular life within the integrated services. The same group is described by means of personal interviews, identically structured, carried out on two occasions. The survey is not primarily an evaluation of changes undergone by the persons themselves but of the changes occurring in their living situation.

Model and method

The purpose of the study, to describe everyday patterns and living conditions, influenced the character of the descriptions. By everyday patterns we mean the way in which the individual lives - places and living environments which he frequents and the activities he participates in. But the purpose of this study has also been to facilitate a description of more qualitative aspects of the life of the individual. The method which has been evolved describes everyday patterns and living conditions for the same persons on two occasions. The first occasion was while they were still resident in the institution, the second took place two or three years after they had moved. A structured questionnaire has been devised for this purpose.

The questionnaire

The questionnaire provides a broad description of the life of the person with intellectual handicap, both in the institution and in the integrated setting. The areas described are primarily the person's home and the daily activity outside the home. In addition to these two basic living environments, the person's participation in different activities in the community is also described. A qualitative evaluation of the person's everyday pattern of life is achieved through the description of his living conditions.

Other material

Particulars were also gathered, from the medical and institutional records for the persons concerned, regarding their current social, psychological and medical status. The semantic differential has made it possible to obtain the view of the staff concerning both the intellectually handicapped person and the content of their work. This, then, is a subjective personal experience and not an objective description of the individual.

DIMENSIONS	EVERYDAY PATTERN	LIVING CONDITIONS
THE HOME	13 questions about the person's own room, sleeping habits, food and leisure, work in the home and social relations	35 questions on the person's MATERIAL STANDARD, INFLUENCE and PRIVACY
DAILY ACTIVITIES	11 questions concerning the place of occupation, extent and type of activity, social relations	11 questions on the person's MATERIAL STANDARD, INFLUENCE and PRIVACY
COMMUNITY PARTICIPATION	18 questions about the neighbourhood, different types of services, recreation outside the home, working life, transport, friends and relatives	18 questions about the person's MATERIAL STANDARD, INFLUENCE and PRIVACY
BACKGROUND DATA LIVING ENVIRONMENT VARIABLES	73 questions about background, viz institution, personal needs, secondary disabilities, behavioural disturbances, medical status, form of housing, staff, medical inputs and speech capacity.	

Procedure and implementation

Most of the forty persons described moved from the institution in 1985. They moved to 22 different group homes. These homes are variously designed. Some individuals live in detached houses or terrace houses, wheras others live in apartment blocks. All the homes are integrated in ordinary residential areas. The persons have their daily occupation at nine different day activity centres. About 25% of the group are women. Many of them are persons with relatively extensive intellectual handicap, often combined with secondary disabilities. The group had previously lived in six different wards of the institution.

Each person was interviewed twice, once in their home and once at the day activity centre. Each interview lasted for 1-2 hours. The staff answering the questions were those with most knowledge of the person with handicap.

Results

The following selection of tables illustrates, in a variety of aspects, the personal consequences for the intellectually handicapped individual, of moving from an institution to an integrated home. Some results are not found in the tables, existing only in the form of a conclusive text. This is a schematic description of the entire group. A description of paired comparisons is also planned, referring to the change in each individual person's life.

The home

Table 1. Name on the outside door or letterbox?

Form of support	Yes n %	No n %
Institutional	0 (0)	40 (100)
Integrated	11 (28)	29 (72)

Nobody in the institution had their name on the outer door or its equivalent. After moving there was an increase, 28% having their names put up. But 72% of those who had moved still do not have their names on their own outer doors.

Table 2. Number of visits by relatives.

	Never	Once / few times / year	Once / few times / month	Once / few times / week
Form of support	n %	n %	n %	n %
Institutional	16 (41)	14 (36)	6 (15)	3 (8)
Integrated	11 (28)	20 (50)	8 (20)	1 (2)

There is an increase in the number of visits paid by relatives to the intellectually handicapped person's new home, not only that more visits are being paid to those who received visits previouly but also persons are now receiving visitors who have not done so before. Two persons who used to be visited frequently have experienced a decline in the frequency of visits. This agrees with the experience that some parents see no reason for paying frequent visits after the move because they now consider that their child is well looked after.

Table 3. Is there a mirror in the room?

Form of support	Yes n %	No n %
Institutional	17 (44)	22 (56)
Integrated	28 (70)	12 (30)

The most conspicuous change in connection with moving out is the distinct rise in material standards. This is reflected, for example, by 26% who previously lacked such an obvious possession as a private mirror acquiring one after moving. It is remarkable, however, that as many as 30% still do not have a mirror.

Table 4. What time does the person go to bed?

Form of support	Before 19.00 n %	19.00-20.00 n %	20.00-21.00 n %	21.00-22.00 n %	After 22.00 n %
Institutional	3 (8)	4 (10)	12 (30)	16 (40)	5 (12)
Integrated	1 (3)	4 (10)	11 (27)	16 (40)	8 (20)

There are no dramatic changes where bedtime is concerned, though some people seem to be keeping somewhat later hours. Consideration for staff working shifts leaves its mark even on the group home, and a large proportion, about 40%, have already gone to bed by 9 p.m.

However, the collective element diminishes considerable as a consequence of new residencial settings, people now having more possessions of their own. The nine persons to whom this does not fully apply were those found not to have their own soap. Instead they shared a common liquid soap holder. Nearly all of them also shared bathroom facilities with one or two fellow-residents.

Table 5. To what extent do the persons only use their own soap, towel and dressing gown?

Form of support	Not at all n %	One item n %	Two items n %	All three items n %
Institutional	2 (5)	15 (38)	20 (50)	3 (7)
Integrated	0 (0)	0 (0)	9 (23)	31 (77)

All the persons who had moved acquired a distinctly better material standard of living, for example, having a personal mirror. Most of them also gained better access to private possessions like clothing, food and so on. Social relations increased between those who lived together, while on the other hand relations with former residents outside the home remain very sparse.

Participation in various household tasks increases somewhat but remains low as regards laundry, cooking, shopping etc. Greater privacy and respect for the individual developed after moving, this being reflected, among other things, by a larger number of positive qualities being attributed to the individual. However, certain things are still lacking, for example, having ones name on the door.

Daily activities

Table 6. No. of hours activity spent outside the home, at a day activity centre or elsewhere.

	0	1-15	16-30	over 30
Form of care	n %	n %	n %	n %
Institutional	2 (5)	9 (24)	24 (65)	2 (5)
Integrated	1 (3)	5 (13)	15 (39)	18 (46)

Since moving the majority have increased the amount of daily activity they are engaged in, but this mainly concerns those who already were well occupied, these persons having acquired more activities. There are, however, still many who do not have a full day. One person still has no daily activity at all.

Table 7. Number of hours per week spent on social contacts.

	0	1-10	11-20	Over 20
Form of support	n %	n %	n %	n %
Institutional	14 (63)	8 (22)	12 (32)	3 (8)
Integrated	10 (26)	15 (39)	7 (18)	6 (16)

The number who lack any social contacts outside the day activity centre has diminished somewhat, but at the same time one might feel that the proportion of contacts with the community could have increased more, in view of the integrated nature of the services. 25 % are still reported as not having the opportunity of spending time outside the day activity centre.

Table 8. Frequency with which the individual has lunch in an ordinary canteen or restaurant.

	Never	Once or so every year	Once or so every month	Once or so every week
Form of support	n %	n %	n %	n %
Institutional	24 (63)	13 (34)	1 (3)	0 (0)
Integrated	20 (54)	13 (35)	3 (8)	1 (3)

Here one can see even more clearly how seldom these people get away from the day activity centre, in spite of it being integrated in the community. Only one person at the institution lunched out at least once a month but even after moving from the institution, the total number doing so is still only four. The day activity centre has a dining room and the most common arrangement is that everyone has all their meals there. In the institution, people mostly returned to the ward for lunch.

However, the great majority have more activity and a greater variety of daily occupations after having moved. Contacts with the surrounding community also increases, but there is still a great deal of isolation regarding daily activities. Social relations, during leisure hours, with fellow day activity centre participants also seems to be very rare.

Community participation

Table 9. How many times has the person been to the cinema, theatre or a sporting event etc. in the past month?

	Never	Once or twice	Three, four or five times
Form of support	n %	n %	n %
Institutional	9 (23)	21 (54)	9 (23)
Integrated	13 (32)	17 (43)	10 (25)

For those who have moved it is more common to go to an ordinary hairdresser for a haircut. But there are still examples of the staff cutting hair, most frequently as a matter of convenience when someone is available who can do the job.

Table 10. Who cuts his / her hair?

	Usually the staff	Varies - staff or hairdresser	Always a hairdresser
Form of support	n %	n %	n %
Institutional	6 (15)	14 (35)	20 (50)
Integrated	2 (5)	8 (20)	30 (75)

Opportunities for recreational activities appear to have diminished after moving from the institution. The staff report great difficulty in attending various activities mainly because of insufficient staffing. In the institution there were special recreational staff who organized outings and visits to various leisure activities. This indicates quantitative differences but says nothing about the qualitative difference between the two forms of care.

Indicators

Table 11. How common are different measures for treating infections and stomach disorders?

	INFECTIONS			
	None	Once or twice a year	Several times a year	Frequently, chronic
Form of care	n %	n %	n %	n %
Institutional	17 (14)	11 (28)	3 (8)	8 (20)
Integrated	22 (55)	8 (20)	2 (5)	8 (20)
	TYPE OF TREATMENT			
Institutional	21 (55)	1 (3)	2 (5)	14 (37)
Integrated	34 (85)	0 (0)	0 (0)	6 (15)

Proneness to infection seems to decline, above all as regards skin complaints and similar ailments. The more harmonious atmosphere in the smaller group accommodation is above all reflected by the incidence of treatment for various gastric disorders. The use of laxatives, diet instructions etc is reduced greatly after leaving the institution.

Contact with neighbours is completely lacking in the institution but very often develops after having left it. There is, however, no evidence of deeper contacts, although a positive acceptance is often apparent. Contact with next of kin appears to have increased both quantitatively and qualitatively. Moreover, many individuals have, as a result of leaving the institution, come geographically closer to their parents or siblings. There is also more contact with various commercial services, for example, post-offices and shops, but even these contacts are still very limited.

Summary

The circumstances at the institution has influenced the collection of data to some extent. The phase-out was in progress during the period in question, with uneasiness and turnover among both staff and the intellectually handicapped persons themselves. However, the interviews took place without difficulty and the possession of professional insight into the informal culture prevailing at the institution proved an advantage; sometimes it was critical to the interpretation of an answer. A certain observation fatigue existed among the staff, due to the ongoing process of moving.

Moving from an institution to an ordinary home with a small group of people generates a host of positive effects for the individual. Moving from the institution is an essential requirement but is in itself not enough. Prospects improve but opportunities are not necessarily fully utilized. To assure the individual of a harmonious living environment and optimal results from the new situation many additional requirements must be met.

Determined efforts are therefore needed to develop integrated housing. To this end passivity and institutionalizing factors must be eliminated and activating and developmental circumstances be reinforced. Active staff procedures are essential for ensuring that integrated housing be a positive experience for persons with intellectual handicap.

Living in an institution or living in an ordinary home is like living in two different cultures. The institution has its own system of norms, its own values and a distinctive language, while in the community at large the only norms are those which we all live by, with all their merits and shortcomings. All that the intellectually handicapped persons in our institutions ask is to be allowed to share these things with us - to be allowed to live like the rest of us and together with us.

BECOMING VISIBLE

Maj Thorsell, Kent Ericsson, Peter Brusén

The study

What are the consequences, on a personal level, of people moving from an all-embracing institution to integrated care? To shed light on this question, we resolved to carry out a follow-up study of a group of people who, in 1982, had moved from a residential institution to various types of small group homes in the community.

Method

This is a qualitative study and, in our choice of methods, we were inspired by Glaser and Strauss (1968) and their research strategy, termed "grounded theory". This method is particularly useful in new fields where well-developed theories are lacking. The work is characterized by a constant interplay between data collection in the field and the task of analyzing these data at one's desk and in the seminar room.

In the work on field data, each piece of information is compared to new data with respect to meaning. Out of these comparisons, concept categories emerge; subsequently, these categories govern further data collection. This is called theoretical sampling. Collection, coding and analysis of data thereby constitute a simultaneous process that continues until new data no longer provide additional aspects or enhance the depth of the category, which is then said to be saturated.

When a category has emerged, one can return to the indicators and see that groups of indicators illustrate a particular aspect of the category. These component aspects of the category are called dimensions.

Procedure

The sample selected for this investigation was a group of people who, in 1982, moved from institutional to integrated care. The group we studied are 24 people with severe, moderate or mild intellectual handicap. Members of the group also show various types of additional handicap, such as motor impairment or epilepsy. Only five people use well-developed speech as means of communication.

To obtain an illustration of individual consequences of moving from institutional care, 56 interviews were conducted. Of these, 24 were with staff giving support to the people in their homes and 24 with staff providing services to these persons at their day activity center. To gain a deeper understanding, four relatives and three of the persons with intellectual handicap were also interviewed. Two members of staff were present at most staff interviews.

In most interviews, at least one and usually both of the respondents had been in contact with the person since his move from the institution and until the occasion of the interview. The period for which the staff had worked with the persons concerned, was at least two years.

The interviews were unstructured, except for the introductory question. This was as follows: "Tell me what kind of life X leads today. Please focus on situations where you have perceived changes for the better or for the worse. Remember that negative changes are as important as positive ones."

In the subsequent conversation, lasting between 1 and 1,5 hours, the respondent associated freely and talked about the lives of the person at home and during his daily activities. The interviewer sometimes guided the interview to areas where concept categories had begun to emerge, according to the method of theoretical sampling.

The interviews were tape-recorded. The recordings were transcribed word for word, and indicators were extracted from the interviews. The interviews gave rise to about 600 indicators describing changes on a personal level connected with the move from the residential institution to a home in the community.

These 600 indicators yielded four categories, which are described below.

The method calls for a form of reporting that makes the results accessible to the people affected - in our case, primarily the staff. They must be able to read them and gain an understanding of their content, and this understanding should bring about a modified approach in their work with persons with an intellectual handicap.

By giving categories and dimensions an everyday character, like "Dad's coming even if it rains", to describe a changed family relationship, we hope to communicate the results in a way which gives understanding and insight.

Results

The four categories, and the various dimensions of each category, are presented here, then a report is given on each category.

Category one has been called "Becoming a person", and the three dimension of this are "They do listen to us", "Now I dare to say 'no'" and "The staff can cope with me too".

Category two is "Finding a home". It contains four dimensions namely "Having one's own home ...", "... with a kitchen", "Whose is the food in the fridge?" and "People have personal relationships."

Category three has been named "Something to do all day". The two dimensions illustrating this are "Passivity - my protest" and "I'm needed".

Category four is presented by the expression "Dad's coming even if it rains" together with the four dimensions "There's room for the family", "Supposing I asked her to dinner?", "Phone calls - a way of getting together" and "Fellow human being wanted."

"BECOMING A PERSON"

What consequences for the person are concealed in this
category?

1. They do listen to us

At the large institution, day-to-day decisions - such as the dinner menu or which fruit is to be served - are taken by somebody in a central kitchen. That person certainly knows a great deal about nutritious food, but is unaware of what the favorite dishes of the various people in the ward are.

When interviewed, people talk about an incipient interaction in which people verbally or non-verbally start expressing their will in everyday situations, for they know that the staff have a capacity to listen. Most everyday decisions are taken by staff working close to the person with handicap.

Although the acquiescent attitude is deeply rooted, the tale is told of a person who removed the cucumber from his sandwiches again and again, until everyone in the staff group grasped that he disliked cucumber. The staff also relate of one woman that she only now dares to opt out of the gymnastics program at the day center, although she has probably always hated gymnastics.

Daring to have a will and express it is what we have called "They do listen to us", an important consequence and part of the category "Becoming a person".

2. Now I dare to say "no"

If Jill wanted to get rid of a yellow skirt, she stuffed it under the mattress, solving the problem for the time being. If the staff accompanied Barbara to the lavatory, she used to sit there regardless of whether she wanted to use it. If the staff thought Charlie should eat in the service apartment at the weekend, he would do so without a thought for what he himself wanted.

Now, Jill decides for herself when she is out shopping whether something appeals to her or not. The manger - who, to Jill, is an important person - may suggest buying a certain garment, but she says no if she does not like it. This reflects a steady change over three years, with immense readiness to listen on the part of the staff, since Jill's signals are neither clear nor loud.

Today, Charlie decides for himself whether he wants to do his own cooking at the weekend or join in the meal, together with the others, in the service apartment. Charlie had a tremendous capacity for trying to work out what the staff wanted and saying no to a staff suggestion, was a big problem for him.

Now, when the staff accompany Barbara to the lavatory and she feels no need to use it, she says so clearly.

All these changes witness to the fact that these persons with an intellectual handicap have, with varying degrees of awareness, discovered that it is not their primary task in life to satisfy the staff, but rather that the staff are there for them and that their personal needs are the starting point for services.

Saying no to the staff and being respected for it, is a fundamental discovery that emerges in various forms in many interviews.

The staff role also includes a need to take the initiative and arrange matters with the best interests of the person with handicap at heart. In the interviews, there are several examples of persons now daring to reject this form of consideration. For example, one staff member felt that financial resources did not for the time being stretch to a major capital purchase for a man. But he preferred the drawbacks of shaky finances to going without this capital item. An attitude of this kind would have been impossible for this man during his first year, when acquiescence dominated most expressions of his will.

3. The staff can cope with me too

You need not hold on to a member of staff physically in order to get attention! At first, Anna behaved like a postage stamp. The staff were naturally irritated and Anna incurred many reactions of rejection and annoyance. Although the outcome was usually negative, her habit of clinging to the staff's apron strings persisted for a long time.

Nowadays, Anna can enter the kitchen, say hello and see who is on duty, and then go back to her room and occupy herself with her own things. She has discovered that the staff can cope, they are there when she needs them; she no longer needs eye contact and physical closeness to know that they are there.

In the beginning, Molly lost her temper if someone else in the group home came into the kitchen when she was busy there together with staff. She demanded to be alone with the her and refused to share the contact. Today, someone else can be there too - Molly takes it entirely in her stride.

Persons in the small group are beginning to understand that they can count on the staff being able to cope with each one of them.

Summary

When asked about the biggest change that has taken place with the person, staff have frequently answered "It's that she / he has become a person".

Saying no, expressing one's feelings, daring not to acquiesce and trusting the staff to provide attention - these perhaps make up one element in what the staff call "It's that she / he has become a person". One consequence on the personal level can therefore be called "Becoming a person".

"FINDING A HOME"

1. Having one's own home ...

A parent said "At the institution, there was nothing private, nothing owned. The four-bed room makes it difficult to see one's child as a person with a separate life to lead. Now she's got her own room, become a person and learned the words 'mine' and 'yours'".

In an interview with a man with an intellectual handicap, I asked him what he regarded as the best thing about the move. "That I've got a home, so I can have all the family's fine old furniture in my home", was his reply.

Staff and relatives refer to the discovery of a room of one's own as an opportunity for comfort and privacy, while some still associate the room with a place in which one merely sleeps or, perhaps, old memories of being sent there in disgrace.

With the discovery of the room as something cozy and personal come cautious demands for new wallpaper, purchases of plants, ornaments, etc.

With one's own room, participation in housework comes too. Staff say that a woman whom they knew in the institutional environment as well now, makes her own bed. She was capable of doing it before, but never did so. Cleaning and arranging things in one's room and buying a plant as a decoration are described as positive and pleasurable everyday activities that confer a sense of belonging on the personal level.

In several interviews both staff and relatives associate the possession of a room of one's own with some kind of perception of the person with handicap as an individual. In this context, they also see the change from an irresponsible child to an adult who shares responsibility; or, as one relative said "I'm automatically much less motherly now that she has her own home".

2. ... with a kitchen!

What is a natural domestic role? It is to take part and join in, each according to his or her capacity. For one person, being part of what goes on in the kitchen means gradually learning all the stages in making pancakes; for another, it means being in or around the kitchen, smelling, watching and perhaps tasting, when the staff - who are there to compensate for the obstacles imposed by the handicap - make the pancakes.

Participation in the kitchen serves a much broader purpose than to win praise from the staff, for example telling Peter, how clever he is to lay the table. Meal preparations culminate, after all, in a situation that is intrinsically positive and rewarding in many homes. Sitting down to eat with other people is an important situation which exerts beneficial effects on many.

The ability to use skills and know-how in everyday domestic life is clearly focused on mealtimes. In the training flat, where daily activities take place, numerous people in institutional care over many years have doubtless learnt to make a salad or a sponge cake. The subsequent discovery that this knowledge has a practical importance in everyday life, and that cooking is a way of giving pleasure to the people one lives with, gives the individual a new role vis-à-vis his surroundings.

The experience of being able to do things for oneself is important to everyone, but for someone who has lived in an all-embracing institution and, moreover, is confined to a wheelchair and thus more dependent on the staff in more situations than many other people, "doing it oneself" is that much more important.

Taking one's own plate out to the dishwasher just like the others - all in their own special way - gives a sense of belonging and a feeling of competence that cannot be dismissed by rational arguments about time, mess and the risk of china getting broken.

3. Whose is the food in the fridge?

Many persons show great uncertainty in the novel situation of having access to the kitchen and refrigerator. What is in there, and what is allowed? One initial thought is, of course, that everything is there for the taking if it is not locked up. In fact, people approach the matter cautiously and need many assurances and a great deal of encouragement that they are allowed to take something to eat out of the fridge if they feel peckish during the evening. As a resident, one can go to the fridge and take a sandwich without stealth or a bad conscience, or sit in the kitchen and enjoy an evening snack instead of first hiding the sandwich under a cushion and then surreptitiously popping it into one's mouth.

This realization that one is entitled, in one's own home, to take things to eat and drink without permission or encouragement is a big change for most people. However, many show signs of understanding the new system. Today, one woman takes something to drink if she is thirsty, but must still be encouraged when it comes to fruit and other food. Learning to take a bun from a plate on the table uninvited, and also daring to take fruit out of a bowl, is a process that has taken time for another woman, but such behaviour is now becoming more common.

Charlie comes home from the day center while I am there for an interview. He takes off his jacket in the hall, says hello to the staff on duty and goes into the kitchen. There, he opens the fridge door and takes out milk, cocoa powder, bread and butter. He makes himself a small snack, to keep him going until dinner two hours later.

This same man used to stand outside the locked kitchen door in the ward at the residential institution, waiting for his dinner portion from the central kitchen, utterly incapable of having a spontaneous snack with his 23 fellow-residents as spectators. The contrast is immense. For the person, it must be a tremendous experience to have access to things one appreciates, even if they are such everyday commodities as milk and cocoa powder.

Charlie has not become any more intelligent or been taught how to make cocoa. No doubt he has always known how; but using a skill when one feels like it is a new experience that imparts satisfaction and a sense of well-being. Charlie often says that he does not want to move back to the institution, since his new home is better. He has difficulty in defining exactly what is better, but perhaps the cocoa and sandwiches when he himself wants them, and this without anyone's permission, is part of the story.

4. Persons have personal relationships

In the large institution, although more than 300 people lived there, there were very few indeed who had mutual friendships in the ward or at the day center. Before the move, there were very few who had close friends whom it was important to be able to move out with. Is this absence of friends due partly to the fact that the staff are so important to keep an eye on that no room is left for fellow-residents? Is it partly because of the large group? Being with 24 others in the same day-room perhaps imparts the feeling of "self" versus "others". The others become merely a large mass in which single persons, to build a relationship with, are indistinguishable.

Two and a half or three years is a short time for adult people to make new contacts and to create relationships.

The indicators include descriptions of person's wordless incipient discovery of each other, also of mutual friendships between people of the same or opposite sex which become deeper and gain new dimensions as time passes.

Two women had lived in the same ward for many years, but the reason for their moving together was not that they had a mutual friendship. Now they have found each other as persons there is a budding relationship between them.

One major change on which several interviews shed light, is daring to say no to a fellow resident, instead of always saying yes and being acquiescent. It may be a matter of doing favors, but it may also be a question of putting up with noise and disturbance of various kinds.

From the four-bed room in the single-sex women's ward accommodating 24 people to the three-room flat with two bedrooms and a living-room is, after all, an almost breathtaking change.

When, for a woman, the change also leads to a mutual relationship with a man, the effect is striking. Growing, becoming stronger in one's femininity, having the refined and womanly side of one's nature reinforced and wanting to be ladylike becomes more and more important and may sometimes touch on extremes.

Building a relationship with someone of the opposite sex may be difficult if one has lacked natural role models. Having grown up in an institution and seen neither one's parents' marital relationship nor older siblings' and friends' ways of interacting and behaving with the opposite sex, creates problems.

The absence of mutual relationships in the institution is something that has always bewildered and amazed me. Despite the short period, it is clear that mutual relationships of various kinds or a more diffuse sense of belonging are developing. In the world of community services, it is perhaps possible for people to see and experience one another as individuals with traits, feelings and needs.

Summary

Opportunities of taking part in everyday domestic activities change radically when one moves. Many of the tasks now performed daily, were formerly carried out by someone else, away from the living quarters.

The view of the person as a householder and the impact of this role on integrity and the staff's duties, are illuminated in, for example, the section "Whose is the food in the fridge?"

Getting one's own home does not mean just assuming another role in practical terms. Relatives think that relationships, too, are affected by an apparently external, physical change in living conditions.

The sections "Having one's own home ...", "... with a kitchen", "Whose is the food in the fridge?" and "People have personal relationships" clarify the impact of "finding a home" on the person. This physical change has a direct influence on the person, but also on the his relationships with staff and relatives.

"SOMETHING TO DO ALL DAY"

Daily activities at the residential institution and in integrated services, are partially similar. The number of handicapped persons is usually 20-40, and many activities take place within the four walls of the day activity center, not in interaction with the surrounding community. A trend towards increased social participation is developing, but this takes time.

The interviews with staff of the day centers did not yield many indicators, but I shall discuss two major aspects which have been important on a personal level.

1. Passivity - my protest

Several of the persons who moved were extremely passive, and it was difficult to find activities they could cope with, since many day centers were established during the 1970s, when people with severe and multiple handicap still lived in residential institutions. By their passivity, they gave the staff a bad conscience, and forced them to enter into far-reaching discussions on the objectives and content of activities. At several day centers today there are groups with a structure and content adapted to the needs of the severely handicapped for experiences and learning situations.

Variations on this theme recur in several interviews, and what they have in common is that the passivity of the mentally handicapped encourages the staff to be creative and start developing methods. A place with daily activities created in interaction with the mentally handicapped has an impact on them as individuals: they pose demands, make choices, express their feelings and form bonds with staff and employees, provided they have a framework adapted to their needs.

2. I'm needed

Underlying this dimension are indicators showing that the individual has been given a task that is useful to people other than himself. Being in charge of making coffee for everyone at the day center and delivering the daily news papers to another group are two examples. Assuming a role that is also useful to others has an impact on the personal level.

The right to two environments - a home and a place for daily activities - is a basic precondition of increased social participation.

"DAD'S COMING EVEN IF IT RAINS"

1. There's room for the family

At the interviews, one father said: "It's such a boon that I can now visit my daughter even when it's raining". I listened and listened, silently repeating to myself: "It's such a boon that I can now visit my daughter even when it's raining". It was not as if the roof had leaked at the institution. I felt confused, the father saw my questioning look and started talking about the dormitory, the insecurity and the need for privacy and closeness that were ruled out. If the father and daughter went for a long walk together, this might give part of what one sought and wished to give as a visitor, but a rainy autumn day could make visits impossible, or at least make it difficult to give them a meaningful content.

In integrated homes, each person always has a room of his own. There, one can sit in privacy, without supervision, if one is uncertain in dealing with others and unsure of what the staff think and feel, or if one just wants to be alone because that is best.

Moreover, the group of residents and staff is easy to grasp. After a few visits, their faces are familiar and a hug from some other residents with inadequate social distance does not feel so dangerous and threatening. One knows what the woman's name is, and when the staff, without any great fuss, have explained that she unfortunately has no other way of saying hello, her behaviour does not seem so strange and off-putting any more.

As a visitor to someone's home, one can contribute one's knowledge and experience if, for example, they have practical problems. A tape-recorder needs to be fixed to the table so as not to break when a spastic hand turns it on and off. As a relative, one tries to co-operate with the staff to find a solution to the problem, and also help to implement it.

After 17 years' one-sided visits to a contact family, the mentally handicapped person can suddenly invite them back. Aided by the staff, one can be a hostess, offering coffee and buns: this gives a new dimension to existence. So, too, does getting a phone call and hearing a familiar voice say: "We're in town. Does it suit you if we look in for a cup of coffee?"

Many interviewers talk about obtaining more contact, except in a few interviews in which the assurance that the son or daughter is getting on well in his or her own home has led to reduced contact. The former frequent contacts were prompted by the need to ensure that the mentally handicapped member of the family was happy, rather than by a mutual need for contact and interaction.

"It's marvelous to be able to relax and not to worry in case something happens. It's an enormous relief to dare to count on her being happy."

2. Supposing I asked her to dinner?

At the institution, much is determined by routine. Contact with the family, too, can easily become a fixed routine - for example, visits every Saturday, every other weekend, birthdays and Christmases, etc.

In an integrated home, there are routines that are beneficial and necessary for the functioning of a group home, and for the creation of a basic structure that the mentally handicapped can recognize and feel secure in, and that is easy to transfer to temporary stand-in staff.

But leisure time, in which interaction with the family forms a natural part, is not governed by routine. This allows spontaneity and flexibility, as some relatives have begun to find out. Trying out new ways of being together alongside the secure, habitual one imparts excitement and satisfaction. Inviting one's own daughter - on her way into the adult world - to dinner one Friday evening after work and then seeing her make her own way back to her own home, satisfied and contented, gives new options. People then learn that it is good for both sides for this not to be repeated every Friday for the foreseeable future, but that this is rather one means of getting together, out of a whole range of possible ones.

In the whole of integrated care, routines do not govern interaction with relatives. Going to see relatives and have dinner with them on an ordinary weekday affords new options. Everyday life can be shared, and the interaction becomes more natural.

3. Phone calls - a way of getting together

"I want my own telephone with my own number in my home."

Although the county council had installed a telephone in the flat at a lodging house, one man demanded his "own". Being a person who can give his own telephone number in contacts with people in the outside world, being able to pay the phone bill and to make calls when, where and however often one wishes is something quite different from having to use a telephone on which it is, perhaps, impossible to make long calls.

Although the resident may not be able to speak very well, the telephone gives a contact with the outside world. Being able to hear one's mother or brother talking on the other end is not the same as getting a message from the staff after a phone call is over. If one is missing Mum badly, one can ask the staff to help by ringing her so as to hear her voice, even if a meeting is impossible on this particular day.

"Coming - not coming" - one man worries about whether his visitor will come or not. His anxiety mounts and the staff ask whether they should ring to find out for certain. Being able to hear his brother's voice saying "Next weekend I'll come and see you and we can go on an outing" makes the situation clear and relieves his worry. A pattern emerges and the telephone becomes a natural part of interaction with relatives.

4. Fellow human being wanted

If the relatives are dead or, for various reasons, do not constitute a natural part of the social network, the need for substitutes is clear. In an integrated home, perhaps two or three people have regular and close contact with their families. In contrast, the need of those who have no one are clear. What will the first Christmas be like? How shall we arrange things for the two who are "left over" when everyone has gone home? And what about the staff's own Christmas schedule - how shall we arrange that? The mentally handicapped have their own words and signals to express loneliness, lack of contacts outside the home or missing an aunt who never rings, and these are perceived by the staff.

All these everyday signals lead to the staff taking the initiative to find contact people and families outside the home. The situation of the mentally handicapped with regard to relatives has not changed as such, but the need for someone who is not a professional carer and does not receive any formal payment for meeting and spending time with them becomes clearer and leads to action.

Interaction with the contact people and families takes a wide variety of forms. For one man, his relationship with the contact family is his first link with an ordinary family. He spends time periodically in their home, where things often happen in the domestic environment. But just as important as these visits is if someone phones him, or if he has someone to phone.

Another man is in touch with his own family, whom he meets regularly several times a year. For him, the relationship with the contact person is a complement. The initiative always comes from the man himself, and he has clear expectations of his visits to the contact person. This is a person who, on his visits, concentrates solely on him, so that he does not have to compete with fellow residents; such competition is often manifest in a unit with a low staff-resident ratio. The staff seldom have the capacity for help, support and personal interaction. Unfortunately, the latter is much too often relegated to bottom place on a list of planned priorities.

Summary

The move has given relatives the opportunity of creating new and more personal ways of spending time with the mentally handicapped man or woman.

At the big institution, there was no room - in either the physical or the psychological sense - for relatives to play a more extensive role. The buildings took shape at a time when the commonest answer to parents was: "Hand over your child, and forget". If one refused to forget and wished to visit the child, there was seldom any room in which parents could be with their children in peace and quiet.

Psychological space was lacking as well. The interaction and caring that surround the development of relationships between parents and children were provided by others. Some relatives refused to renounce their participant role, but were sometimes labelled as troublemakers and busybodies who made care more difficult. These parents were often not particularly troublesome, and the staff were not ignorant and incapable of listening; the problems stemmed from unclear expectations and diffuse roles created by the institutional structure at such all-embracing institutions. Relatives were never envisaged as an interest group that should or might wish to participate in care and discussions on the content of care.

The above descriptions of interactions with relatives are various expressions of the way in which the change from homeless person to householder imparts new perceptions of, and ways of dealing with, contact with relatives as well. A homeless person cannot receive visits. A homeless person cannot be a host and entertain guests. A homeless person cannot go away, since he or she has no home to go away from and no home to return to.

If one regards homelessness as one of the problems of the mentally handicapped at institutions, one can see more clearly the breathtaking opportunities afforded by the home in the world of integrated care, and the individual consequences to which integrated care leads.

The sections entitled "There's room for the family", "Supposing I asked her to dinner?", "Phone calls - a way of getting together" and "Fellow human being wanted" elucidate the complete transformation of opportunities for interaction represented by the world of integrated care. These changed opportunities are summarized in the heading "Dad's coming even if it rains".

Adverse consequences

The adverse consequences reported are few, although the interviewer emphasized that the negative side was at least as important as the positive. Some indicators point to an increased dependence on staff when the mentally handicapped live outside institutions. In one case, this could have been avoided if the external environment had been a factor more deliberately taken into account in the choice of home. For some people, this is a reality that will persist for several years - until, if ever, the new surroundings become a secure territory - and some people will always need support from the staff. Where two people are concerned we are told of changes for the worse, in terms of mobility and of independence when going to the lavatory respectively. Whether these are temporary setbacks in reaction to a major upheaval or whether they will persist, the future will reveal.

Increased social participation?

The period for which these people have lived in conditions of integrated care is a short one - about two years at the time of the interviews. Their lives at the institution were considerably longer. A clearer role in relation to the surrounding community is one way in which individual consequences may be expected to increase over time.

Some indicators point to expanded attempts to make contact with shops in the vicinity and with neighbours. Going out to buy buns with a friend, with no help from the staff; going to the dentist after a few visits accompanied by a member of staff; choosing between several different restaurants in the vicinity at lunchtime - these are a few examples of people's approaches to the surrounding community.

At the big institution, contact with the outside world was something that usually had to be organized, and there was very little scope indeed for spontaneity and improvisation. If anyone who needed staff help wished to go to the shopping center, there had to be enough people on duty to perform the normal tasks and care for the other residents. If a staff member fell ill or a mentally handicapped fellow resident became restless, the visit might have to be called off. If the mentally handicapped person concerned had been involved in the plans, a canceled outing could cause disappointment and despair.

When people are living physically integrated in society, the location of the home, as such, involves contact with the surrounding community. Living in a block of flats, one meets people on the stairs on one's way in and out, or when disposing of the rubbish. If one lives in a detached house, the garden borders on someone else's plot.

In discussions on the social participation of a woman with a relatively severe mental handicap, a staff group expressed their views roughly as follows. By the mere fact that she lives here, she shows that mentally handicapped people exist, and affects her neighbours by eroding their prejudices slightly. She opens people's eyes. She shifts the process forward on the imaginary axis from inmate to member of society. This woman does not drop in to have coffee with her neighbours, and no one calls "Hi Sally!" on the stairs. But this is her home, she lives here, the neighbours nod to her as they do to others, she goes for walks in the vicinity and accompanies the staff to the nearby shop. The separation of accommodation and day center, as such, affords numerous natural contacts with the surrounding community. For individuals, there is no limit to how far this can develop; but the locations of the home and the work-place in the community are fundamental prerequisites.

PSYCHOLOGICAL PROCESSES DURING THE CLOSURE OF AN INSTITUTION

Bo Lerman

Background

I have been working for 8 years with the closing of Carlslund, a large institution in Stockholm County Council. At first I worked with research together with Kent Ericsson. We described and compared the conditions of everyday life for retarded persons living in institutions and in group homes in the community. Some of the results were presented earlier (Ericsson, Lerman and Nilsson 1985). After that I worked as a psychologist at the institution and was directly involved in moving almost 300 retarded persons.

The results from the research made me personally convinced that it was a right thing to close the institution. It has been a good help all the time when the closure has been questioned and when one has been surrounded by doubts.

In my work at Carlslund I met many emotional reactions, that sometimes could seem irrational, mostly from staff and families. In order to understand and to help or maybe to prevent some of the reactions it has been natural for me to try to see patterns in those reactions.

During a long period of closure there are all the time persons on different phases in the process of change. For example, when half of the wards had been closed there were still staff in other wards who didn't believe that there would be any closure. From the decision to close the institution it took almost 12 years until the last person had moved in March of 1988.

I will here present some of my experiences as a psychologist during the closure period. I will try to describe some typical reactions and mention some factors that can be a help in understanding the different reactions that can occur during the closure of a large institution.

The two dimensions of institutional closure

Closing an institution is the biggest organizational change that can take place. Many people are effected and naturally many emotional reactions arise during the process. In order to understand these emotional reactions one must analyze the meaning of the changing process for the persons who are primarily involved. One must take into consideration the function of institutions when they were established and the function they have today.

Institutions can be seen as a result of an ideology where handicapped persons were separated from the community, either to protect them from non-handicapped persons or to protect the non-handicapped from them. Special service systems were developed for them. This made it difficult or even impossible for them to move around in the community or to use the same service systems as other people.

Closing institutions is a necessary consequence of another ideology, in which handicapped persons are seen mainly as citizens with a natural right to live in the community even though they might need help and support in order to do so and to enjoy a rich life. Swedish society has made the choice that there must be a place even for handicapped persons in the ordinary community.

The institution has, of course, a special meaning for those groups primarily effected by its closure, namely the staff, the families and the handicapped persons themselves. The institution also has a role in the community as a place where persons for whom we couldn't, wouldn't or hadn't the money to arrange adequate care in the ordinary community have been placed.

This is no longer possible in Sweden. A new Act from 1986 stipulates that services, for example housing, day activity centers and other facilities, should be provided within the community.

In this sense we can see two dimensions of the closure of institutions. First, it means that the institution as an organization, as a place where handicapped persons have lived for years and where many persons are employed, will disappear. Many relations will be dissolved. The staff will lose their jobs and perhaps get new employment with new demands and responsibilities. The future is unknown and feels insecure.

Secondly, closure is part of the development of the services; it is a consequence of a new ideology. That means that many persons on different levels must change their way of thinking in many aspects. New criteria for the quality of care must be discussed. The closure means that a tradition of care is abolished and that the institutional culture is got rid of. This can be threatening.

Very often the staff identify themselves with the institution and they experience the criticism of the institution as a criticism of themselves and their work: "Have I done a bad job all these years? No!"

It can also be threatening for the families. Even though they might have had no choice, they once made the decision to send their son or daughter to the institution. Was that a wrong decision? "Have we done wrong all the years when we let our son stay in the institution?" Of course not.

In the light of these two dimensions of institutional closure many of the emotional reactions during the closing period can be understood. It is also important to see the two dimensions as it leads to different steps that must be taken in helping the effected persons through the process of change.

It has also an impact on how those inside the institution work with the closure process and how the alternative forms of housing and daily activities are developed. Democratic methods must be developed and different means found for a real participation in planning for the staff, the families and the handicapped persons themselves.

A link in a historical process

Another help in understanding the reactions of those directly involved is to look upon the closure as a link in a historical process.

What were the earlier conditions in different aspects for the people who are effected by the changing process? How have the families experienced the stay in the institution of their sons or daughters ? How do they experience the attitudes in the community towards handicapped people? What does it mean for the handicapped person to move? Has it been a punishment or a reward? What opportunities have the families or the handicapped person had to influence his situation and to participate in the planning of the care? Have the staff any experience of being actively involved in planning or in changing processes?

If we sincerely seek the answers to questions like this and relate the answers to what we want to achieve, it will help us to understand different reactions. It will also give us a guide to relevant education and support during the closing process.

A complicated process

Closing an institution is a very complicated process, extending from the day of the decision until the day the last person has settled in his new home and started his new daily activities. The process concerns not only the individuals in the institution but also other parts of the community.

When persons with handicap live in the community they will also, to a large extent use the general service systems. Therefore, closing an institution also concerns the general health and welfare service and of course the whole service organization for the handicapped. It likewise concerns shops, post and bank offices, bus and taxi companies, people in the neighbourhood etc.

Many persons and groups of persons are in some way effected by the closing of the institution. People change during the period of closure. They learn and have new experiences. Those who are directly involved will of course change most. This means that the basic conditions for the task of closing down the institution changes continuously. It is necessary to alter and adapt the content of the education and support given to groups and individuals during the process.

As the retarded persons begin to leave the institution consequences are felt for those who are left on the wards. The groups get smaller and competition for the staff's attention may be reduced. New relations can occur between the residents.

Unless everybody leaves a ward at the same time, it is impossible to reduce the staff in the same proportion as the retarded persons leave. This means that the staff level will increase which can have positive effects. Maybe some persons in the institution, can, for the first time during the closure period, participate in daily activities. This can make some persons feel very much better and can reduce a lot of behavioural disturbances.

The staff not only learn and gain new experiences. Some will leave and new staff will be employed. Those who come know from the beginning that the institution will be closed. They are not emotionally involved in the institution. This makes it easier for them to accept the new ideas and to take an active part in the task of closure. Even if it must be an ambition to get the staff to stay, it's not only negative when new staff joins the institution.

These are some of my comments on the three groups that are primarily involved in the closing process.

The retarded persons

A general description of the adult retarded persons living in swedish institutions can look like this. Most of them have lived a very long time in institutions, perhaps in big groups with an insufficient staff level. Many of them, often the most severely handicapped, have had none or very few daily activities. Their experiences of ordinary home activities and of the community outside the institution are very few.

They can be described as the group that was left behind. Following the 1968 legislation many group homes and day activity centers were built. As there were very few staff these homes became a realistic alternative only for the least handicapped persons. In the institutions the least handicapped persons were put on a waiting list to move to a group home. They were given a lot of special ADL-training. However, many were not successful or capable enough to "earn" a place in a group home.

Many don't talk or have other problems with communication. Some of them talked a little when they were younger while others have such a severe handicap that they never learned to talk.

Many are multi-handicapped

Because of their degree of mental retardation most of the persons in the institution cannot understand the real meaning of moving to group homes when it is talked about. They need concrete information.

But many have experiences, not always positive, of being moved between institutions or between wards. Moving the retarded persons has sometimes been used as a way to solve some kind of problem. I have even heard a retarded person threaten himself with moving to a special hospital unless he behaved well.

If the task of closing the institution is taken seriously, it's impossible to move the retarded persons around in the institution during the closure period unless it means an obvious improvement for the individual or is a positive step towards moving to a group home.

The retarded persons in the institutions have had very little, if any, influence over their own future.

Many have a very fragmented personal history, especially those who don't talk and those who have little contact with their families. They have moved and staff have changed. Things that they have experienced and appreciated and earlier friends might have been forgotten.

Closing an institution means that a number of individuals will move. It means that there will be fewer and fewer left on the wards. It will be easier to get the attention of the staff. As the groups get smaller, the uniqueness of each individual will be more easily seen.

Surprisingly enough, there are very few friendships between retarded persons in large groups. One explanation can be that they are all competitors for the attention of the staff which is so important for those who are completely dependent on staff.

Negative reactions among the retarded persons brought about by the closing are generally very rare. Some may wonder what happened to their former fellow residents. Even if we don't see any special reactions we don't know what their fantasies can be. One person I met thought that they died when they moved from the institution. Even if this is a very special and unique fantasy, it illustrates how important it is that we in a concrete way explain what will happen and let those who are left visit those who have moved.

The retarded persons must be prepared for the future. This means that they, as soon as possible, must be given information about what will happen in an understandable way. Opportunities must be given for them to get acquainted with the new group. They must get to know the new staff and they must get acquainted with the new home and it's surroundings. If this preparation is well adapted to each individual, the negative reactions when they move will be the exception.

The families

If closing an institution presents the biggest changes for the retarded persons, it is often a more difficult change for the families. It can be described as if the families move as well.

First I want to say something that might not be so obvious from the institutional point of view. The families never forget their children even if they have no contact or contact only a couple of times a year. One mother, for example, who never visited her son said that she every night in her prayers prayed for her son. There are many examples that retarded persons have got renewed contact with their families after more than 20 years when the institution closes.

There are many reasons why contact in many cases has become more and more rare. The distance from home and the difficulties of getting to the institution is one. Parents have also told me that it was very difficult to see so many severely handicapped persons at the same time.

Some said that when they left their child at the institution they felt that society took over the responsibility and that there was no place for the families anymore. Some parents can even relate to how they were not allowed to visit their child. These earlier conditions are seldom known to the staff today.

It is very important that we really talk to the parents and openly listen to and accept their experiences.

Even if parents had no real choice when they 10, 20 or maybe 30 years ago left their children at the institution, they once made the decision to do so. The closing of that institution will mean a questioning of this decision. "Was it wrong to leave our son at the institution?" This is a question that they might have asked themselves before. But since there were few alternatives at that time and the institution was the best alternative they had, it was not a wrong decision.

It is natural when one faces a question like this and judges the institution, that what one sees is good and sometimes becomes idealized. This is one reason why the first reaction to the closing of an institution very often is negative among families.

To change attitudes towards the closing is even more complicated if it is going to take a very long time. How can anybody accept that there is a better alternative for their son or daughter if they have to wait five, maybe ten, years. It is also difficult to talk about ideology and explain why the institution will be closed if the families have to wait a long time for the alternatives. It is important that the conditions for those who remain behind can continually improve during the closure period.

The attitudes of the families toward the institution are often a mixture of very strong positive and negative feelings. They can with great bitterness talk about lost or destroyed personal attributes, about how the retarded person has become passive and lost his initiative etc. At the same time they can tell how good it has been for their son or daughter and they will not accept that he or she must leave the institution. The institution represents safety, a safety which is often connected to a trust in the staff, who unfortunately have been changed too often.

Even the families need to be prepared for the change. They need a lot of information. They must also be sincerely involved in planning for the future of their handicapped relatives. They must have the possibility to see different kinds of alternative housing and daily activities. They must also have possibilities to talk about their feelings and to share them with others in the same situation. Family education at residential weekends is one good way of providing this kind of support.

The staff

The third group primarily effected by the closure of an institution are the staff. As a consequence changes will be dramatic! Of course, individual reactions can vary greatly depending on how they regard their jobs, what gives them work satisfaction and how they perceive their possibilities of getting new attractive jobs.

However, some common reactions can be described. One can see a chain of reactions which starts with some kind of protest. The staff can refuse to accept the decision to close the institution. How this protest is expressed can vary depending on how the decision to close is made. In our experience from Carlslund there was an unexpected decision which staff and families read about in the newspaper. That, of course, brought about a sudden reaction filled with anxiety.

Since 1986 there is new legislation in Sweden that says that all institutions must be closed and replaced by group homes in the community. Naturally this will take a long time. That should make reactions in the future much calmer. When we today talk about closing an institution some people say: "Good, at last more resources for these persons with handicap, but prove it first". Others say: "Impossible". But perhaps the most common reaction is not to bother, a silent belief that there won't be any closures anyway.

Following the decision to close the institution, there is much planning to be done. Perhaps it takes some years until it is clear that the closing of the institution is to become a reality. There is a period of denial. It is important that the decision is made clear and that it is not doubted by the politicians or other leaders in the organization. Otherwise the period of protest and denial will be longer than necessary.

The most important carrier of information is reality itself. When more and more retarded persons move from the wards to group homes it then becomes obvious to the staff that the institution will be closed. This is not a question of intellectual knowledge. The staff may have heard the facts for years. It is instead a question of believing and accepting.

This insight seemed on some wards to be a group reaction which came at different times on the different wards. We could see it on the last ward first ten years after the first decision to close the institution. Several wards had already been closed and there were less than a third of the retarded persons left at the institution. There was suddenly an increased anxiety among the staff and many of them wanted at that time to quit. Some of the staff will lose their involvement while others will be even more engaged and now see a real meaning with their job.

Two different types of reactions connected to the two dimensions of the closing can be seen. First reactions as a consequence of seeing the closing of the institution as an organizational change. This means that the staff will lose their job, colleagues will disappear, groups will be split-up, retarded persons one has known for a long time will move away etc.

Feelings of separation and fear for the future are common. Many of the staff are deeply involved in the lives of the retarded persons for whom they work. Sometimes they stay on the job only to make sure that "their" retarded person's last months at the institution are positive and that they are well prepared to move to a group home. Sometimes they have strong feelings of anxiety about separation. Maybe many of the ordinary staff members have already left. In time there is a risk for resignation. One of the staff could tell how she just didn't care anymore when her best friend on the ward decided to quit her job.

In this phase it is important that staff do things together. It can be to arrange parties or to fix something on the ward. The organization must be flexible and sensitive so it can respond to staff initiative in order to keep an increasingly split group of staff together. Most important is that the staff as soon as possible get some guarantee for the future and information about where they will work after the institution is closed.

The other category of reactions is connected to see the closing of the institution as a consequence of an ideological change. The staff will experience the criticism of the institution as criticism of themselves. Some will feel incompetent or a failure while others strongly oppose the changes. Their natural refusal to accept that they have done a bad job makes it more difficult to accept the new ideas. The feelings of failure will be even stronger if the retarded persons seems to have a good, or even better, life since they moved.

Many rumors can also be spread about failures in the closing process. This reaction was particularly apparent in the beginning and was underlined by the fact that the staff in the group homes felt themselves to be superior as they represented a better form of care. This, of course, is not the truth.

Perhaps the most important educational task during the closure period is to help staff see the difference between their work and the conditions for their work. To make the staff see that they quite possibly did a good job under the prevailing circumstances. What was wrong and what is criticized is the institutional structure and the conditions the institution provides for the staff to work in. When the staff understand this difference, the closing of the institution will be a little less threatening and it will be easier to discuss the problems that need to be solved.

The staff in the group homes must also be given information and education about institutional conditions. They need to be informed about the differences between institutional and integrated services and how these effect the retarded persons and the staff.

There must be a ambition to get the staff at the institution and the staff in the group homes to cooperate in preparing each individual who is going to move. Otherwise there will easily be unnecessary conflicts, if for example the staff in the group homes does not think they have anything to learn from the staff at the institution. The retarded person's life history at the institution is a mixture of good and bad experiences and as a part of his personal history it must be treated with respect.

The different steps that must be taken to help the staff, the families and the retarded persons through the changing process can be expressed in three points.

Information and education
What will happen, how and why must be explained in different ways. Especially for the staff and the families it is important to know about the

background, the history of care, and for all to know what the alternatives are and what the future will bring. As the closing of the institution is a process it is impossible to foresee it all from the beginning. Therefore, information must be part of a continuing process.

Support

The people affected must be given opportunities to express their feelings about what is going on and to receive help and support. For the staff it has not always been convenient to talk about their own feelings and their own anxiety. If they do not have opportunities and are encouraged in this it is probable that they will project their feelings but as an expression of what they consider best for the retarded persons.

Participation

The most important goal for the changing process is to provide services in the community based on the retarded person's own terms and related to each individual's needs and wishes. If the retarded person has difficulties in speaking for himself, those who best can interpret his needs and wishes are the staff and the families. Therefore, besides the retarded persons themselves, the staff and families must be given realistic opportunities to participate in the planning as many circumstances, interests and needs must be considered.

This may be a new experience which is of value even for the staff's own sake. This is not an easy process and I am sure that the goal cannot be reached during the closure period but it is a step in right direction.

DAILY ACTIVITIES IN THE LOCAL COMMUNITY

Ingrid Nilsson

INTRODUCTION

This paper presents results from an investigation aimed at studying what happens at a small day activity center during its first three years of existence. The focus of the project is on societal participation for the intellectually handicapped persons, and on social processes generated by the existence and localization of the center.

The 1985 Act about special services for persons with intellectual handicap (SFS 1985:568), is more than any previous law based on the normalization principle (Nirje 1969). It has as its main goal that the persons in question should be given the opportunity to "live like others, together with others" (SFS 1985:568). The special services, which are voluntary, should be based on individual needs and preferences.

Special services to persons with intellectual handicap are normally provided through the county council. This new law, however, makes agreements possible between the county council and the local district council, about the distribution of responsibility for the special services. The local district council has a basic responsibility for all the residents in the local community, including handicapped people, stated in other laws (SFS 1980:620).

As a special service during daytime, the law specifies day activity centers or other daily activities. This means that day activity centers should be available to those persons with intellectual handicap who cannot get employment through ordinary channels on the labour market.

Activities provided at a day activity center vary a lot depending, for example, on the kind and degree of handicap of the persons attending the center, and on conditions in the neighbourhood. The activities often include textile printing, carpentry work and piece work (sorting, packing, etc). They also may include adult education of various kinds.

A person attending a day activity center does not get a salary. He is considered a retired person and therefore has his pension, irrespective of whether he participates in any activities during the day or not. However, he receives a small payment, "habilitation money", which is worth about SEK 400 (USD 65) per month, if attendance is fulltime. This payment is reduced in relation to the person's absence from the center. The activities at a day activity center are mostly organized in small groups and has been formalized as a tool in pedagogical models (Walujo and Malmström 1983). In a small group the individual becomes visible, even if he may have limited abilities to express himself. A small group, consisting of 3-6 persons, is for many persons with intellectual handicap an optimal number in a complex environment. He or she may feel safe there.

The term center is somewhat misleading, because it seems to emphasize the house rather than its content, i.e. the activities going on there (Ericsson 1979). As a consequence, new centers are often built to contain all kinds of activities within the building. This leaves few reasons to search for suitable activities in the surrounding neighbourhood. Thus, there is a risk that the activity center becomes a mere segregated institution rather than a base for integrated daily activities.

The fact that the centers are the responsibility of the county council, probably does not make an extended integration easier. Neither the staff, nor the persons attending the center are necessarily living in the community where the center is located. They often do not know people living there and are seldom familiar with the neighbourhood.

If the local district council was responsible for the day activity center, it would follow that only persons living that particular community would be allowed to attend the center. Further, the majority of the staff would probably be recruited among the local citizens. In addition, it is assumed that the local district council, because of its knowledge of the community, its citizens, and local businesses, could assist in the search for suitable daily activities within the local community.

Based on the law and accumulated experiences from day activity centers in Sweden, a model is proposed (Ericsson 1987) which in the present context contains the following: (1) daily activities should be based on individual needs and preferences, (2) daily activities should be provided during normal working hours, (3) daily activities should be construed so as to give access to normal working environments, (4) daily activities should take place in the local community where the person lives, (5) daily activities should be organized in small groups, (6) the distribution of the responsibility for a daily activity center should be stated in an agreement between the county council and the local district council.

The purpose of this paper is to present some results on the accessability of normal environments for persons attending a small day activity center, under the auspices of the local district council. The following questions are to be answered: (1) Which environments do they have access to? (2) Does the accessability change over time, and if so, in what way?

METHOD

The local community

The local community in question, Lidingö, is an island due east of the city of Stockholm, with about 39 000 inhabitants. The mean income is above and the income tax below the average in Sweden and in the county of Stockholm (Official Statistics of Sweden, 1988). Politically, there is a non-socialist majority in the local district council.

The day activity center

The day activity center is under the auspices of the local district. The agreement between the county and the local council states that the social services authority in the community has responsibility for the activities being provided, the staff, the premises and the equipment. The county council provides the money that is needed, decided upon in an annual budget (the center is not, however, allowed to cost more than the average costs at any other center of the same size). It is also stated in the agreement that the supervisor of the activity center has responibility for integrating the persons at the centre into the society.

The day activity center is located in a service building with apartments and special facilities for elderly people and persons with handicap. There are about 150 residents in the building, where there also is a reception desk, a cafe, a restaurant, and nursery centre for preschool children. In the neighbourhood there is a small shopping center with post office, a bank, a couple of grocery stores and some other shops.

At the beginning the staff consisted of 3 persons (all female) and today the number has increased to four (3 females and 1 male). The mean age was 42 years in 1985 and 39 years in 1987. All but one of the original staff members are still working at the center. The manager of the center is an occupational therapist.

The center was originally planned for 11 persons with intellectual handicap. Six of them arrived in the spring of 1985 and the rest of them throughout the following winter. At the end of 1987 the number of persons attending the center had increased to 14.

Persons

The subjects in this study are the six persons who have attended the center since its opening in the spring of 1985. There were 2 females and 4 males. The mean age was 28 years in 1985, and, accordingly, 30 years in 1987. The degree of handicap could be regarded as ranging from moderate to mild retardation. All but one speak with full sentences but only two are easy to understand. Four of them can read. Half of the group have additional psychological problems, such as stereotypic, autistic or aggressive behaviour. No one has any physical handicap. In 1985 four of the six persons lived with their parents, and two lived in small, integrated group homes. In 1987 the situation was the opposite: only two persons still lived with their parents, while four lived in group homes.

Procedure

The staff were asked to record, for each person, all visible contacts (greeting, talking to, etc.) with people not connected with the center, during one, more or less randomly selected, week. With whom was contact made, under what circumstances, and in what situation?

This procedure was repeated once each year. The whole period of registration spanned over about two weeks each year, due to the fact that no member of the staff could make registrations of more than one person at a time.

There is, however, a major problem with this method. The persons cannot be under observation all the time, because most of them often go errands or take a walk on their own. What is recorded must therefore be regarded as an underestimation of the contacts actually taking place. Due to this unreliability, it was therefore impossible to report the frequency of social contacts occuring during one week. What is reported in this paper, is merely what kinds of contacts these six persons have had and in what environments. These results are displayed in sociogram.

RESULTS

Figure 1 displays the results of the registrations in the spring of 1985. The innermost box represents the day activity center. The next box represents the building where the center is located. The next box is a representation of the nearest neighbourhood, that is, the shopping center. The outermost box indicates the border of the local community. The elipses represent the various environments where social contact has taken place. The lines display

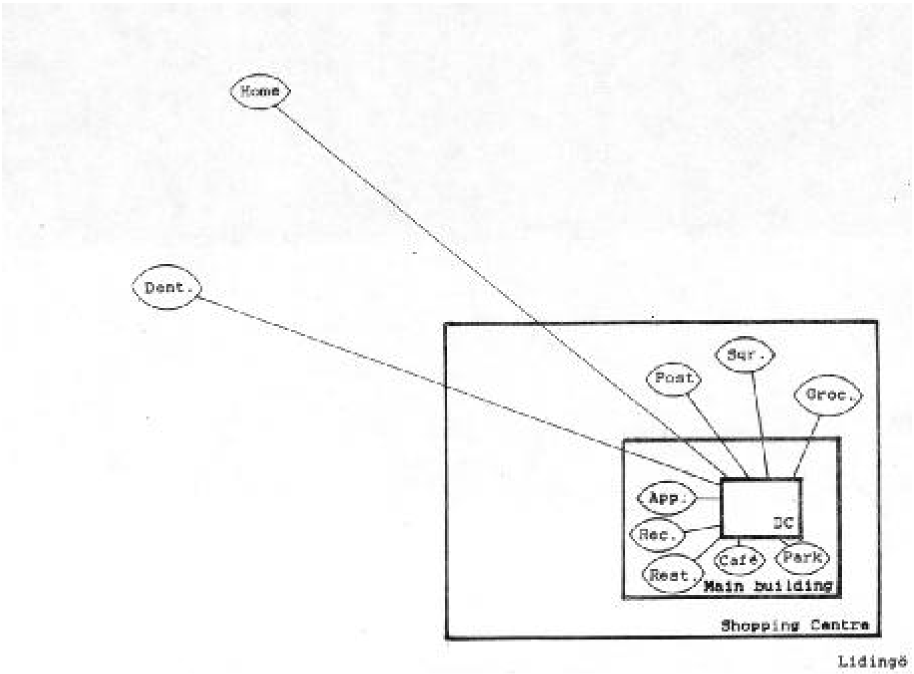


Figure 1. Sociogram of the social contacts occuring during one week in the spring of 1985, in the group of the six persons attending the day activity centre in Lidingö since its opening.

connections between these environments and the place where the persons have their main activities.

All subjects had their main activities at the center in the main building. These activties consisted mostly of sewing (e.g. curtains for the center and the restaurant) and piece work. As can be seen in the figure, contact took place at five places in the building during that particular week: in an apartment in the building, at the reception desk, at the restaurant, at the cafe, and in the park surrounding the building.

There were also contacts taking place in the surroundings, that is in the local shopping center, in the square, at the post office and at the grocery store. There were also contacts taking place at two places outside the nearest neighbourhood, in the home of one of the staff members and at the dentist's.

As can be seen from figure 1, most contacts are concentrated to the main building.

Figure 2 displays the results from the autumn of 1986. All persons still had their major activities, mainly textile printing and piece work, at the center. As can be seen in the figure, the contacts in the main building took place in about the same places as before.

In addition, contacts took place in a hobby-room in the basement. Contacts also took place in the shopping center, at the grocery store, at the post office, at the tobacconist's and in the square. There were also contacts at five places outside the nearest surrounding, at a cafe, at an afternoon home for school children, at the dentist's, at the ice hockey rink and at the doctor's.

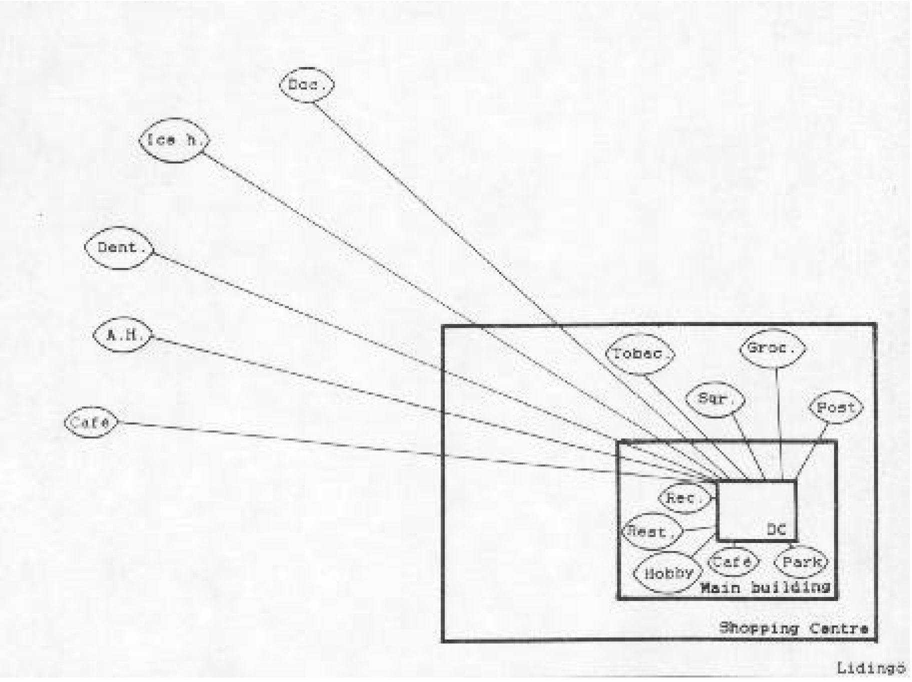


Figure 2. Sociogram of social contacts occuring during one week in the autumn of 1986, in the group of the six persons attending the day activity centre in Lidingö since its opening.

As is seen from the figure, although the pattern of contacts are similar, there were more contacts spread over a wider area of the neighbourhood, not just in the close proximity to the center.

Figure 3 displays the results from the registrations in the autumn of 1987. First, there are four more boxes in the figure. They represent places where some of the persons have their major activities.

At the hospital the task is to distribute the mail. In one of the two public relations firms (1) the task is to go errands, to answer the telephone, to make coffee, and so on. At the other firm (2) the activities includes sorting, packing and printing. The handcraft group is a mobile group aimed at doing repair jobs on community property.

Second, the encircled numbers within the boxes indicate how many of the six persons, attend each place. Third, the small circles within three of the boxes represent work mates, that is, persons normally working there.

The persons having their activities in the places represented by the two boxes to the left in the figure, are there half of the time, the other half at the activity center. At the places displayed by the three boxes to the left, there are no staff member from the activity center present all the time. They visit these places regularly, perhaps a couple of times a week, depending on the amount of support needed. The handcraft group has its own group leader.

As can be seen in the figure, the one person, still at the activity center, had contacts with other people at two places in the building, in the reception and in the restaurant. This person had no contacts in the nearby surrounding during this week. However, he visited a restaurant outside the local neighbourhood.

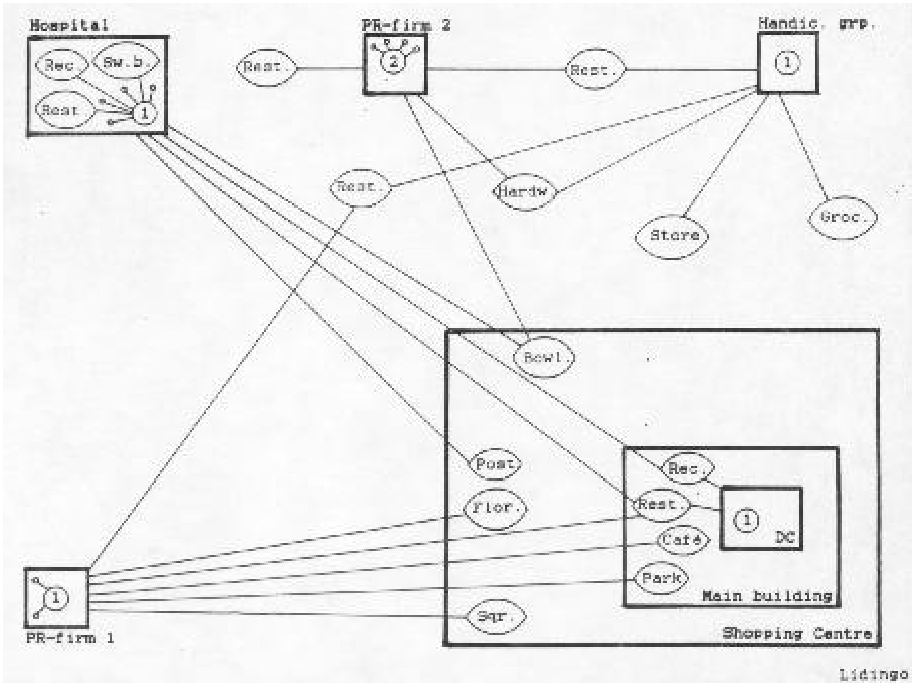


Figure 3. Sociogram of social contacts occuring during one week in the autumn of 1987, in the group of the six persons attending the day activity centre in Lidingö since its opening.

The two persons with part time "jobs" at the hospital and at one of the public relations firms (1) had both contacts in the building where the center is located, at the reception desk, at the restaurant, at the cafe and in the park. These two persons also had contacts in the neighbourhood of the center, namely at the post office, at the florist's, in the bowling alley and in the square. One of them also visited a restaurant in another area.

In addition, the person at the hospital met people when distributing the mail to the restaurant, reception desk and to the switch board of the hospital. These two persons also had contacts with work mates.

Neither the two persons at the other public relations firm (2), nor the person in the handcraft group, had any contacts in the main building of the center. There were almost no contacts in the shopping center for these persons, except in the bowling alley.

These persons, both at the public relation firm and in the handicraft group, made contacts mainly in other parts of the neighbourhood for example at various restaurants, at a hard ware store, at a store room and at a grocery store. The persons at the second PR-firm also met work mates.

As is clear from the figure, the main activities for most of the persons have been moved from the activity center to places all over the local community. This has also changed the character of the social contacts, from primarily being in the neighbourhood of the center to inside and outside these new environments where the activities now take place.

DISCUSSION

To summarize, the persons at this particular day activity center had access to environments of three kinds, namely the building where the activity center is located, its immediate surrounding and other parts of the local community. The contacts which have taken place have changed, from occuring mainly in the close neighbourhood of the activity center, to other parts of the local community.

In what way are these results specific to this particular day activity center? There are at least five conditions basic to this question. Firstly, the original agreement between the county council and the local district council stated a main goal for the center, namely integration into the ordinary society, a goal to which the staff were "socialized" right from the start.

Secondly, all the staff members live in the local community of Lidingö, and are therefore relatively familiar with the community. Thirdly, the parents of the persons attending the center are very much involved in the center. There are regular meetings, twice a year, for parents, and they phone the center very often. They very emphatically demand information about what is going on, and some of them forcefully protest when they dislike what is going on. This is not the case at most ordinary day activity centers, where the parents usually play a less active role.

The fact that the center has been part of a study during these years has, of course, had an impact on the results. this can be seen as a fourth aspect. It has given the staff opportunities to think more about integration and participation in the community and perhaps they have more actively strived to accomplish this goal, than they otherwise would have done.

The intellectual handicap of persons in this group is not very severe. However, several of them have pronounced psychological problems. This can be seen as a fifth aspect.

In what way are the results specific to this particular local community? First, as reported in the section on the method used, Lidingö is a very wealthy community. This is a place where the successful people live, people for example in big business and showbusiness, people who normally get what they want, and make sure they will get it. The parents, for example, have, for a long time, strived to get a day activity center in their community, and have been very much involved in the planning of the center.

They also had influence over the decision that the center should be under auspices of the local district. One representative for the parents participated in the group making up the agreement between the county and the local council.

Second, the local community, from the beginning, showed a great interest for cooperation with the county council. In fact, the idea that the day activity center should be run by the local community was initially taken by the head of the local social service department.

Does a day activity center have to be run by a local authority in order to give persons with intellectual handicap access to normal working environments? The county of Stockholm is a very large county, as regards the population. The geographical area is, however, not so large. To make provision of special services to persons with intellectual handicap more efficient, it is possible for the county council to place persons in day activity centers, where-ever there is a vacancy, regardless of where the person lives.

In a geographically large county, with a small population, with long distances between the populated areas, this cannot be done, unless the person also moves into the new area. Furthermore, where there are long distances, the staff have to be recruited among people living in the area, or among people willing to move there.

With these circumstances being taken into consideration, it would not be impossible to organize daily activities elsewhere, along the same lines, in order to make available normal environments in the local community.

THE EVERYDAY LIFE
AT THE LARGE INSTITUTION

Stefan Lycknert

THE RESIDENTIAL INSTITUTION

Since 1980 I have worked as a psychologist at a large residential institution in Stockholm county, where adult persons with intellectual handicap are living. This presentation is based partly on experiences from this work but mostly from experiences gained from an extensive inventory I conducted on the everyday life of those living in the institution.

At the time of the inventory 169 persons with severe to mild intellectual handicap were living in the institution. It consists of seven pavilions, each with up to four wards, located in attractive grounds with lawns and woodland. Both pheasants and deer can be seen in the fields during the summer months.

There are up to 8 residents (R) on each ward, each with a total of 12 staff (S). About 450 permanently employed staff work there. The residents can attend the day activity centre, located within the institution, up to 5 times a week. Leisure time and recreational activities are well developed. The general policy is to create as homelike an environment as possible for the residents.

Describing the everyday life

The inventory describing the everyday life at the wards of this institution comprised of 169 structured interviews, each interview covering one resident. Participants were the staff who best knew the resident. Each interview took 1.5 to 2 hours. It took approximately one year to carry out the inventory.

The material includes a lot of information about the person. Apart from information on background, e.g. category of handicap, there is material concerning the residents' contacts with people in their environment. The communicative ability describes the person being active or passive in contact and in his social relationships. Activities with residential staff, respective R's relation to his / her own staff, is also an illustration of this.

Information on behaviour with regard to the everyday activities of a home, whether one participates actively or passively in household duties, is also described. This also goes for self-initiated activities. The expression "a varied day" is intended to describe variations during the day.

There is also information on contacts with the surrounding community, for example people who are met daily, contacts with various establishments in the community, means of transport etc.

Finally, the staff were asked to describe what they personally wanted to be done for the particular resident.

RESULTS

In order to give a summarizing picture of life in an institution for persons with a severe intellectual handicap I wish to return to the expression "a varied day".

The staff were asked to record, in every detail, for the contents of a day specific for R. It was to be an ordinary week-day when he spent the entire day on the ward, not attending the day activity centre. Information was recorded on a time chart covering all of the day. This meant, as with the inventory on the whole, that staff for a moment came very close to the person being observed and saw them from a new perspective. "Just think, he's sitting there on the sofa all day long -one doesn't really think about it when one is busy all the time with practical matters".

Afterwards, impressions from the entire day as illustrated on the time-chart have been put together. There one can find information reported on variations in his position and what was regarded as physical variation on the ward. It is also clear what changes occurred as regards social activities, self-initiated activities and periods of rest, that is to say, if staff made any special offers and the extent to which R is capable of making use of opportunities that arise. Finally there is a description of how great a part of the day is characterized by waiting.

Five categories could be formulated regarding the degree to which the day had a varied content for the individual. Two alternatives which expressed lack of variation are termed "a day without variation", here labelled (- -), and "a day with limited variation" (-). There is also a neutral category where it has not been seen as purposeful to term the day as varied or not (0). When some variation occurred it has also been expressed in two categories "a day with some variation" (+) and "a day with varied content" (+ +).

The persons observed have also been categorized according to degree of their intellectual handicap. The three categories are severe, moderate and mild intellectual handicap. There is also a fourth which includes persons who are regarded as psychotic or having such physical or psychological additional handicaps, that a judgement of their intellectual handicap has not been possible.

	Degree of variation of day at ward					
Degree of handicap	-	- -	0	+	++	Sum
Severe	30 (41%)	21 (28%)	11 (15%)	7 (10%)	4 (5%)	73
Moderate	4 (10%)	5 (13%)	10 (25%)	17 (43%)	4 (10%)	40
Mild	5 (25%)	4 (20%)	1 (5%)	6 (30%)	4 (20%)	20
Undecided	17 (53%)	6 (19%)	6 (19%)	3 (9%)	0 (0%)	32
Sum	56	36	28	33	12	165

Figure 1. The relation between degree of handicap and the everyday life at the institution. Percentage in each row represents the distribution within that sub-group.

As can be seen from the figure the final column presents the groups according to category of handicap. Only a minority of the group, 20 persons, have a mild intellectual handicap. The remainder have more severe forms of handicaps.

As regards the variation within each group the results show that the majority within the group with persons with a severe handicap, 69%, have a day characterized as lacking in variation or which is varied only to a slight extent. Half of those with a moderate handicap, 53 %, seem to have an acceptable degree of variation during the day.

The reason why there is no clear tendency for persons with a mild handicap is probably connected to their age variation. Some of them are very old, at the same time with a dementia, whereas others can vary their day and make use of all the opportunities available.

The institution is not able to give those who are psychotic a varied day. 72% of the persons in the fourth category experience a day with limited variation.

Finally one can say that the institution, as a form of service, seems suited for, or at least shows an ability to give persons with a moderate handicap a daily life with variation as characterized in this study. For other groups of persons, those with severe handicaps or the psychotic, the institution is a less satisfactory form of service.

EXPERIENCES

When I got the information from staff about the residents, I was struck by the way they spoke about them. Figure 2 is intended to exemplify the choice of words used. A person with severe intellectual handicap is often spoken of as "my son/-daughter". The staff address themselves as "ward parents" for R. The expression "ward parent" is a general term used throughout the institution.

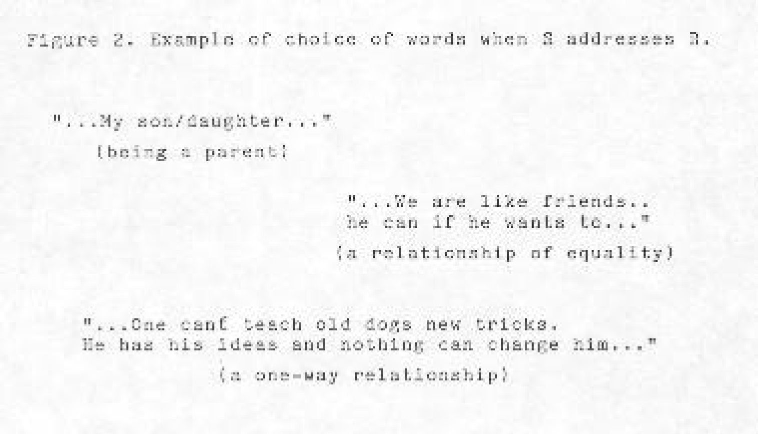


Figure 2. Example of choice of words when S addresses R.

"...My son/daughter..."
(being a parent)

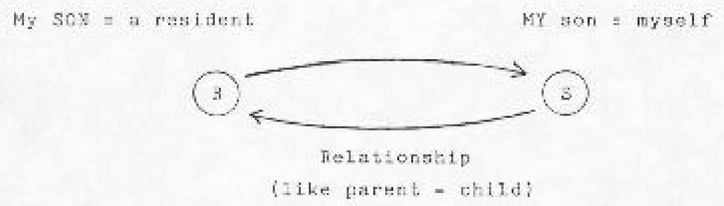
"...We are like friends..
he can if he wants to..."
(a relationship of equality)

"...One can't teach old dogs new tricks.
He has his ideas and nothing can change him..."
(a one-way relationship)

If the resident has a moderate or mild intellectual handicap one can hear staff say "in a sense its like being friends (a relationship of equality: my comment)..... he can if he wants to". If the person has a mild intellectual handicap or is older, as the mildly handicapped often are at this institution, a conversation can often end by saying " one can't teach old dogs new tricks. He has his ideas and nothing can change him".

The term "my son / daughter" has an important message. What one is then saying, as I understand it, is partly my SON, that is to say the person with intellectual handicap (R) and partly MY son, that is to say, I myself (S). One describes a relationship, as that of parent-child, as is illustrated in figure 3.

Figure 3. What one talks about.



If one presumes that the person with intellectual handicap psychologically is at an early developmental level one can expect that the relationship / exchange between R and S will activate a caring pattern which at a deeper level is comparable to other relationships between a person at an early and another at a late level of development.

I am thinking of the relationship Mother - Child (M - C). The relationship Staff - Resident (S _ R) does not, for natural reasons, have the same unique qualities. This caring pattern, or type of relationship which activates, includes the symbiotic "suck", which also can be expressed in contradictory terms "... it is not wise to get attached to R, more than anyone else, as it would only hurt him if / when I leave ...".

I believe that many working within these services struggle with this dilemma. It can be described on the one hand, if I exaggerate somewhat, as giving up ones own needs and on the other hand feeling guilt for relinquishing the needs of the other. One can speak of a continuum, nearness-distance, or within-outside the private sphere. Finding a constructive balance between nearness and distance can be difficult.

What I am speaking about is the first dilemma which can be summarized as the difficulty of finding a constructive balance between nearness - distance vis avi C at an individual level. What I describe is however part of the dynamic field on which services are borne. My intention is not to present the moral aspects of the concepts nearness - distance, as it is not always desirable to acknowledge "the suck".

As an example I will take the very beautiful young girl who on one occasion took part in an introduction course held at the institution. She had been employed a few months and fought a heroic but losing struggle to be accepted as a "weekend parent" for a person with severe intellectual handicap who lived on the ward where she worked.

That this can occur I believe has its explanation in the fact that the relationship between C and P resembles that between M and C but does not have the same unique quality. I think one can speak of a shift - at the time of placement at the institution - from nearness in an original relationship to nearness in another relationship which, to begin with, is much more general in nature.

The difference can be expressed as follows: " Rosemary, just like her grandfather, has a birthmark behind her ear ..", that is to say the personal as regards belongingness and as a sign of a unique relationship. The following is the contrast: " Rosemary is physically handicapped and requires a heavy lift ..", - the general as an expression for a common relationship. The person in question is perhaps more dependent on C, than C is on her.

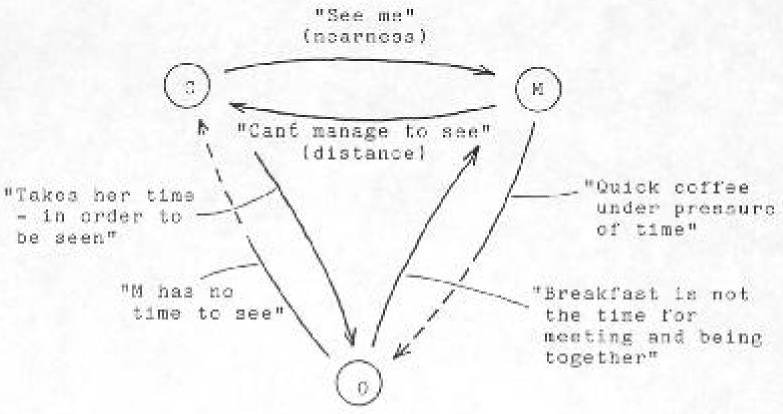
It is of particular interest to try to see how the characteristics of the interaction / exchange reflects on the outer world that is to say how we arrange situations and daily life for ourselves, and the opposite, how it in turn influences relationships.

An example - the breakfast

An example acts as a model to show how this can occur. I have chosen the breakfast situation as a theme. M lives with her daughter C. C often has stomach pains and is "difficult" in the mornings (figure 4).

M has recently begun to feel more and more tired and depressed in the morning.

Figure 4. Breakfast with M and C.
(O= the outer world= breakfast as theme:
a complex event with sequences which both share)



She has no time for herself and knows that just now she cannot cope with giving C. the attention she demands. She has a gnawing sense of quilt about this and the mornings are always rushed.

What happens can be described in the following way: C does everything possible to be seen and given attention by M. But M's own needs prevail and she can't manage to see. At the same time or parallel M. declares breakfast to be " a quick coffee under pressure of time", which reduces the time available: " Breakfast is not the time for meeting and being together / M has no time to see .." C responds by "Taking her time - in order to be seen.." M says at the same time "There is no time to be difficult ...".

What M is doing, in interaction with C, is sorting out her behaviour towards the outer world (figure 5). Partly she is communicating with / to C and partly arranging the breakfast scene in a specific way. C is affected in that there is no time to be seen and M places responsibility beyond herself. She says "There IS no time.."

If M should stop and regard the situation she would hopefully see that she is the primary "motor" to changing the situation - the division of responsibility is clear - but she cannot cope with it right now. And she feels guilty.

If one projects this situation to breakfast time on a ward one finds that circumstances are different, the outer conditions are different. The size of the group makes the division of responsibility unclear. If S then, because of the character of the relationship, (see the first dilemma) cannot manage to see, then the collective, the group, can be characterized as in the example above.

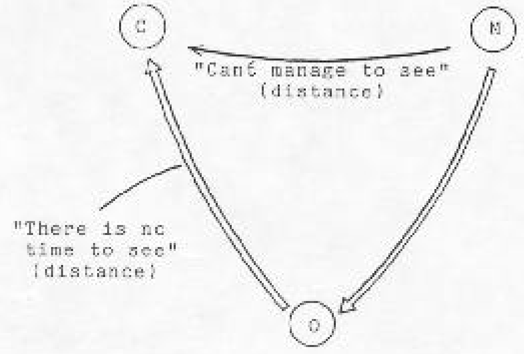


Figure 5. M sorts out her behaviour towards the outer world.

But where, or with whom, the "motor" to change lies is difficult to know. The question can lack interest for the actors, or it can be a matter which lies beyond the group, right or wrong, for example with the administrators. " I can't do anything about it.., IT has always been like this.." Rules, habits and routine can tend to acquire a general validity as unchallengeable and lacking in personal responsibility. This becomes a barrier for developing the nearness which is being sought.

An illustrative example are the old ladies who, at every meal-time, queue up at the kitchen door. They don't need to, but they have always done so. According to the staff they could take part in preparations, but they want to stand there and in that way they simplify the job.

In this way there is always the risk of "gliding" from nearness to distance in relationship to R in many of the themes of everyday life, a tendency reinforced by the habits and routines within the institution, partly influenced by the historical background that the individual is regarded more as an object than a subject.

It is difficult for S to know what limitations are set by outer conditions. This is a dilemma, the second dilemma. And as with the first, and the example above, I think it is not uncommon that staff reproach themselves even if they verbally put responsibility on the system. In the imagination there are always unlimited resources. This can also take the expression as follow: the staff maintain that there is always money for extra staff in a time of crisis, while the manager of the institution claims the opposite. Or the work leader implies that staff could achieve more if they wanted to, if they were prepared to make an effort. The outer conditions must be clarified.

The second dilemma can be summarized as the difficulty of finding a constructive balance between nearness and distance at a structural level.

If we now return for a moment to the parallel M - C and that relationships relation to the environment, the following can be said: in her actions M involves herself in undertakings which for C and M concern matters beyond their relationship and which reflect on it. Example: "The fine tablecloth is always used on special occasions. C is there and feels the cloth." The tablecloth as bearer of experiences which unite and confirm the unique and private in the relationship - to belong to - and at the same time being a theme for dialogue.
The same ambition to manifest belongingness exists on the ward. Like the staff group on a ward who want to have special china with a blue pattern instead of

using the plain white china of the county council. But the usual thing is that money is over on the equipment account: "..we have money over, why not buy a new tablecloth. The one who bought it has left. What bad taste she had ..".
The cloth as an expression of feelings but with the risk of being short-lived as staff-groups come and go, as do things. Perhaps R had experienced the cloth for many years but for S it was relatively new and had no significance other that it was unmodern and should be changed. Thus things - material things - and even habits, as active parts of the fabric of events which bind together and indicate belongingness perhaps do not include R to the same extent as his staff. The staff group, like a newly made family, wants to acquire new things and habits. The pattern of non-permanence in relationships characterizes the fabric.

If the example of the beautiful girl can exemplify what happens when, or as a consequence of, a shift from the private to the general sphere at individual level, then the example of the table-cloth is intended to illustrate the phenomena at a structural level, based on another shift. Namely that from a societal belongingness to non-societal belongingness, that is to say living in isolation within the total institution.

From what I have said I see it as being our task to encourage good relations between persons - the first dilemma - and to encourage a normal pattern of life generally - the second dilemma - which implies that a ward should be regarded as a home. That the pattern of daily life which is developed there should as far as possible resemble a normal life. In other words, scrutinize the themes that build up everyday life, e.g. breakfast. Themes which divide up the complex of events, or sequence of events, in which the person with intellectual handicap actively or passively participates.

The inventory which I carried out gives a very good picture of the pattern of life in the institution.

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