

**DEVELOPMENT AND DISSOLUTION  
DURING THE NORMALIZATION PROCESS**

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## 1. THE NORMALIZATION PRINCIPLE OF 1946

### **Persons with handicap in the welfare society**

The change from an institutional system, where care was provided in residential homes, to community services provided through housing, in employment and through life in the community, has its roots in the welfare society which has been under development since the 1940:s. Its creation gave rise to new means of providing support and service to these persons. A more modern system of social services had to be developed if the idea of the welfare society was to be realized. This, parallel to the institutional service system, gave society two ways of channelling its support to persons with handicap (Ericsson 1985, Ericsson 1986, Ericsson 1987).

As a result of the debate on the nature of the support of society which took place at the beginning of the 1940:s, "The Committee for the Partially Able-bodied" was given the task of finding the forms of support to persons with handicap, that they were to receive welfare and a good life. They began by discussing the services of persons with handicap in relation to the welfare society.

### **The Committee for the Partially Able-bodied**

On many points the committee was critical of the care being provided for the partially able-bodied in residential institutions. It was thought that responsibility was only being taken for those already cared for in the institution while no concern was given to preventive health work, something which was considered necessary by the committee. They were also critical to the coercive system represented by the institutions and the patriarchal view which characterized attitudes to persons with handicap (SOU 1946: 24).

On the basis of their criticism of institutional care, and a vision of new opportunities for service in a welfare society, the idea of the committee was that the partially able-bodied should also have a right to avail of the services being established within the framework of the welfare society.

### **The normalization principle of 1946**

The view of the committee on these persons right to avail of the services of a welfare society was expressed in their report (SOU 1946:24, p.28):

... a given principle, that the partially able-bodied should, as far as possible, be included in the ordinary system of social services, which is under development in our land.

In order to realize this it was considered important that the support of society be built in such a way that it be available for all:

The institutions of society must be adjusted so as to justly, and preferably in context, include all individuals, irrespective of whichever category they belong

One also reckoned that this would have positive consequences for the persons concerned:

Psychologically 'normalization' of living conditions, education, employment support etc. for partially ablebodied persons, is surely a great advantage

That the welfare society should also take responsibility for persons with handicap was, according to the committee, an expression for

... a civic basic demand: it is in entire accordance with the essence of our democratic concept, that equal human values and their equal rights be placed in the foreground

In these quotations a socio-political idea was expressed which was termed the normalization principle (Kommittén för partiellt arbetsföra, 1949):

'The normalization principle', as prescribed by the committee, proposes, amongst other things, that special institutions for the partially ablebodied, for education, training, etc. should be the exception, not the rule.

This implied that a stand was taken for the normalization of the conditions of life for persons with handicap, a policy which should be pursued as an alternative to living a life separated from the lives of those without handicap. The means of achieving this was through the development of modern social services, within the framework of the welfare society, which were accessible to all persons.

The motive of the committee for their normalization principle, the right to avail of the services of a welfare society, was based on these persons' democratic rights. It was considered a basic civic demand that they had the right to avail of the same support offered the citizens of a welfare society. This motive should be seen in the context of the socio-political ideas formulated in the mid-forties, at the end of the second world war, in a period of democratic and economic optimism.

The committee did not refer to any special group among the partially ablebodied but included all persons with handicap, even the "feeble-minded", the expression used for persons with intellectual handicap. This idea, however, only applied to those with a mild handicap, who, as a consequence of receiving support could increase their productive ability and thereby their ability to support themselves. The policy of the committee did not include those with a more severe handicap, those termed "unfit for work". They were instead referred to "modernized institutional care" that is to say, to a continuation of the institutional system.

## 2. A NORMALIZATION PROCESS

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

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

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

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

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

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

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

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

desire for such a life becomes the starting point for the type of support offered (Ericsson 1986, 1992a, 1992c, Ericsson and Ericsson 1989).

### 3. INSTITUTIONAL CLOSURE

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

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

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

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

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

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

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

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

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

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

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

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

#### **On the closure of Carlslund**

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

In order to cope with the large need for places in this type of institution, a series of residential institutions were built all over Sweden, starting in the middle of the fifties, ending 20 years later. These were residential institutions for children and adults with a severe intellectual handicap, persons earlier called "uneducable" and therefore thought to be in need of the residential

institution. The original Carlslund was extended and modernized as the first institution in this series. It was therefore natural that Carlslund was also the first of the series to be closed.

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

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

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

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

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

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

### **Evaluation**

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

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

The great difference between institutional life and life in the community, is that these persons participate in daily activities outside the house. This was

something which was offered to only a few at the institution but it is a logical and natural part of community services. This is also a service available for all, even if some have chosen to stay at home during the day.

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

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

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

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

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

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

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

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



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

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

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

### **Some contributing factors**

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

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

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

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

One factor facilitating this change from institutional to community services, was knowledge about where the person was going to live after having left the

institution. When relatives and staff were informed about the house where the person was going to live, the more concrete view of the alternative to the institution enabled them to participate with less anxiety, and in a more constructive manner, in the process of change which was going on.

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

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

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

### **Experiences of institutional closure**

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

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

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

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

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

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

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

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

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

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

#### 4. TOWARDS A CITIZEN PERSPECTIVE

##### **Social roles**

In a study of the closure of a large residential institution (Ericsson 1994), a man who had moved to a new home told us, when interviewed about his new life, that he was very happy and satisfied. He had got a new home and new daily activities in the community which he once had left for the care of the institution. But when commenting on his new letterbox he said: "I got a new letterbox, but there is no name on it!" In Sweden when you live in a semi-detached house, you have a letterbox by the road, most often with your name on it. Naturally for the postman and visitors, but also for those passing by, to know who lives in the house. For this man it was also a sign of being visible and to have an identity in the community. He had come back to where he once belonged and he wanted to be recognized!

In the present change of societal support to persons with intellectual handicap, a system of institutions is being replaced by community services. Large residential institutions are being replaced by housing and premises for daily

activities, in those places in the community where others live. A physical-structural change is taking place. But the man's comment draws attention to the fact that this change has to do with more than mere physical restructuring of services. How can this aspect of the process of change, the fact that he had not become visible in his community still lacking an identity in relation to the world around him, be expressed?

In this comment the person with handicap becomes the focal point, how he is perceived by others and how he perceives himself. In a more general sense it also raises the question of the perspective from which persons with intellectual handicap are viewed, their role in society and the nature of the relationship between them and the world around them. One way of expressing this can be found in the analysis made by Wolfensberger (1969) concerning how social roles are associated with the organization of support of society. He found a relationship between the nature of these organizations and the social roles assigned to these persons.

When they at one time were regarded as "L'enfant de Bon Dieu" it was the church who took responsibility for these persons. When they were thought of as inhuman they were looked after in large institutions, often under inhuman conditions. The medical tradition of care coincided with the period when these persons were seen as sick persons, whereas when they were regarded as developing persons the educational and therapeutic professions were given greater influence over the formation of the support provided by society.

These represent a number of roles which have been ascribed to these persons, expressing different views and thereby different perspectives, from which one can perceive them and their needs. From one perspective one focuses on certain aspects, while other are not given the same attention. The aspects which are not focused on are not, however, denied. In this way perspectives differ from each other regarding what is given attention, and what is considered to be of interest and importance. With regard to institutional and community services, these roles and perspectives can be seen to express differences concerning the background of ideas. This comparison concerns itself with the shift of perspective associated with the ongoing change from institutional to community support.

### **The competence perspective**

When Swedish institutional services were originally established the boarding school was given a central role, as it was there that education was provided for those who were regarded as "educable". Those who were seen as "uneducable", were referred to the asylums. Two social roles, the pupil and the patient, were thereby attributed to persons with intellectual handicap and they have become a fundamental characteristic of these services. This was expressed as late as in the 1950s when it was declared that the two main tasks for the services was the provision of education and care (Ericsson 1995).

There are of course major differences between these two roles, but there are also similarities as they both express the view that persons with intellectual handicap are lacking in competence. Those regarded as pupils lack in knowledge, and are therefore in need of education, whereas those termed patients have disabilities, and are therefore in need of care. This lack of competence becomes a common characteristic for residential institutions, and comes into focus in this perspective. The idea behind the work being carried out at institutions, if it took place in a planned and purposeful manner and routine and resignation not allowed to bear influence, was to achieve an increase in competence for these persons. This was brought about through the main tasks of education and care.

In order to ensure that these persons really got the support needed to ameliorate this special lack of competence, provisions were made through special institutions. These offered not only what was thought necessary to modify their competence, but also other forms of services required. The traditional institution acquired the character of a miniature society where everything could be found that contributed to the well-being of the person. At the same time the ordinary community outside the institution was relieved of its responsibility for these persons. As they did not have the knowledge to meet the special needs of these persons, they were not seen as resources for the support of these persons.

At the institution it was regarded as natural that a resident would at some time leave the institution for a life outside. The goal however, was that this would take place when the person was competent enough to meet the demands made by the ordinary community, without support from others. Those who were able to meet these demands were allowed to move, whereas the others had to remain behind. It was therefore natural that those with a mild form of handicap were the first to leave the institution, while those with a more severe handicap had to stay. In the competence perspective there is therefore an aspiration towards community participation, but its realization will depend on the person, who by way of increased competence must qualify for participation with others, and to live the normal life (Ericsson 1994).

Today when community services are being developed and institutional services dissolved, a physical restructuring of services is taking place. It is not natural though that the competence perspective, emanated during the institutional tradition, is left behind. Often it is being brought over to community services (Ericsson 1992a,1993).

#### **A citizen perspective**

When looking for the origins of community services and the perspective associated with this tradition, one finds that they derive from the idea of the welfare society as it developed during the 1940s. It was during this period that the socio-political objectives for the support of society to persons with handicap changed. In Sweden this was expressed in 1946, in what was called the normalization principle (Ericsson 1985).

The original idea of this social policy was based on three components. With regard to the person with handicap, the intention was to create opportunities for more normal conditions of life than was possible within the institution. As a means of achieving this persons with handicap were given the right to the use of the social services, which were then under development as part of the emerging welfare society. These were the two components which were given most to attention and which were, to a certain extent, to be realized.

However, there was a third component in this socio-political idea, which was considered to be the underlying motive for reform. It was, namely, considered a basic civil right for persons with handicap to avail of the services provided by the welfare society. By thus viewing these persons as fullworthy citizens one also took a stand on the question of the role of persons with handicap in society. But to begin with this was something which applied only to those with a mild handicap, "the partially ablebodied" as persons with handicap were called at that time. Those with a more severe handicap were not originally affected. The developments which have followed during a 50 year period, have however, when it concerns persons with intellectual handicap, come to apply to all.

As the process of development away from institutional services, deinstitutionalization, originated in this socio-political idea, one can see that there exists a fundamental intention behind community services. If one takes this original vision of a social policy seriously, one finds the claim that not only new forms of support are needed in order to replace traditional institutions. They should also in their content be characterized by the idea of these persons as fullworthy citizens.

The basic idea of the role of the citizen is the democratic right to a life outside the traditional institution and the participation in community life. Thereby are the similarities recognized between persons with handicap, and the population in general, concerning human values and rights. This perspective focuses on persons with intellectual handicap as fullworthy citizens, with a right to the normal life and to experience the welfare, which others have the possibility to experience.

Against this background it is natural to emphasize that intellectual handicap is a normal societal phenomena and that persons who are bearers of this handicap belong to society in a natural way. This handicap exists as a consequence of man's initial conception, of his existence as a foetus, of being born and of a period of development during the early years. This course of events is a time filled with risks and some times it is being disturbed. The great majority are not affected, but there are some who are, and whose normal intellectual development becomes retarded. The size of this group may vary between cultures, societies, epochs and geographical areas but the group, however, does always exist.

A person is born into a family and comes therefore to belong to this family. In this way a person acquires his heritage and is bound to a wider circle of relatives. These have their roots in the community where the family grew up and the person with intellectual handicap will, as all others in the family, belong to this community.

With the understanding of the person as a fullworthy citizen, irrespective of whether he has a mild or a very severe handicap, follows the right to influence over his life. This can naturally be exercised by the person himself, but if the person can't express his requests, there are members of the family who can provide this support. There are also others who can be chosen as either a formal or an informal spokesperson.

As the purpose of support from society is to contribute to the person being given access to a good life, it is important that knowledge is acquired about the nature of the life desired by the person. The question of what sort of life the person wishes to live is therefore a key issue, to the understanding of his request for support. It should also be the starting-point for the choice of support to be offered by the service organization to the person. The life to be led by a person, needs therefore to be formulated and expressed by him, often together with his spokesperson.

The person's participation in community is, from this perspective, a civil right and a self-evident task for the services being provided. The extent to which this participation is realized will depend on the services received by the person. Are they adequate to give support for a life in the ordinary community to be a reality?

But what about the competence of the person? This is of course important even in this perspective. As for all others each has a reason for wishing to increase his competence through care, treatment or by improving his capacity by other

means, and this, naturally, applies even for persons with handicap. But when this does occur activities should be in relation to, and with respect for, requests by and integrity of the person as regards what aspect of competence, and what sort of means used for treatment and training (Ericsson 1994).

### **Autonomy and influence over personal life**

The question of autonomy over one's own life was not an issue within institutional services. In older institutions, with a patriarchal tradition, it was the head of the institution, as of the family, who made all decisions. When institutions were modernized and increased in size and numbers at the beginning of the 1950:s they maintained a hierarchical structure with centralized decision-making. The centralized service organization, also established during these decades, was also hierarchical in its organization responsibility being placed with central functionaries. As their task was to place persons in the facilities where services were provided, there was less opportunity for any form of personal autonomy.

The idea of a citizen perspective is based on the concept that these persons with handicap, as well as for all others, should have autonomy over their own lives. Of course there are obstacles and restrictions in a society which limit the realization of the visions of a good life of a person. The base remains though the same, the respect for each person's idea of what constitutes a good life for him. This applies of course also for persons with intellectual handicap, even if the handicap can restrict their ability to formulate and express their dreams and visions. The question of autonomy over one's life can therefore be said to be one of the most important distinguishing characteristics between these two perspectives.

In the early legislation which had given rise to the centralized and regional organization of services the issue of self-autonomy was not mentioned. During the legislation of the eighties this issue was, however, brought to the fore. It was there specified that the first step towards planning for support and service was to be the person's request for services, submitted by him or by a spokesperson with legal right to represent him. If a debate arises as to whether this request is legitimate or not, it is possible for both parties to have the decision tried in a legal court. The person with intellectual handicap is no longer someone who can be placed, but a partner in a discussion as to how his life should be shaped. The fact that this issue has been regulated by law indicates that the question of autonomy had formally been given a place in the services.

For persons with intellectual handicap the question of self-autonomy is naturally difficult to realize, these being persons who have difficulty in expressing their needs and wishes, and in asserting themselves. This can, of course, vary depending on the person's disability. It is therefore quite natural that a spokesperson should represent them if necessary. As a major task for a spokesperson is to relate to the organization which provides services, it is natural that they do not themselves belong to this organization. Members of the person's family, parents, siblings or others, can of course take on the responsibility of guardianship. It may also be provided by persons with special qualifications with regard to how one represents these persons in order to protect their rights and interests.

A change which may need to take place as a consequence of the citizen perspective can therefore be the development of the service organization, in order to create situations where the wishes of the person, perhaps through his representative, can be expressed in a natural way. In the group-home it is for example necessary to create conditions and occasions to discuss the way the

person wants to live his life, and its consequences for the running of the group home. It is also on these occasions that one needs to discuss the person's life in the community. These issues also apply to the services providing daily activities. As it is there responsibility lies for the activities available to the person, a forum is required where discussions on the choice of activities can take place.

This formal aspect of self-autonomy is not the only consequence of the citizen perspective. A more informal side concerns social relationships between the person with intellectual handicap, and his family, the public in general and the staff who provide the services. In order for the person to exercise personal influence, these relationships they must be characterized by openness, sensitivity and respect from those involved. This is not always the case in reality. Where there are shortcomings in this respect a citizen perspective will give rise to new demands being made on the persons concerned, requiring them to change their pattern of behaviour.

## 5. "SVARTE PETTER" - THE ULTIMATE CHALLENGE

### **"Black Peter"**

"Svarte Petter", or in English "Black Peter", is a card game known in many countries often under this or a similar name. The purpose is to form as many families as possible. In the pack though, there is a card with "Svarte Petter". The winner of the game is the player with the most families, the loser, the one with "Svarte Petter"! Nobody wants to be left with "Svarte Petter", the card that cannot be paired off, the card that does not belong.

### **From the back wards**

The experiences presented here, summed up in the seven conclusions to follow, stems from a long-standing work in services for persons with intellectual handicap, especially among those most in need of support, those at the bottom of the line, in the back wards not just of the institutions, but also of services. A major task in our work has been to understand the basic requirements for a good life to be achieved, and to find ways to provide them with such a good life. Our experiences are that these are the persons with the most exceptional needs. These are the persons who are most unique, and therefore the ones in need of the most unique support (Ericsson and Ericsson 1975, Ericsson, P. 1978).

### **The competence perspective**

A dominant tradition in Swedish services is the perspective of competence, characterized by measures being taken mainly with the objective of increased competence as a means of qualifying for a good life and participation in society. We have seen that "Svarte Petter", when viewed from this perspective, will seldom be regarded as competent enough to attain the awards of the good life! When seen from the competence perspective the good life is something that one has to qualify for, the burden of proof lying with the individual. The question that arises from this perspective is what is to be done for the person who can never qualify?

This perspective is related to the "Funnel of Care". Each level of support in this funnel is standardized and leaves no place for individual differences. The task of the authority responsible for support, is to place each person on the right level. The less support you need, the higher up you are placed in this funnel, the more support you need the lower down you fall. The only way to move up in this funnel, and to live closer to or inside the ordinary community, is to qualify for such a life, to increase the competence to meet the demands of community.



### **The citizen perspective**

If persons with the most exceptional needs are to be given access to a good life within the framework of the ordinary community they have to be viewed from another perspective. An alternative frame of reference is necessary in order to see and to meet their very specific and personal needs. Each has to be seen as an individual with a right to his handicap, and a right to support from society. In recognizing this perspective one refutes the view of these persons as a group or category, with common needs which are to be met in a common manner, where the purpose of which is merely to increase their competence though not necessarily providing a good life.

The citizen perspective represents a frame of reference where other ways of viewing these persons, and therefore other forms of support, becomes self-evident. Some of these are summarized here in a series of statements.

### **Seven consequences of the citizen perspective**

#### *1. Unique persons in need of recognition*

It is necessary to accept that these are unique persons whose uniqueness has to be recognized - no two are alike! They can be seen as diamonds, rough diamonds perhaps, but unique as diamonds are. We may discover that these persons have common characteristics in what they do, or how they behave, but in our experience we have seen little in common with regards to why.

#### *2. Unique persons require unique support*

Recognizing that each person has a unique quality requires that the support provided also has unique qualities. Personal means of support have to be created on an individual basis, seldom to be found in the existing provisions of mainstream services. There are no standard solutions, no common cures or methods of treatment. For these persons there are no "off the rack" ready-made clothes, for each a new solution needs to be fashioned and tailor made!

#### *3. A lifestyle, not a treatment or cure*

Having recognized and defined these persons one knows that they are not those with temporary problems. They are persons with deep, complicated and long-standing difficulties, and therefore there is no need to find a temporary cure or method of treatment, but instead to create and develop a lifestyle, for life.

This means that solutions can seldom be found by temporarily sending the person away, turning him into somebody else's problem. Being seen as a citizen in need of a supportive lifestyle requires that it be provided where the person is, and most often on a lifetime basis. Temporary placements are seldom longterm solutions. Instead solutions have to be created here and not there, now and not later!

#### *4. Commitment for life, not just a project*

Acceptance of the existence of a longterm and lifelong need for support for the person concerned, calls for commitment on the part of the service provider. And a longterm commitment requires involvement and responsibility on the part of the authority or agent providing that support.

The experience many have gained in working with these persons is often the opposite. Services and other provisions have often been granted on a short term and success-related basis. Special units have been established, often as time-limited projects. Resources been allocated, on an annual funding basis. Investments have been made in walls and buildings but not in persons whose needs will change.

Commitment can often be found in the front-line of the service, among those who are the personal supporters and know the immediate needs of the persons, but this commitment is often lacking with others concerned. It has to exist throughout the entire organization responsible for services provided.

*5. First, not last*

If the needs of this group of persons are to be met, they must be given priority. They cannot be the ones left behind, those waiting until the needs of all others have been met. Their needs have to be those which steer the running and development of services. Their great contributions to services is the reality that if their needs can be met, so can the needs of all others!

This issue becomes particularly pertinent at a time of institutional closure. It is often this group of persons who have remained behind, the ones on the back wards, whose specific needs become apparent when traditional alternative services are found to be inadequate. It is at this time that they should be the first ones to be listened to, to be planned for and the first to move.

*6. First rate, not second hand*

At present there is a need for new and innovative services. So far services offered these persons have had their origins in a competence perspective, provided within a traditional system of "service hierarchies", these persons often remaining at the bottom of the "funnel of care".

To build a service system based on the citizen perspective, new thinking and new initiatives are required, based on vision, risk taking and lack of prestige. When lifelong lifestyles are to be developed, new approaches have to be tried. This often requires new philosophies concerning staff requirements, skills and recruitment. Neither second-hand services, nor staff, are adequate starting points for the development of new services, no conversion of the old! Instead creative services and new recruitment is needed!

*7. A life with compromise*

But naivety cannot be allowed. In order to create a good life for these unique persons, within the framework of the ordinary society, compromises have to be made, limitations to be set. Restrictions and limitations of the individual's freedom of will and choice must be accepted as certain limits of society can not be breached, certain rules can not be violated.

If a person's life style is a threat to others then certain restrictive measures will have to be taken. If behaviour is a disturbance for neighbours, protective measures have to be implemented. But these, like all supportive measures for these unique persons, have also to be related to that person and not seen as a general measure applicable for all.

## 6. A TWO-DIMENSIONAL CHANGE

Viewing the change from institutional to community services denotes something more than merely moving from a residential institution which later is closed down. This is of course, in itself, a very important step which has to be taken. But the institution stood for more than just a number of buildings on institutional grounds. Within its walls an outlook had developed with regard to the persons with intellectual handicap, their potential and the views held with regard to how their problems best should be dealt with. I have described this aspect of the institutional problem as being a question of perspectives, and have summed up the ideas which arose within the institution as a competence perspective.

If one introduces the issue of perspective into the change taking place it will also be included in the task of renouncing the outlook which had been created, and had prevailed, within the institution. It is possible to move from a residential institution, but at the same time retain the institutional tradition and perspective. What one needs to relinquish is not just the institution in a physical sense but even the institutional tradition. It is easy to point out that one wishes to overthrow a perspective. But it is also necessary to develop and acquire a new viewpoint, that which I have here called the citizen perspective.

The question of development and dissolution applied to the normalization process, as there must be alternative services to move to for each person, if closure of the residential institution is to take place. In the light of the issue of perspectives one can also talk about the development and the dissolution of a perspective. It is a matter of formulating, developing and acquiring an alternative perspective, in order to terminate the competence perspective derived from the institutional tradition. In this way the dissolution of the institution will not only be a matter of creating new buildings. Dissolution also becomes a mental process.

One can therefore talk of this development as a two-dimensional change. It is not just the physical and structural form of services which should change, here described as leaving the institution and moving to new buildings. It is also a matter of change in outlook. I see it as very difficult to initiate this shift in perspective while still within the institution which is to be vacated. The change of physical premises and the move between the two environments is a big enough issue in itself. It is therefore more natural that the shift in perspective occurs at a later stage, after the physical change has taken place. It would also seem more natural to have a discussion on the new perspective from within community services, those which are the outcome of the citizen perspective. Development and dissolution need, therefore, to continue after the institution has been closed down. The question of the content, the character of process of development away from the institutional tradition has only hinted at in this discussion on these two perspectives. This needs to be further developed even if it is unclear where such a discussion would lead.

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