

**DEINSTITUTIONALIZATION AND COMMUNITY
LIVING FOR PERSONS WITH AN INTELLECTUAL
DISABILITY IN SWEDEN:
POLICY, ORGANIZATIONAL CHANGE
AND PERSONAL CONSEQUENCES**

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INTRODUCTION

An intensive period of change in services to persons with an intellectual disability in Sweden has taken place. Today we are at the end of a period when community based services have been developed, at the same time as institutionally based services were dissolved. A decree from Parliament gave the last of December 1999 as the final date for the residential institution to be recognized as a service (SFS 1997:724). As of January 2000, all forms of support to persons with an intellectual disability should be channelled through community based services.

For a researcher interested in the welfare of persons with an intellectual disability this transition of services is important. For this to be a reality, community based forms of support have been developed, requiring that we extend our knowledge about how to offer support. The new lives of persons, when they live like others, together with others, teaches us about the real character of intellectual disability.

The focus of interest for my research has been to understand this shift from an institutional life to participation in community life. I would like to present some experiences which I think will elucidate the development of support to persons with an intellectual disability in Sweden.

POLICY OF DISABILITY

A new socio-political idea

The question of finding ways for society to assist its citizens to lead a life of welfare, has been given attention in Sweden since the beginning of the 20th century. The economic depression of the 1930:s gave new impetus and the question as to how to organize a welfare society was recognized as a major political task. This led to a programme of modern forms of social services (Lindberg 1999).

Persons with a disability were, of course, hard hit by this depression and they, through the disability movement of the time, also expressed requests for welfare. As a response to this a public enquiry, "The committee for the partially able-bodied", was set up in 1943. In 1946 it presented its suggestions. "Handicap" was not the term commonly used, instead "partially able-bodied" was the expression of the time, at least for those with a mild form of disability. The choice of term illustrates that the committee was concerned about the welfare of all persons with a disability, not only some diagnostic groups. This expression also shows optimism as those with a disability were seen as persons with abilities (SOU 1946:24).

As new conditions of delivering support would be introduced by the modern welfare services to the general public, the committee was faced with two alternative ways of providing support to persons with a disability. Should support be channelled through the traditional residential institutions, common at the time, or through the welfare services to be introduced? The discussions of the committee ended with a recommendation that society should open up the welfare services so

that they also had the responsibility to give their services to persons with a disability. The expression “partially able-bodied” shows, however, that they only meant those with a mild disability. It was recommended that others with a more severe disability were to be served by traditional residential institutions.

In this way society took the first step away from the residential institution as a service. Deinstitutionalisation had begun. With the position chosen by the committee, a new socio-political idea was introduced.

The normalization principle of 1946

A quotation from the report of the committee gives an idea of their thinking:

... the agreed upon principle that the partially able-bodied to as great an extent as possible be included in the ordinary system of social services which are being developed in our country. ... It is hardly necessary to emphasize that this, even for the partially able-bodied themselves, must be seen as a basic right as a citizen; it is entirely in keeping with the very essence of democracy that equal human value and equal rights are put in the foreground. ... Psychologically this “normalisation” of conditions of life, education, employment exchange etc. of the partially able-bodied must be a great achievement. (SOU 1946:24, p.28)

Here one finds three components which together express the new socio-political idea. What is specified is the principle that welfare services, those with a task to guarantee the welfare of the general public, also should be available for persons with a disability. This was regarded to be a democratic right. In this way this idea expressed the view of persons with a disability as citizens, and members of society. The committee also expressed an expectation that this way of organizing services for the persons themselves should bring about a normalization of their conditions of life. Because of this expectation, the idea was called the normalization principle.

The motive for this normalization principle was, of course, to guarantee a good life and welfare for persons with a disability. But there were also societal motives, often of an economic nature. These were associated with the introduction of a welfare society, with social insurance and economic support as important forms of benefits. If the partially able-bodied were to become more productive, and more able to support themselves, demands on economic social support would decrease. One even went so far as to suggest that the existence of measures to increase the ability for the partially able-bodied to earn an income, was a basic condition for the realization of a welfare society.

Here one also finds a position being taken on how to view persons with a disability. Their participation in the welfare society was seen as a democratic right, which granted, and confirmed, their role as citizens. As such they made up part of the general public, whose welfare was to be guaranteed by the new services which were to be established. It was, therefore, seen as natural to make the choice that even these persons should be allowed to avail of ordinary social services.

But even this democratic motive had an economic dimension. The day when a welfare society, with an ambition to guarantee welfare for the entire public, also perceives persons with a disability as citizens, all must be granted the right to have their needs provided for. If these needs should be realized through the provision of specially built residential institutions, with a standard seen as acceptable to a welfare society, it would be an impossible economic task. One would not be able to build specially designed institutions for all! The only way to meet their needs for welfare was to open up the general welfare services (Ericsson 2001).

Four Acts of Parliament

These personal and societal motives together became the driving force behind the realization of the normalization principle. Being a general principle, this realiza-

tion has, over the years, taken place for the various disability groups. The basic condition for this has, of course, been the extent to which the welfare society has been realized for the general public.

As regards to the field of intellectual disability, four Acts of Parliament, 1954, 1967, 1985 and 1993, have gradually introduced community based services, while institutionally based services were being dissolved. A notable Act of Parliament is the one of 1985 which, for the first time, clarified the right for everyone with an intellectual disability, even those with a severe form, to participate in community life. These more than 50 years of transition of services ended in 1999, when the residential institution ceased to exist as a service (Ericsson 2001).

During this period, Niels-Erik Bank-Mikkelsen in Denmark (1964) and Bengt Nirje in Sweden (1969) have had important contributions in bringing this general normalization principle of 1946 into the field of intellectual disability.

TWO TRADITIONS OF SUPPORT

The conditions of the 1850:s

The residential institution, as a way of delivering support from society to persons with a disability, grew out of the conditions in the second half of the 19th century. This was a period of change in Sweden when an old agrarian society was transformed into an industrial society. During this change persons with a disability became “visible”, a group among others. The families of these persons turned to society for assistance but there were few public services at that time to respond to the needs they expressed. A natural consequence was that private organizations for assistance were created. Later on public bodies also began to form disability services. The support of this period was delivered through residential institutions, where a group was taken care of, often in the countryside. Education was arranged for the “educable”, care for the “uneducable”.

During the 19th century work was carried out with optimism, and an ambition that persons would return to those communities from which they had originally come. But the eugenics of the first half of the 20th century gave new conditions for disability services. A more protective attitude created walls, physically and metaphorically, around the residential institutions. They became places where large groups were kept under poor conditions.

The conditions of the 1950:s

The normalization principle of 1946 illustrates therefore, how a new society reacts towards the services which were previously offered. With the new conditions of the period, a democratic society, a disability movement and ambitions for welfare for citizens, new services were formed.

In the early 1950:s in Sweden, one therefore finds two traditions of support. An institutional tradition which had grown out of the 19th century, had been developed further during the first half of the 20th century, residential institutions being the dominating form of service of the time. But a community tradition had been formed with the normalization principle of 1946. In the early years of 1950 it merely gave a vision of new services, but had started to be implemented with the 1954 Act of Parliament.

Two traditions

The two traditions of support differ in significant ways. The community tradition sees persons with an intellectual disability as citizens of society, with a right to welfare and participation in community life. The services to be used by them are the services of other citizens, that is, the welfare services used by the general public. Persons with a disability, their life and support, are seen from a citizen perspective in this community tradition.

The institutional tradition is characterized in another way. With the emphasis on education and care as the main services to persons with an intellectual disabil-

ity, the roles attributed to persons are those of the “pupil” and the “patient”. Focussing the deficiencies created by the intellectual disability, it becomes natural to create special institutions, with special staff and special methods. Bringing persons there creates institutional lives. With the lack of competence of persons seen as a central phenomenon, the increase of competence becomes the major task of the institutional tradition. A competence perspective can be seen as the position from which persons with an intellectual disability, their lives and services are being defined (Ericsson 1999a).

Deinstitutionalisation

Deinstitutionalisation is a concept often used in international literature to describe the development away from residential institutions. However, when working with the development of community based services, and the dissolution of institutionally based services, the concept becomes vague, and gives little help for moving ahead.

With the two traditions of support as a frame of reference one finds the direction for development. On an individual level, persons leave an institutional life for participation in community life. On an organizational level, institutionally based services are being dissolved and community based forms of support, as part of the welfare services of society, are being developed as alternatives. On a cultural level, a shift of perspective takes place. It is necessary that a citizen perspective be conquered, while a competence perspective is left behind (Ericsson 2001).

PERSONAL CONSEQUENCES

With such an extensive and intensive transition from institutionally to community based services it is relevant to ask about the consequences for persons. I have carried out a number of studies and based on these I will give some comments on this issue. Before making my comments I would like to stress the fact that I will be talking about persons with an intellectual disability, whose disability is severe! Therefore they once lived at residential institutions where those with the most severe disability were placed by society.

Community living

When one looks at everyday life, one finds that a new and more normal life has been formed. Today, housing for persons with a disability can be found in all types of houses which you can find in the community. To respond to the needs of persons, some with limited, others with extensive, needs for support, there are staff-groups of varying sizes. A group-home, emanating from national planning bodies, has been common when housing was created as an alternative to the residential institution. Such a group-home contains five small private apartments, one for each person. A staff-group allocated to this group-home provides the assistance necessary. Living in a group of five is therefore common today.

Daily activities outside the home are a natural part of community based services. To create a programme with purposeful activities for a week, it is common that the person is involved in a number of different activities. These take place in traditional day activity centres, as well as in settings of the local community. The staff-group providing support during daytime is one which has the task of arranging these day services. Therefore, it is a different one from those who give support in the home. A person therefore meets one group of staff in his home, and another during his daily activities.

Participation also takes place in the life of the local community, where others lead their lives. This becomes a reality to the extent that staff provide assistance. In this way persons with a disability take part in their own shopping, and are involved in leisure and cultural experiences. As local welfare services for health and social well-being have been opened to persons with an intellectual disability, they also use the social services, health centres, the dentist and the pharmacy of local community.

Why describe a normal life for persons with an intellectual disability? It sounds so normal and undramatic! The fantastic thing is that this life today is led by persons with a very severe disability! Just some years ago these persons were kept at residential institutions, under extremely poor conditions. They gave a very deviant impression, and their possibilities for personal development and a better life were viewed with pessimism! But this is not the case! By leaving the residential institution for community based services they are transformed as persons and now give a very normal impression! You could express the development in this way: if persons are given better conditions of life, irrespective of their having a disability or not, they will respond by living a richer everyday life as well as experiencing a personal development (Ericsson 1993; Ericsson 1995; Ericsson et.al. 1988; Ericsson, K., Ahlström, J-Å., et.al 1992; Ericsson, K., Gilbertsson, S., 1992).

Interviews with persons

It is a positive picture of the new lives which emerges when persons themselves are interviewed about the consequences of leaving the residential institution. No-one expresses a wish to return to the residential home! However, it is not a life of strong and intense emotions, nor one of dark or gloomy experiences. The conversations which took place were instead dominated by the events of everyday life, the pluses and minuses that are experienced by all (Gilbertsson 1992; Gilbertsson & Ericsson 1995).

The positive experiences consisted largely of these persons having acquired something which was their own. Having their own home where they are able to decide for themselves and to give their lives a personal touch, meant a lot to them. That this emerges as a dominant feature is perhaps natural, seen against the background of their previously being unable to encounter such experiences at the residential institution.

At the same time even these persons are faced with the annoying and problematic sides of daily life. The young man who summarized his experiences of dealing with financial matters with the words "*money, it's difficult, it is*" probably expressed a more general feeling and not just one experienced by the person who has left an institution! There are also many formulations in these interviews which with delicacy and nuance express not just their own but more general impressions. The role of recreational activities is well perceived by the one who said "*leisure, this we spend together*".

There is one quotation which stands out as particularly challenging as it can be seen as summarizing this process of change. It is a comment made by a man who was pleased about receiving letters in his own postbox which was outside his new house. His comment, when he went out to show it to the interviewer, was "*... it's good to have one's own postbox, but there is no name on it*". He had acquired a new life which mainly consisted of a considerably higher material standard than before. Regarding his own person he had, however, not become visible or publically recognized in his local community. He, and all others who had been away for a long time, had a need to announce that he once again belonged to, and participated in, the life of a community, which he once had left.

The interviews show that these are persons who have profound views regarding the life they live and the support they receive. When questions are put to them one also gets answers. This is perhaps nothing one should be surprised about, but it needs to be said.

Interviews with families

When families are interviewed about the consequences of their family member leaving the residential institution for community based services, one finds a major group who have changed their views. When they got the news that the residential institution was to be closed and persons would receive new community based services, they reacted negatively. After having seen the new services and when they saw the new life which they offered, they changed their attitude and became

positive to the family member setting up a life in community (Tuveesson 1992; Tuveesson & Ericsson 1995; Tuveesson & Ericsson 1996).

A striking impression from these interviews was the very strong relationship of the family to the person living in the institution. He was remembered as part of the family, even if he did not receive many visits. When a family member viewed this process of change from a lifelong perspective, it was clear that the person had been thought of, in spite of his being far away. The commitment which was shown illustrated that the family felt a responsibility for the member with a disability. "The person belonged to the family", even if he had not always been a part of its everyday life.

In this lies an important assertion. The person with an intellectual disability does not "belong" to the institution. Instead the responsibility of the family to its member with a disability should be recognized. A natural consequence of this is to invite the family to be included when choosing the type of life which the son or daughter, sister or brother, is going to live. The family should also be a natural part of the new life.

Community participation

When you look to the normalization principle of 1946, participation in community life was seen as a right for persons with a disability. The question as to whether persons with an intellectual disability did participate in community life when living in community based services, was analysed in a series of studies (Lerman, Ericsson & Nilsson 1986; Brusén, Ericsson & Thorsell 1988; Ericsson 1993; Ericsson 2001).

Homes of persons are located to housing areas of community and daily activities take place in those places where others spend their days. Persons with a disability also use the social and health services for the general public. Participation concerning the basic patterns of everyday life is therefore a reality.

However, when one looks to the involvement of persons in the life of the local community, for example the use of commercial services, contacts in local activities for leisure and culture, or establishing social relationships, participation becomes more limited. The normal patterns of everyday life, lived by others in the community, which is what one strives for, does not become a reality. Instead, special lives for persons with an intellectual disability, with several aspects similar to those lived at the residential institution, is too common! In evaluating personal consequences against the socio-political idea of this transition of services, a lack of community participation should be seen as a major problem.

A comment

New lives have been created by the introduction of community based services. As these new services have been built with a present day standard, housing is related to the standard of housing of today. This material and social standard is, of course, much more attractive compared to the one offered by residential institutions, which were built decades ago. A major reason for this transition of services to take place, and to be met in such a positive way, is the simple fact that leaving the residential institution for community based services offers a life which is seen by the persons, and their families, as one with a much better standard .

At the same time as this is said, one must point out that these new services can be used in many ways when providing support. For the major part of the group, the transition of services has meant important enhancements of life. For some, personal development has been extremely successful! But it must also be said that experiences for some persons have been negative. There is no guarantee that bad management of disability services disappears when community based services are introduced!

ORGANIZATIONAL CHANGE

Development of community based services

Today persons with an intellectual disability live a life in the local community. Residential institutions have been closed and are no longer recognized as a service. How did this change take place?

To understand this development one must see that this has been a 50-year period, during which a transition has taken place from institutionally to community based services. In the beginning of this period the residential institution was the only way of organizing support to these persons. The challenge to these services came from the normalization principle of 1946, a vision about a more normal way of life for persons with a disability. This idea inspired the establishment of community based services and these have since gradually been developed in order to offer support outside the institution. According to the extent to which these new services have been made available, persons have been able to leave the residential institution.

These new services, located to the communities where persons with a disability and their families live, have also made it possible for persons with a disability, born during this period, to grow up with their families. In this way it has not been necessary for them to go to the residential institution. This has contributed to the decreasing number of persons in residential institutions.

The first generation of services

I see three generations of community based services. The first has a background in the traditional way of seeing persons with an intellectual disability as either "educable" or "non-educable", thereby separating those with a mild form of disability from those with a more severe one. The first group of community based services were offered only those with a limited need for support. These services were easy to establish as the normal settings of a community were used and few staff were needed. Persons with the more severe disability were seen as being in need of the residential institution. Therefore, no attempts were made to offer them a life in the community.

The second generation of services

The next generation of community based services came when all persons with a severe disability were offered support outside the residential institution. These demands came from representatives of those persons who had grown up in their home and who, as adults, requested a community life. As they had grown up in their family, they did not accept going to a residential institution.

The new structure of community based services, which took place in small groups and personal living rooms, also created a demand for a higher living standard at residential institutions. As several persons often lived in the same room on a ward, there was a development towards single rooms, with one person per room. The consequence of this was a decrease in the number of beds at institutions, which of course led to persons having to leave. For this to become a reality, community based services for those with a more severe disability had to be established.

The idea that all persons with a severe disability were to leave the residential institution was recognized in 1976, when the first decision was made to close a large residential institution. Development and dissolution can be said to characterize the following years. Development of community based services was necessary in order to replace the residential institutions which were dissolved. With a competence perspective, which saw a life in the community as a reality only for those with competence enough to manage themselves, this development was seen as incomprehensible. But with a citizen perspective, which saw the right of all persons with a disability to participation in community life, this decision was seen as logical.

The third generation of services

Today we see a tendency towards a third generation of community based services. As residential institutions no longer exist, those who request support are those who have grown up with their families. They are all well aware of their rights to participate in community life and to be partners in the process when services are being formed. In this way they are able to influence the course of their lives. This development is supported by the present Act of Parliament (SFS 1993:387).

When a person gets the opportunity to control his own life, he does not ask for special services, that is, special houses with special staff. With a new form of support, personal assistance, they can get staff support for the number of hours per month needed. As this staff support is personal, the person can take this with him to the place where he wants to live.

Therefore, as an example, four men left a traditional group-home and bought themselves a house and became the owners of their own home. Their personal assistants gave them the support they needed in their new house. In this way influence over their lives increased, they could buy the house they liked and they received the amount of support per month they needed. As the task of the personal assistant is to assist a person with a disability, support has become more personal. This has increased the possibility for the person to control his own life (Ericsson, P. & Ericsson, K., 1995).

Closing the residential institution

Dissolution and closure of a residential institution is a complex process. It is therefore important to focus on the essence of such a process. As services are about providing support for a good life for a person with a disability, the aim of dissolution must always be to contribute to a better life for those who live at the institution. As there are persons in need of support even after they have left the institution, there must be services in the community which guarantee a better life. The key task during dissolution is therefore the development of services and better lives outside the institution, for each one who leaves.

This change often gives rise to dramatic reactions and a sense of destruction for those who are not fully informed. However, when one finds that a development of modern services and better lives is the task for the transition from institutionally to community based services, this becomes a process with a positive content.

The most dramatic reactions can be found during the early stage of the transition process, when knowledge about the new life for a person usually is lacking. When all have left and one meets the person again, this time in his new life, together with his family and staff, one finds that they can talk about all phases of the transition. They talk, however, very little about what they have left, more about the new life and the new services which have become a reality (Ericsson 1993; Ericsson 1995).

Closing the institution in our mind

The work towards an increased participation in community life only becomes understandable and realistic when one sees the person as a citizen, belonging to his family and community. As such he has a right, like everyone else, to grow up and to live together with his family. But as a citizen perspective is being developed, the competence perspective associated with institutionally based services, has to be left behind. This attitudinal shift, as mentioned earlier, is also part of the transition between the two traditions of support. It is easy to change the physical facilities of services, but it is more complicated to change attitudes. This task has therefore been expressed as one which aims at "closing the institution in our mind".

Some problems in the shift between the two traditions of support have been pointed out in this presentation. Most of them have their roots in the lack of a perspective which recognizes the person with an intellectual disability, even when

this is severe, as a citizen with rights and thereby giving logic to his participation in community life (Ericsson 1999a).

DISCUSSION

A personal reflexion

Here I will allow myself to make a very personal note in relation to the shift between the two traditions of support which I have already presented. I have seen persons with severe forms of intellectual disability in residential institutions, I have seen them leave and I have seen them set up new lives in the community. When this is done in the correct way, fantastic changes take place! It is not that the disability disappears! But in spite of this they, with suitable assistance, have acquired entirely new lives.

“Becoming a person” is a most suitable expression for the change which has taken place. It was formulated to describe what staff, in community based services, saw as the most significant change after having left the institution for a new life. This was a way of summing up all their comments in relation to being a person with ones own home, instead of being one in a group, on a ward. In this process of change personal preferences about food, clothing and social relationships were expressed. What they had noticed was part of the process away from seeing persons with an intellectual disability as a group, with characteristics attributed to this group. Instead they saw persons who were developing their personalities and preferences. They became persons, each one with his own requests for a good life (Thorsell, Ericsson & Brusén 1988)!

Having seen this development one cannot argue for turning back! It is also my belief that other persons who have been involved in this shift between traditions of support have seen these changes. Families, staff, administrators, politicians and the general public who have witnessed this development with persons with an intellectual disability have also recognized that there is no turning back. This concern for people has, in my opinion, been a strong factor which has given support to this shift between traditions.

International relevance

In describing the change from institutional life to community participation for persons with a disability I have used material from the ongoing transition in Sweden. The reason for this has not been chauvinistic, giving credit to ones own country. Instead it has been a way of using my own research to bring forward some key concepts and major experiences from this period of change. Do these results have any international relevance?

There is, of course, a national dimension to what has been described here. The form of the process of change is naturally related to Swedish legislation and the Swedish way of organizing schooling, housing and the labour market, as well as the welfare society. International comparisons show however, that there are many similarities in the structure of this process of change. Norway is another country in Scandinavia which has closed all its residential institutions (Mansell & Ericsson 1996). When working together one finds many similarities during the transition of services.

Swedish involvement in the transition of services in Amman, Jordan, also shows that the basic structure of this shift between traditions of support has got many similarities, in spite of their taking place in very different cultures (Ericsson 1999b). This is also the conclusion when comparisons are being made between intellectual disability services in Scandinavia, Britain and the USA (Mansell & Ericsson 1996).

The global strategy of UN, “equalization of opportunities”, has created a new platform for international cooperation in the field of disability (UN 1994). Working in projects in Sweden and internationally, within the framework of this UN strategy, has convinced me that there are more similarities than differences in

this shift between traditions of support concerning persons with an intellectual disability.

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