

SERVICES IN SWEDEN TO PERSONS  
WITH AN INTELLECTUAL DISABILITY:  
A SHIFT BETWEEN TWO TRADITIONS OF SUPPORT

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# SERVICES IN SWEDEN TO PERSONS WITH AN INTELLECTUAL DISABILITY: A SHIFT BETWEEN TWO TRADITIONS OF SUPPORT

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## INTRODUCTION

Services to persons with an intellectual disability have seen an extensive change in Sweden during the last 25 years. In the beginning of this period institutional forms of support dominated, at the same time as there was a limited number of community based services. Today all services are based in the community, with only a limited number of places in residential institutions. From January 1, year 2000 the residential institution is no longer accepted as a form of support.

As a researcher interested in how the welfare of a person with an intellectual disability can be promoted through his services, this dramatic shift of support becomes an interesting problem to look into. I have therefore carried out a series of studies in Sweden to understand this ongoing change. I see this as a shift between two traditions of support (Ericsson & Ericsson 1999).

The concept of the community based approach to services for persons with an intellectual disability is discussed here on the basis of experiences gained in Sweden. Because of unique circumstances dramatic changes have taken place as regards services to persons with a disability. During a 50 year period there has not only been a gradual expansion of services but also a unique change of direction regarding the support provided.

During the early years of this period it was expected that new services being established should be in the form of residential institutions. But since the 70:s a dramatic shift has taken place. A community based approach became the basis for ongoing work. At the same time residential institutions were dissolved and closed.

## COMMUNITY BASED SERVICES

### *Persons with a disability in the welfare society*

The 30:s were years of scarcity because of economic decline. The consequences of this was felt by people as it led to unemployment and poverty. This was even more so felt by persons with a disability. Residential institutions were built to an increasing extent and persons were admitted to be given care under poor conditions. Putting people away was possible as the attitudes towards persons with a disability were generally pessimistic, leading to restrictive measures being used

and those who were not admitted to institutions had to live without the support they needed.

As a reaction to the conditions of the 30:s the idea of a welfare society was formulated together with modern forms of social support. When welfare services were to be formed for the common man, the question arose as to whether persons with a disability should also be given the possibility of using them. This was discussed at length in a public enquiry, made up not only of administrators and politicians but also of persons from organizations representing persons with a disability.

Two alternative ways as to how to meet their needs in a welfare society were discussed. One meant that residential institutions with their roots in the nineteenth century should be modernized and used by society to channel its support. The other alternative meant that persons with a disability should have the right to use the same welfare services as those being used by the general public. The discussion in this committee ended by recommending the second alternative to the Parliament (Ericsson 1993).

### ***A new idea***

A new socio-political idea was formulated by the committee when they made their suggestion about the use of public welfare services for persons with a disability. This idea was characterized by its three components. Organizationally, it meant that services provided for common man were also to be used by persons with a disability, this being achieved by giving them the right to avail of the general welfare services. In order for this to become a reality, the competence of these must be comprehensive enough to meet the needs of all persons. The intention was that when welfare services became available for all, the person with a disability could stay in the community to which he belongs and there lead the normal life, the life led by his family and others. This meant that the normal life, the second component, became a goal to strive for when delivering support and services.

The third component concerned the social role attributed to persons with a disability. The committee maintained that it was a democratic right for persons with a disability to use public welfare services, like everyone else, and to lead the normal life of the community. Thereby they clarified that they saw these persons, irrespective of type of disability, as citizens belonging to society. As this idea expressed the normal life of others as the life to be offered to persons with a disability, it was called the normalization principle.

### ***The context of the normalization principle***

The committee saw the community based approach to support as desirable as this was a way of providing a guarantee for welfare to persons with a disability to the same extent as it became a reality for other users of the same services. But they also had economic reasons for their choice. The day when all persons with a disability are recognized as citizens with a right to welfare, their support cannot be met by building residential institutions, separate special services, for all. This would never be economically and practically possible for a society!

The only way to meet the needs, when all have gained a right to support, is to open up the public welfare services and to give these organizations the task of satisfying all needs, expressed by persons with a disability as well as by others.

That is why local health and social services were given responsibility for all and why schools have been opened up so that even children with a disability can attend. When leading the normal life, being part of one's local community, these persons not only become recipients of support but also active and contributing members of society. When the adult has been given the possibility to have a job, he starts earning his salary, in part or fully, thereby decreasing his demand for support from welfare services (Ericsson 1993, 1996).

## **INSTITUTIONALLY BASED SERVICES**

### ***Persons with a disability during industrialization***

Up until the middle of the nineteenth century, support to persons with a disability was to a large extent the responsibility of the family. In the agrarian society, dominant at the time, there would most often be a family member who could give some support.

Industrialization during the nineteenth century created the new conditions leading to institutionally based services. This restructuring of society put new demands on the population as new types of jobs required competence other than that found in the agrarian society. Urbanization meant that families left rural areas and moved to town, often leaving a large part of their family behind. When support was needed by the urban family, e.g. when a child with a disability was born, expectations were that society, instead of the family, should provide the necessary assistance.

This industrialization also had consequences on the manifestation of intellectual disability. Compulsory education was introduced at the middle of the nineteenth century and was gradually extended. In school demands were made on children to learn to read, write and to do arithmetic. As intellectual disability is characterized by learning difficulties, and compulsory education make demands on learning, this led to a higher number of children being identified. Methods, for example the intelligence test, were developed during these years to identify those school-children who were slow learners. When identified, they were taken out of class and admitted to special education.

As the public school did not take responsibility for the education of these children, private organizations were formed to arrange this. Most often they bought a small farm or some other large facility in the countryside, away from the urban centers, where this special education could be made available. Optimism and hope for positive results characterized their work as they wanted to create a sheltered setting for the education of children with an intellectual disability. Their responsibility was however only for those children admitted, not for others.

The newly established private organizations made important contributions when they set about organizing services. In this way the first residential institutions were formed. They soon became more established and grew in size. There was also a variation of institutions, where one type had the task of providing education and the other the task of merely caring for those with more extensive needs for support. With an institutionally based system, services were located only to these institutions. Persons in need of support were therefore taken to these places where support could be found.

The residential institution was organized as a small, specially formed, community where all facilities thought to be needed by these persons were to be found. These institutions had a patriarchal character, as in the family of the period, the father of the family having the task of fostering its members. Only for those persons with a disability who had learnt to master the demands of the institution and who had increased in competence, did it become possible to leave for a life outside.

### ***The idea of institutionally based services***

It is possible to describe institutionally based services with the same three components used to characterize community based services. On the organizational level support is channelled through institutions specially formed for persons with an intellectual disability. Outside these there is hardly any form of relevant support. The layout of the institution, its size, the type of buildings and facilities which could be found, made up the setting for the life of the person living there. On an individual level the consequences were that the person lead the institutional life which was offered by the institution, and not that of the community at large.

The social role attributed to persons with intellectual disability, the third component, was that of the citizen in the community based approach. With an institutionally based approach other roles are found. Those with a mild form of disability are usually seen as pupils, persons in need of education, while those with a more severe disability are seen as patients in need of care. Although there are differences between these two roles, there is a similarity. The main one is their focus on the deficiencies of the person, his lack of knowledge or abilities, with a consequence that both emphasize his lack of competence in meeting the needs of the community. His deficiencies are in focus, not the normal needs of a person (Ericsson 1993).

## **TWO TRADITIONS OF SUPPORT**

### ***Institutionally and community based services***

The distinction between institutionally and community based services can best be described by the term two traditions of support. These have grown out of contrasting societies and there are differences as regards their structure. One creates special services for persons with intellectual disability while the other opens up the services used by the general public in a community. They also strive towards different goals, the aim being to offer the institutional life in one tradition, while the other offers the normal life of the local community.

There are also important differences between these traditions regarding how they relate to persons, the institutional tradition seeing them primarily as pupils or patients in need of an increase in competence in order to be able to leave the residential institution to take part in community life. The community based tradition, on the other hand, sees them as citizens with a right to participation in community life, irrespective of the degree of disability.

As community based services are seen as desirable, as expressed in the 1985 Act of Parliament regulating the delivery of services, their realization has been the basis for present transition. These services are promoted and development is going on to fulfil their task of offering a good life to persons. As institutionally based

services do not meet the present day demands, they are being dissolved and closed down (Ericsson 1998). In Sweden the residential institution is illegal from January 1, 2000, thereafter not being permitted as a way of channelling the support of society.

### ***Deinstitutionalization: development and dissolution***

Experiences of deinstitutionalization show that this concept needs to be extended to describe the essence of what is really going on. The key to success lies in the services created as alternatives to those offered by the residential institution. Community based services have to be developed so that persons in the institution can have their needs satisfied after leaving. Hand in hand with this, work has to take place to dissolve and finally close the residential institution. Development and dissolution are therefore the two activities which need to take place during the process of deinstitutionalization.

It is very easy to let one's attention be caught by the energy and resources needed for development and dissolution of services. Basically, however, this process concerns the lives of persons. The motive for carrying out this transition is to achieve welfare for persons and their families. The core activity is therefore the development of a better life for the persons who move from the institution.

## **DEVELOPMENT OF COMMUNITY BASED SERVICES IN SWEDEN**

### ***Support to the child and his family***

When developing support, the ambition is to offer a life to the person with a disability which is the same as others. This means that it is possible for the child to grow up in the family and to leave the family as adult. As a consequence support needs to be oriented towards giving the family support, in order to be able to live with its child at home during infancy and school years. When it becomes an adult, the family has become older and is no longer able to give its support, the person needs to establish his own adult life. The task of services for the adult should therefore be to give support in his home, and in activities and work outside his home during the day.

When having the child grow up in the family, something which is often experienced as a burden on the parents, practical and psychological support is needed. Assistance can be given by a person coming into the family to deal with other practical matters while the family gives its attention to the child.

The psychological needs of the family should not be neglected, as a child with a disability is seldom expected. In such a situation there could be a period of disappointment and resentment. Other families, who previously have had similar experiences can then be a support to turn to for early information, as to why this has happened and what can be expected from the child and life in the future. When parents want to give their attention to themselves or to other members of the family, it can be desirable to have relief from others. An extra family could for example be appointed as a form of support and of assistance in such a situation.

Early intervention means that not only the family but also the child is in need of support. As an infant it will have the same need of attention and care as other infants, but because of its disability there may be a need for extra support to cope with the various stages of normal child development. Pre-school activities outside

the family can contribute to the child's play and social interaction with other children.

As all children with an intellectual disability have the right to education, schools and the education they offer must be organized for this to become a reality. For each child to have his educational needs satisfied it is understandable that there must be a variation of solutions on offer. Special schools are no longer recognized, instead the education of children with a disability takes place within the framework of ordinary schools.

But this does not mean that all children at all times are part of the ordinary classes of that school. The task is to create a situation when the child will gain educational experiences important for him. This can be achieved through the ordinary class or in a special setting. In reality the child's week will consist of the activities which are found suitable for him, these taking place in various settings within the school. Sometimes these will take place together with children who have got a disability and sometimes the activities take place together with others. A major experience is that the smaller the group in which the child takes part, the more attention the teacher can give the child thus enabling him to experience personalized education.

### *Support to adults*

When the person has become an adult, compulsory schooling ends. If the person has the possibility of getting a paid job like most people, he will go to work. Even if the person has a disability, if it is a minor one, he might have the possibility of getting a paid job, but a job when he still receives some support from others. He can receive a full salary, but this being subsidized by some national employment body.

If he cannot get a job because of his disability, he can instead take part in day services, organized as daily activities with support. The idea with these daily activities is to give the person the opportunity to leave his home during the day and to take part in purposeful activities during the five days of the week. The type of activities will depend on his needs and requests. In this way it is possible to create a week of work for one person, whereas for someone else needing extensive support, the week can be filled with activities which give stimulation and pleasant experiences of value for his personal development. Others may have adult education as part of the weekly programme. Earlier on these activities usually took place in special day activity centers. Today, when there is an ambition to participate in community life, the tendency is to create settings in the ordinary community, specially organized for small groups of persons.

It is common that the child lives with his family during school years. But as he grows older he leaves the family for his own home. Because of his disability he may be in need of support, this being limited if he only has a minor disability. In that case he can get an ordinary apartment of his own, like other young people, but with staff who provide support in the home when he needs it. If he is not self-sufficient and has more extensive needs for support, a group home is an alternative. This can be a large apartment or a house where a group of persons live. In such a home there are staff on duty around the clock, the number of staff being less if the needs of the persons are limited. But if the needs are more extensive, for example

for persons who once lived at the residential institution, the number of staff needs to be higher.

The brief presentation given here can only be a general one. For each person there must be a personal choice of services, applying the alternatives which are available at the time. The requests from the person and his family will of course influence how services will be formed. Contributions to the choice of services are also related to the degree and character of disability of the person. The cultural context will also influence services of the person, e.g. housing in the countryside being different to housing in the large city (Ericsson 1996).

## **DISSOLUTION OF INSTITUTIONALLY BASED SERVICES**

### ***The logic of the institution***

When no support was available or when there were only services of a low quality, the establishment of the modern residential institution was a great achievement. Its services meant a better life for persons in need of support. This was the case from their introduction up until the 50:s.

The 70:s was the decade of change. New experiences were gained about community based services and these were seen and accepted as positive. By offering a more normal life, in small groups, with a higher material standard and with some participation in community life, they set new ideals which could not be found in the residential institution. As they were gradually developed and their numbers increased, they were sought after by the persons themselves and their families.

This created a challenge for the institutions which consequently led to a development of the services according to the new ideals. The groups became smaller and they offered a more normal life and a better material standard. But still, this was a large place with many persons living there, most often far away from home. Therefore there was a movement away from the institution towards life in community.

As the first to leave the residential institution were those with a mild form of disability, only community based services offering a limited support were needed. But as persons with a more severe form of disability also left, services providing extensive support were established. When community based services had been developed to the extent that they could provide support and services to all, irrespective of degree of disability, these were seen as desirable. Consequently residential institutions could be dissolved and finally closed down. After year 2000, the residential institution is no longer recognized as a form of service in Sweden.

### ***Closing the institution***

Dissolution and closure of a residential institution is a complex process. It is therefore of importance 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 previously lived 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 outside the institution.

The dissolution and closure of an institution often gives rise to dramatic reactions and a sense of destruction. However, when one finds that a development of modern services and better lives is the task for the transition of services this becomes a process with a positive content. The most dramatic reactions can be found during the early part of the transition process. When all have left the institution and one meets people who once lived there, their families and staff, one finds that they can talk about all phases of the transition. They talk, however, very little about what they have left and more about the new lives and services which have become a reality (Ericsson 1996).

### *Closing the institution in our minds*

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. But for the citizen perspective to be developed, the competence perspective associated with institutionally based services, has to be left behind. This attitudinal shift is also part of the transition between the two traditions of support. Ongoing projects have shown that this is a most difficult task. 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 heads” or as a “deinstitutionalization of minds” (Ericsson 1998).

### *Persons experiencing a new life*

It is only since the early 70:s that we have seen persons with intellectual disability move from an institutional life to participation in local community. Thereby a new pattern of life has evolved, with new qualities not previously experienced. The ambition has been to establish a more normal life, for these persons to live where and as others live. This has been made possible through the development of support in ordinary housing and through the provision of daily activities and work.

When people talk about their new experiences they express a new sense of freedom. They also talk about having got their own home, their own furniture and belongings. “My own ...” is an expression often used by them. But they also talk about the common issues of everyday life, like not having enough money, the absence of some of their friends and about not having a job that gives satisfaction. They, like we all do, talk about everyday life, with its positive and negative aspects, and how this life can be improved.

Parents whose adult children have now left the residential institution recollect how they saw the period of transition with some anxiety. During the years they had become used to the idea that their child had been handed over to an institution. Today, when they talk about their sons or daughters having moved from the old institution to new services, they talk of their earlier doubts about them not being able to manage this change. Afterwards, when the persons live in their new house, parents instead talk about their happiness when they see them experiencing the new life. But they still make demands for a better life when they find out that some basic qualities are still lacking.

The change which has taken place cannot be described merely as a change in pattern of everyday life. These persons have also acquired another role in their

local community and in society as a whole. There are examples of persons who previously were merely receivers of care. Today they have important tasks and functions in their community. They have taken on roles as citizens of their community and they participate in local activities. There is for example a group of persons whose task in their community is to inform the children in local schools on issues related to handicap. Because of their intellectual disability they are considered as experts. They have done this during one year, in this way meeting more than 2.000 children.

The main trend, even if there are exceptions, can be characterized as having introduced more normal patterns of everyday life and through these brought about closer contact with the ordinary man. In many situations persons are seen as citizens and met with respect. In this way new and fundamental experiences have been gained during these years. These more normal conditions of life have also important personal consequences for personal well-being and development (Ericsson 1998).

### **AN INTERNATIONAL COMPARISON**

How does this development in Sweden relate to what has taken place internationally? An overview of development in Britain, Scandinavia and the USA (Mansell and Ericsson 1996) shows that a gradual development has taken place during the last 50 years regarding support to persons with an intellectual disability with the 60:s as the main decade of change. The International League of Societies for the Mentally Handicapped, a worldwide organization representing a large number of organizations promoting the interests of persons with intellectual disability, published its "Rights for Persons with Mental Handicap" in the 60:s (1968). Today the organization has changed its name to Inclusion International, thereby pointing to what they see as their main task, to work for the inclusion of these persons into ordinary society.

The normalization principle was a general disability concept developed in Sweden in the 40:s and then brought into the field of services to persons with an intellectual disability by Niels-Erik Bank-Mikkelsen (1964) from Denmark and Bengt Nirje (1969) from Sweden. Later these concepts were brought into the international domain in the 70:s and have since then been developed further by a large number of people.

The shift in the USA towards a community life for persons with a disability took place in the 60:s and was manifested in the 1969 report from the President's Committee on Mental Retardation "Changing Patterns in Residential Services for the Mentally Retarded" (Kugel and Wolfensberger 1969). The changes referred to in the title was the transition away from institutional forms of services to those based in the community. The ideas presented in the report have since then been accepted, and even developed further, during the years which have followed.

The basis for UN in its work to promote the lives of persons with a disability has its roots in the human rights formulated by this organization in 1948. In the 70:s a number of policy documents were drawn up underlining the rights of persons to be part of their community. As a consequence the concept of CBR (Community Based Rehabilitation) was formed during this decade. The International Year of the Disabled in 1981 was the occasion when this position became public. This was followed in 1982 by the start of the decade of the

disabled. During this 10 year period work took place on preparing the Standard Rules for Equalization of Opportunities (UN 1994). This offered a global strategy to the international community on how to organize support and services to persons with a disability.

The European Union has recognized this development towards a policy based on the rights of persons with a disability to use the resources of the local community and to participate in the life it offers. It also adheres to the UN strategy of equalization of opportunities for persons with a disability as a means to achieving this (EU 1996).

These policies focus on the development of new ideas for the delivery of support. The background for their promotion is of course a very extensive organization of residential institutions. The concept of two traditions of support is therefore a most relevant concept also in other countries. The process of developing the community based tradition at the same time as dissolving the institutional one, is an ongoing process also internationally.

#### **A FINAL COMMENT**

What is to be found is a complex change of services between two traditions of support. Introducing a new socio-political idea, emphasizing participation in community life, suggests new goals to be realized when delivering support and services. To bring this about community based services are needed. If adequate forms of support do not already exist they have to be found. Those forms of support which do not contribute to participation of the person in community life are no longer valid and need to be dissolved. Some aspects of how this work has been carried out in Sweden have been exemplified here.

Hopefully this has not been presented as an easy task! Organizational restructuring has opened up a number of problems to be solved, often requiring social innovations. One must also recognize that there have been anxieties during a period of change when new forms of support have been vague, and irritation when mistakes have been made in delivering the new community based services.

But during this change between traditions of support there are a large number of persons with intellectual disability, mild as well as severe, who have expressed tremendous joy when experiencing a better life! When families have seen their sons and daughters, brothers and sisters living under more normal conditions and developing personally, even they show unexpected happiness! This shift of support has now been going on during a 50 year period in Sweden. This has only been able to continue as long as it has led to positive consequences for persons concerned!

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