

COMMUNITY BASED SERVICES AND THEIR CONTRIBUTION TO A NORMAL LIFE

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INTRODUCTION

The first part of this paper gives a brief view of the Swedish disability reform. The intention is to give a background so as to clarify what is going on in Swedish disability services. Without this, activities in this field would be hard to understand. A key concept commented upon here is the fact that there is a shift going on between two traditions of support, an institutional tradition is being dissolved while a community tradition is being developed.

The ambition of the second part is to give some rationality to the community based services being formed. Here is the idea of a normal life even for persons with a disability, being used. Community based services which at present contribute to this life are being presented. The importance of these is that the success of the ongoing transition lies in the availability of these services. Some achievements have been made, more need to be done.

The final part gives some conclusions relating to the ongoing shift between traditions of support.

THE SWEDISH DISABILITY REFORM

Support from society for persons with intellectual disability has undergone a dramatic change which culminated, on the last of December 1999, with the termination of residential institutions as a form of service for these persons. From then on, only community based services were recognized as applicable for persons requesting support. Of course this was not a sudden or unexpected decision. The actual transition from institutional to community based services had been taking place for three decades, during the 70:s, 80:s and the 90:s. And even this process of change had begun much earlier. The first time criticism of residential institutions had been publically voiced can be found in an official enquiry in 1946. A more detailed presentation of the change which has taken place has been presented elsewhere (Ericsson 2002).

In the enquiry of 1946 a new socio-political idea was presented. This pointed to the right of persons with a disability, irrespective of type, to use the modern welfare services which were to be developed in the welfare society being established after the second world war. By availing of public services, it was hoped that this would lead to a more normal life for persons and that they thereby would experience the same welfare as that being offered to the public at large. There was also a value dimension attached to this new idea, namely that it was a democratic right for persons with a disability to use these welfare services. Consequently they were recognized as members and full citizens of society. This new idea was, however, only applicable to those seen as "partially able-bodied", the expression of the time used for those with only a limited need for support. This new idea was called the normalization principle.

In the 40:s this principle characterized an idea, a vision, for new services and for a better life for persons with a disability, a view of life promoted by the disability movement of the time. Reality was, of course, another thing. During the second half of the 19th century residential institutions had been established and an institutionally based service was still dominant during the first decades of the 20th century. In the 40:s an institutional life, characterized by deficiencies and poor living conditions, was the only alternative offered to persons with intellectual disability. The realities of an institutional tradition, and reactions towards it, as expressed in a new socio-political idea represents therefore

the commencement of the Swedish disability reform which has continued for more than 50 years.

The means by which this change has been implemented has been through a series of Acts of Parliament, these being the official guidelines of society, setting the rules and providing the regulations for the delivery of services in all its aspects. Four acts were introduced, in 1954, 1967, 1985 and 1993. In consequence of their introduction a gradual shift towards community based services has taken place at the same time as institutionally based services have been phased out. The act of 1997, enforcing the closure of residential institutions as a service, dealt only with this issue.

The Acts of 1954 and 1967 stipulated the full responsibility of a special organization at county level, a regional organization, for persons with intellectual disability. Other welfare services were therefore relieved of any responsibility for these persons. This situation changed with the Act of 1980 which stipulated that the municipality had the ultimate responsibility for the welfare of all its inhabitants, including persons with a disability. This had consequences for the Acts of 1985 and 1993 which required that a special organization took responsibility for this special support which is supplementary to the welfare services as regulated by the Act of 1980.

In accordance these Acts specified that all persons with intellectual disability had the right to live the normal life in the local community to which they belonged and were to receive support through the local welfare services. The right to lead the normal life in the community to which he belongs, led to the closure of residential institutions. The person's right to use the local welfare services led in turn to the dissolution of the special county organization and, for the first time, the municipality was given responsibility for this group of persons. Through these measures important steps were taken towards the realization of the vision expressed by the normalization principle of 1946.

The first stage of the disability reform, the closure of residential institutions, took place during the 80:s and 90:s. The key to this was the development of community based services for all persons, even for those with an extensive need for support, those who traditionally had been seen as belonging to the institution. This shift from institutionally to community based services was carried out by the special disability organization of the county.

The second phase of the disability reform, the realization of the responsibility of local welfare services to accommodate persons with an intellectual disability, has now formally taken place. The municipalities have now full responsibility and the special county disability organization is dissolved. The task that lies ahead is to develop local welfare services which meet the needs of persons with an intellectual disability.

The implementation of the disability reform has taken place by means of what can be termed social innovations. Community based services had to be developed in order to create an alternative way of channelling the support from society outside of the traditional institutions. When this transition began little was known about how to realize it, but gradually ways have been found in which to organize support outside the institutions. To-day, for example, education is provided in ordinary schools, support to families is available, there are group-homes which make a personal home a reality and day services are established to provide purposeful daily activities.

Characterizing the change which has taken place during these more than 50 years, one can talk about a shift between two traditions of support. An institutional tradition grew out of the middle of the 19th century and a community tradition emerged from the reforms of the mid 20th century. The two traditions differ with regard to their view on the relationship between persons with a disability and society. While exclusion was the implication of the institutional tradition, inclusion into society is characteristic for the community tradition. In spite of the difference, both are a logical and a natural response to the conditions of different times and societies.

The actualization of this disability reform requires a development away from exclusion and towards inclusion into society, this being the major task for the realization of a shift between the two traditions of support. On an individual level participation and inclusion into community life needs to increase. On an organizational level forms of services need to be found in the community which contribute to participation and inclusion of persons, at the same time as institutionally based

services are dissolved. By reference to these different perspectives attention has been given to the change occurring on a cultural level. A citizen perspective needs to be formulated and developed at the same time as a deficiency oriented perspective, focussing on the person's lack of competence, needs to be discarded!

A NEW SOCIO-POLITICAL IDEA

The normal life

There is a relationship between the role attributed to the person with intellectual disability and the form given to services. The inhuman living environments were for example created when these persons were seen as inhuman. It is the church which gets the responsibility to organize support when society sees persons as the "child of God". Services are given a medical character when intellectual disability is seen as a medical problem and training programs are dominating services when the developmental model is applied by the educationalists.

The new idea, which was formulated at the beginning of the Swedish disability reform, saw these persons as citizens with a right to live the normal life lived by others. This meant that they would get the opportunity to live where others lived, to work where others worked and to participate in the community life lived by others. Support for this life would come from the welfare services arranged for others.

The first step towards realizing this idea of the normal life came with the introduction of non-institutional schooling. This occurred on a voluntary basis by some communities in the 30:s but became imperative with the Act of 1954. The school-child then lived in his family and went to school during daytime, just like all other school-children. When the child became an adult and no longer had the school to go to during daytime the need arose for some other form of activity away from home, during the day. This started the movement which led to the introduction of occupational homes, localized to places in the ordinary community. These were legislated through the Act of 1954.

After having lived in the family home as an adult for some time, having day services outside the home, the need arose to get some form of housing of one's own. Gradually this led to the arrangement of housing with support. In the beginning support was given by another family but soon staff was introduced. With housing and daily activities, both functions with support, the first and rudimentary steps were taken during the 50:s to set up what we today will call community based services.

During the 50:s and 60:s the normal life was also introduced when new residential institutions were built. They got their physical structure stimulated by this idea. There it meant that one separated the wards from the school, the daily activities and the sheltered workshops. But this normal life only took place within the grounds of the residential institution. This is the background against which the 1969 version of the normalization principle was formulated.

The right to the normal life for all, irrespective of degree of disability, came with the closure of residential institutions. During the 80:s and 90:s community based services were established as alternatives to the institutions so as to make the normal life possible even for those with a severe disability. These steps taken were important but services were still special in the sense that they were organized by the special organization for persons with intellectual disability, run by the county. Shifting the responsibility of disability services from this special regional organization to the local welfare services of the municipality, is therefore a contribution to the fulfilment of the idea of the normal life.

Everyday life through housing, daily activities and community participation

With an ambition to give support to the person with a disability to lead a more normal life one must clarify some of its characteristics. The major part of the normal life consists of two functions, a place for a home and another place for work. A person therefore needs some form of housing where he can set up his home and he needs a place outside his home where he can work.

There are differences as regards the character of these two parts of everyday life. The home is the

place of a person where he is private. This is therefore the place where he can lock the door behind himself and live the life he wants, without someone observing or intruding. He also gives his home a personal character as regards for example choice of furniture and other belongings. The place of work of a person is characterized by the fact that he is employed and he has the task of doing a job to earn his living. Therefore he is related to others and has got a more public role.

With these two functions as a platform he also participates in a number of ways in the life of local community. This takes place during the free time of a person, that is during evenings and week-ends when he is not at work or carrying out activities in his home. It is during this time of the week that he can do his shopping, see friends and family or enjoy activities for recreation and leisure. But there is also participation in community life during other parts of the day. Going to the dentist, visiting the local health centre or seeing a therapist are just some examples of functions which takes place during daytime, the time when a person usually is at work. Naturally this everyday life will vary between persons as they have preferences about how to live, to work and how to relate to local community.

In a study of persons with intellectual disability a structure was given to everyday life. Four areas emerged as important when this life was to be described. The two main ones are the person's housing and home (A) and his daily activities (B). In addition, the person's contacts with community life is seen as important. As this can emanate from the home as well as from the place for daily activities, two aspects can be described, participation in the life of local community through the home (C) and through daily activities (D). These four areas can be said to describe a person's daily life with regard to how he, in time and space, participates in and avails of settings, environments and activities during the day.

Eleven dimensions were chosen to characterize everyday life. "Activities in the home" (1) related to the activities of everyday life of the person in his home. This one was part of area (A), housing and a home. Participation in community life through the home (C) was covered by five dimensions. "The person and the neighbourhood" (2) illustrated his contacts with neighbours. "Recreation outside the home" (3) characterized the leisure activities in which the person participated. "Commercial services" (4) gave attention to the extent of the person's participation in shopping, for example for food and clothes. "Social contacts" (5) pointed to relations with persons outside the home, e.g. relatives, representatives or others who play a vital role in the person's life. "Services for personal well-being" (6) paid attention to whether the person benefited from services which contribute to his health and social well-being.

A person's life during daytime was characterized by the "person's daily activities" (7), the number of activities in which the person participated during a week. This is the area (B), daily activities. Participation in community life through daily activities, area (D), was made up of two dimensions. "Places and environments for daily activities" (8) and "social contacts in connection with activities" (9) pointed to the relationship to the environments where these activities took place.

While this example gave attention to the everyday life in time and space, these dimensions can also be described with regard to its quality. Three aspects were found as important, namely material standard, the nature of existing social relations and personal influence and integrity.

Services to realize a more normal life

If a more normal life is to become a reality for a person with a disability support must be channelled to places which make up the normal life. Support for housing need to be localized to housing-areas, where others live. Support for work, or some other form of daily activity like school or day service, needs to be localized to those places in a community where others go to school or where they have their place of work. Support must also be found in local community where the person wants to participate.

This has led to the creation of two forms of community based services for adults, housing with support and daily activities with support. These are two services, contributing in different ways so as to realize the two basic functions of the everyday life. As these are two forms of services, there are two different staff-groups who deliver support needed. Housing with support has the task of contributing to a home of the person and to his participation in community life. If the person has got

an employment in the open or the sheltered labour market, then this takes place outside disability services. But if the person hasn't got a job because of his disability, he is in need of support during daytime. Daily activities with support has the task of contributing to a good life during the five days of the week by offering a set of purposeful daily activities.

The residential institution had the task of offering support during the 24 hours of the day, if that was needed. Today when these institutions no longer exist, it is the task of these two community based services to offer support during the full day and night for those persons who have got a need for this.

Housing with support

Today when this service has been in use for several decades, and persons with all forms of disability live where others live, one will find a broad variation of housing with support. It is therefore not possible to describe this service in a simple way. One will find though that housing with support can be described in a number of dimensions.

Type of house will vary as you can find that an apartment, a villa, a semidetached house and a cottage is being used as housing for persons with an intellectual disability, that is all the forms of housing you will find in a community.

The persons in the house will make up its character. Their needs for support is one aspect as some will have a mild, others a more severe disability. Another aspect is the number of persons living in the house as there might be a single person or a group living there. If a public service has set up the house, today the group mustn't be larger than 5 persons.

The staff-group giving support is related to the needs of persons. If they have got extensive needs for support, the staff-group must be larger while if the needs are limited, the staff-group will be smaller. Another aspect of staff is their location in relation to persons. Some, because of their disability, need to have a close contact to staff and these must therefore be in the same house as the person. But there are also persons who manage quite well on their own and only need to have staff outside the house, on call if needed.

Location of the house is another dimension of housing with support. Type of housing-area is one aspect and the choice of this will depend very much on type of house which will be used. But there is also another aspect of location and this relates to the proximity to neighbours. To live where others live should be seen as a general ambition. There can be situations though which demands that the house of a person is set up in such a way that his disability, or unusual demands from a neighbourhood, does not give cause for conflict. This must be avoided and can therefore lead to the choice of locating a house to a place some distance away from neighbours.

Ownership also describes housing with support. The public disability service is naturally an owner of a large number of houses. But they can also be owned by the persons themselves, while the support of staff comes from the disability service. There are also examples where a group of parents buy a large house and rents this to their sons and daughters.

This multi-dimensional approach to the creation of a home for a person with an intellectual disability, naturally leads to the consequence that there is no single type of house which can be seen as suitable for this group. Instead housing and a home is personal. In a municipality, in a housing-area or a part of a community, you will therefore find a number of different types of housing. A staff-group who has got the responsibility to deliver support to several persons may find themselves being related to several types of housing. For administrative reasons there are also possibilities to create groups of housing with support, where this comes from the same staff-group.

The idea of the normal life has consequences for the life in the home. This is no longer a place of care of someone with a disability but a place for a person to lead the normal life he would like to live, naturally with the assistance of staff. The activities of a home will be the ones enjoyed by this person. The usual ones are of course the making of the meals. He also need to take care of his clothes and to clean his home. This is also a place for leisure and relaxation. Personal hygiene and care naturally takes place in the home and what others do behind their closed bed-room door, is

also done by these persons.

To staff in housing, there is also the task of assisting the person as regards his free time during week-ends and the evenings of working-days. This is the time when he participates in commercial services, leisure activities and when he makes cultural experiences. This is also the time when he meets his family and friends. For staff this represents a substantial social dimension of work, which makes working in housing to something more than just being put in a job in a house. At the same time all aspects of participation in community life need not take place with the assistance of staff. An important task is to mobilise the family and the social network of the person, to take a responsibility for some parts of his life.

In the frame-work of the community tradition this is a personal home, not a place of "care" or "training". You eat your food not to be hungry, you do not have "meal-training". You take a shower because you want to be clean, not to have "hygiene-training". You take part in the activities of your home because these have to be handled, not to have "ADL-training" (ADL: activities for daily life).

Daily activities with support

As this is a service its task is to contribute to a good life for the person with a disability. This is done by organizing and offering purposeful daily activities during the five days of the week to those who have been given the right to avail of this day service. One cannot point to any particular activity as being suitable. The activities in which a person will participate are instead related to his needs of support and his requests for a good life. Purposefulness is therefore not a characteristic of an activity but a relationship between the activity and the needs and requests from the person.

As all adult persons with an intellectual disability have the right to this service, one will find a broad variation of activities. A person with a mild disability may participate in activities of a productive nature, while some other with a more severe form of disability will participate in those which will contribute to his personal development. The description of this service in Lidingö gives an example of activities which can take place.

Originally this service was organized as a day activity centre, a house built for this purpose. In this, activities were arranged by a group of staff, with the resources which were allocated for this purpose. Those persons who had been given this service spent the five days of the week at the day activity centre, occupied with the activities available. The basis for the choice of activities for a person was a process of matching the needs of the person to the activities available. This led to an activity programme for the week. The size of the centre would vary as it was related to the number of people in the community which were in need of this service. Centres can be found with 10 as well as 60 persons.

The experiences of Lidingö represent an important new aspect of organizing disability services. While the day activity centre was a natural way for a county to establish this service, there are other conditions in a local community. The county covers several municipalities and has therefore not got local knowledge enough to be able to use local resources. The most easy way for them was to solve the task by building a special house and call it a day activity centre. The municipality has instead got relationships to local business, local organizations and local municipality services. Thereby activities, environments and persons from the local community can be found and make up the local resources which can be used when organizing daily activities. As local environments are available, it is not even necessary to build the special house where the day activity centre is located.

For the local community it is more logic to organize this service as a number of activity groups. This will enhance an ambition to participate in community life. An organization for daily activities will then consist of several groups, the number depending on how many persons have got the right to avail of this service. These activity groups will be localized to different places, dealing with different activities and with a variation of staff support, as the persons making up these groups have different needs. This will be illustrated later on as this is the way which Lidingö has organized this service.

Roles of housing and daily activities

This way of organizing community based services for adults has the consequence that there are

two services which deliver support to a person. The transparency between these two services is an alternative to the closed nature of the residential institution. As there are two staff-groups in this system of services, one delivering support through housing and the other through daily activities, the person's needs and requests are debated on a daily basis. This should then lead to an ambition to further the life of the person.

For staff this has meant a professional development as the rather diffuse role of someone giving care, has been clarified. Staff in the house is there to assist the person to lead the life lived in a home. Staff employed in the day service has the task of developing and delivering purposeful daily activities.

Services for personal development

The life lived through a home, daily activities and participation in community life, is lived by all persons with a disability. However, the variation is large between persons because of differences as regards needs and preferences for support. But there is also a need for personal development emanating from the disability of the person. As the disability is personal, there is no one service which can deal with this type of needs. Apart from the intellectual disability, which will vary as regards type and degree, the person may have additional disabilities for example with sight, hearing and mobility. He may also need help with the furthering of his social well-being and personality.

These are all examples of needs which demand professional support outside home and daily activities. Therefore the person will turn to those generic organizations, those which has the responsibility for the welfare of the public. Social services will assist in some cases while health services, like the district nurse, the local health centre and the various clinics of the hospital, will assist in the areas where they have got competence. To stress their responsibility for all citizens, even those with an intellectual disability, the Acts of Parliament which sets the rules for these areas clearly states the right of persons with a disability to use them.

The process leading up to services

Organizing services for a person with a disability is the result of a process which is being influenced by a number of factors, some contributing others hindering a positive outcome. Without making a full analysis, it must be pointed out that there is a demand for competence as regards community based services from staff and the organization for disability services. This is a period of transition from institutionally to community based services and one must be very clear about the direction of development and the sort of working methods and instruments needed to fulfill the new objectives.

One critical aspect is the perspective out of which the person and his disability is being defined. It has been mentioned that the logic of the community tradition comes out of a citizen perspective, when one sees the person as a citizen with a right to the normal life and the use of general welfare services. Conquering this perspective for staff and concerned people is one of the difficult tasks of this process of transition.

A factor which is brought forward in this tradition is the issue of influence and control over one's life, from the person with a disability together with his representative, in the process leading up to his services. When one sees that it is a natural thing for any person to have some control over one's life, he is invited to be part in the development of his services. This is not only a correct thing to do but it also contributes positively to the services being established as their degree of personal character, and thereby their quality, is increased.

When all persons with an intellectual disability have got the right to participation in community life, the degree of disability becomes a factor to handle when services are being organized. It is possible also for persons with a severe disability to participate and to receive support through community based services. But it becomes difficult to create personal services for these persons, as the present knowledge generally about severe disability is limited, as is the knowledge about the needs of a single person. When these persons are concerned there is a need for a strong commitment to realize a good life and a work which must be seen as a long-term task.

There is naturally an economic factor in this process of setting up community based services. At the same time this is said it must be pointed out that this is nothing special with these services. There is

always an economic issue present when giving support to persons who do not themselves earn their living. It can even be argued that community based services are less demanding economically as the normal life which is being organized is using the normal structures of society. When institutionally based services have the ambition to contribute to the normal life of persons they have to create them artificially. The quality of services is however higher in community based services as the normal life and a higher degree of personal services is present and this has economic consequences. But this does not only concern community based services as a similar degree of quality in institutionally based services would also be economically demanding.

As the form and content of community based services are closely related to the type of community where they are being organized, support to the person will have a local character. This means that type of housing will differ between communities, as a cottage in a village in the countryside may be the normal type of housing in this place, while an apartment in an residence for many families is the normal basis for a home in a large city. The same applies for daily activities. Those which are the more common forms of employment in a community make up the possible jobs from which daily activities are chosen. Persons living in the village and in the large city will therefore have different types of daily activities. It is important though to see that it is the same principle of community based services which is applied in the village as well as in the large city. It is the realization of the same idea, that of the normal life, which will differ.

CONCLUSIONS

In this process of transition between two traditions of support there are a number of conclusions which could be formulated, some will be referred to here. If there are community based services offering support to the extent that the needs of all persons are met, these services can constitute a full organization of disability services. Then there is no need for the residential institution! Persons with a disability are in need of support. If society chooses to localize its services to an institution, people will have to go there. If on the other hand services are localized by society to ordinary community, people can live there.

The key to a successful shift from institutional life to community participation lies in the creation of community based services. The person is of course in need of support and when this is available outside the institution, he can move to a new life. But as long as there are no alternative services, he will stay behind in the institution. When all persons have received services for participation in community life, the institution can be closed. But not until then!

A process of transition is facilitated if people who are concerned get the opportunity to participate. They will then have a role in the creation of community based services and they will understand and see in a concrete way what services are being offered as alternatives to the institution. They will also have a possibility to compare these two types of services. Families can be involved in planning the new life of their son or daughter and staff will contribute with their knowledge. The person with a disability has needs which have to be met and these have to be identified. The more close the relationship is between needs and services, the more successful will the new life become.

There is always a risk that the institutional tradition is being reproduced into the new community based services. This take place if people with an institutional background becomes too dominant in the creation of the new services. Even if there is a good will and ambition, one must recognize that there are limitations to have been running a residential institution if participation is to be achieved. To create good community based services, one must invite people with knowledge of town-planning, good housing and how to create jobs and welfare to people. For this there is often need for competence in social and community matters. The competence in this process of transition therefore needs to be broad, encompassing a wide variety of people.

We also have an institution in our mind! Even if the process of closing the physical institution is difficult, it is even more difficult to close the institution in the minds of people! One can see this as a change of perspective. How the issue of intellectual disability and the lives of these persons is seen will depend on the perspective of a person. The competence perspective of the institutional tradition, focussing the deficiencies of the person, needs to be dissolved and a citizen perspective needs to be conquered, stressing the rights of the person to the normal life.

It is easy to believe that the task is finished when the institution is closed. Unfortunately this is not the case. This is the time when the work starts. The dissolution of the institution was the means by which the normal life in ordinary community was to become a reality. So when the person has left institutional life, the work starts to establish the normal life for this person which was the ultimate goal of the shift between the two traditions of support.

REFERENCES

To get a more intensive introduction into Swedish services, visit my web-site www.skinfaxe.se and go to "Documents". You will find a number of reports, some in English. Ericsson, 2002: "From institutional life to community participation", gives a full view of the process of institutional closure in Sweden together with some of its context.