

A HOME FOR PARTICIPATION IN
COMMUNITY LIFE:
ON A KEY TASK FOR DISABILITY SERVICES

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This report is based on a presentation
at a disability conference in Dobogókö, Hungary
April 2005

It can be collected from the Internet on address
www.skinfaxe.se/ebok/dobo.pdf

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A HOME IN THE COMMUNITY

In Sweden today, all persons with intellectual disability live in community based housing. This is a new phenomena becoming a reality after the closure of residential institutions. The question is why this shift from institutionally to community based services has taken place.

When looking to the Swedish disability reform one finds that this started with a change of perspective on persons with a disability. The old institutional tradition was pessimistic and looked at persons as patients. The logical step was to organize institutions where they were placed.

During the last 50 years a new perspective has been developed, in Sweden and globally. With the oncoming of welfare societies and ideas of democracy and human rights, persons with a disability are being seen as citizens. As members of society, they have the right to live the normal life, the life lived by others in the community to which they belong. With the ambition to contribute to a normal life when organising disability services, the key task is the creation of a home in the community for a person. This becomes the platform for his participation in the life of the community.

THE PHYSICAL HOUSE

The basis for a home is naturally a physical house. But what sort of house can be used for a person with a disability? When looking at Swedish experiences one will find that any sort of house in a community can be used to set up a home. In this way apartments, villas and country-houses can be used. A consequence of this is the localization of homes to the housing-areas of towns and villages.

But there must be a personal choice of house. Not every house is suitable for every person. The disability of a person must be taken into account. When looking for a house for a single person one must choose the house which matches his needs.

For a person to be included into a community the use of ordinary housing is of importance. In this way he is a person who lives like other members of his community. For a group of persons who live together services must only be arranged in small groups. If the group becomes too big, one will not find ordinary housing in the community. The Swedish experience is that a group must not be larger than 5 persons.

The ambition to include the person into the community to which he belongs by choosing ordinary housing, has consequences for the architect. His task is to construct houses for persons with disability which look like ordinary houses for living, located to ordinary housing-areas. The character of the other houses of the community decides what is to be seen as an ordinary house. Local resources and local character becomes important issues in community based services.

SUPPORT FROM STAFF

The house is only the physical setting for a home. For a group to live there, they need support and this is delivered from staff. Like other aspects of disability services, this is personal and related to the needs of those living there. Only when a person receives the support he needs, he can live in the community. If those in a group mainly have a mild disability they need limited support from a small staff-group. The group with persons dominated by severe disability need more support from a larger staff-group.

The profession of members of the staff-group can vary. If there are medical needs in the group of persons living there, a nurse may be part of the staff-group. Another example is the group where persons are deaf. Then members of the staff-group must be able to communicate with sign-language.

A most important part when setting up community housing is to give the staff-group the training relevant for this type of service. Working as staff in the community demands being able to listen to personal needs as the group is small. As the house is situated in the community to which persons belong, there is a closeness to the families of the persons. Therefore staff must be able to relate to these families. Participation in community life means that persons use the commercial services like shops and the activities for leisure and recreation. Staff therefore need to be able to assist persons on these occasions.

SETTING UP OF NEW LIVES IN THE COMMUNITY

The idea brought forward so far has been that disability services are personal. There is a variation of needs among persons with a disability and there is a variation of disability services to be offered these persons. The key task is to create a personal relationship between persons and services. If there is a group who is to live together, the needs of this group must relate to services which are to be offered. Therefore, if a person is to set up his life in a community the task is to find the suitable physical house and the staff-group

which gives the support he needs. An assessment of his need for a home in the community must take place.

The example to follow (Ericsson 2002) illustrates the part of the process of setting up new lives. The group concerned were 322 persons living in a residential institution. Before they were to move to lives in the community, an assessment of each person was made to describe the new life each person was to lead and the services needed for this to become a reality. For each a conference was organised. The family of the person, his staff and relevant experts met to discuss the type of house needed, the degree of staff support and other additional services thought necessary.

The result from this assessment was the basis for the creation of non-institutional alternatives to the residential institution. In this way information was collected for example about the type of housing to be built, day services needed and other forms of welfare services which were to be offered these persons.

This assessment was carried out some time ago. The variation of community housing illustrates what was thought relevant at that time. Since then new experiences have been made and development has taken place. But basically the same process needs to be made today: a variation of housing needs to be offered and persons have to choose the most relevant form of housing.

The three types of housing in this example were: A) an apartment, with staff outside the house, available day and night according to need, B-a) an apartment, with staff inside the house, available day and night, B-v) a villa with a garden, with staff inside the house, available day and night. In housing type A the number of persons in an apartment could be 1-3, while the group in B was 5. The result of the assessment is shown below.

	Number of persons	Sum
Type A:	81 (25%)	
Type B-a:	107 (33%)	
Type B-v:	134 (42%)	322 (100%)

Two comments need to be made to these results. There is a variation in real life as regards the need for support among a group of persons with intellectual disability. The result also shows that persons living in a residential institution have extensive needs for support. They need close contact with staff and they need staff day and night. The follow-up study 10 years later shows that this assessment had been the basis for a building programme of housing for these persons. A slight shift had taken place though, as more persons had requested, and received, a home in type B-v, that is a villa with a garden, as this was seen as attractive.

THE HOME, A PLACE FOR PRIVACY

So far comments have been made about the use of physical buildings and about staff support which makes this into a disability service. But is this a home for persons living there? A home is more than a house and therefore this must be made into a home.

The basic characteristic of a home is its function as a place of privacy for a person, a place where one can live the life found desirable without outside demands on one's behaviour. One should be able to close one's door behind oneself and to live a private life. This is the place where one has got one's personal belongings, be it furniture, paintings and photos, and those small things which gives pleasant memories. A home is also the platform for participation in the life of the community, the place where one can receive family and friends. This is also where he should be able to feel safe and secure.

But how do we know what sort of home the person with a disability wants to live? What sort of private life does he prefer? The reality is that the answer lies with the person. It is he who knows what sort of life he wants to live. The task when setting up a home for him is therefore to get his thoughts and dreams about this life.

This is of course not an easy task. But there are methods which can be made part of a disability service which can give information about large and small aspects of the life he wants to live. If the person finds it difficult to express his requests, he needs a representative and family members to assist him with this (Ericsson et al 2004).

Once we have got his answer to this key question we have the objective for the support we offer this person. The life he wants to live is made up of a number of activities which need to be realized. For staff these are the tasks which are the content of their job, when delivering his disability support. The answer to the question of what sort of life the person wants to live is therefore also a benefit to staff as this gives them objectives and guidance.

A LIFE WITH QUALITY

Of equal importance is the follow-up. The person expressed requests for the sort of life he wanted to lead in his home. Staff then had the ambition to respond to these and to fulfill them. But did his requests become a reality? This becomes the key question for a conversation, the aim is to follow-up which of activities planned became a reality.

There are naturally several reasons for such a follow-up during the course of delivering disability support. One being a way to check whether the work of staff is well organized and carried out with relevance to the objectives of a disability service.

In this process there is also an answer to the quality of a disability service. Its primary objective is of course to contribute to a good life for the person with a disability. The answer of the person expressing the sort of life he wants to live is the starting point for an analysis of quality. The follow-up expressing whether his requests for a good life

had become a reality gives an answer to what sort of support he has received. If the life he experiences corresponds to a high degree with his requests for a good life, one can say that he lives a life with quality. On the other hand, if the life he experiences does not correspond to his requests, he lives a life with a low quality.

A FINAL COMMENT

Setting up a life for a person in the community to which he belongs is something which a disability service needs to be able to handle. Irrespective if the person concerned previously has lived with his or another family or in a residential institution, this is the task which forms the basis for a good life for the person and thereby for a successful disability service.

A home is here seen as having a centre position. This has been a discussion on how such a home can be formed. Finding a physical house is seen as the first step. Making this into a service depends on the support delivered by staff attached to this house. A home becomes a reality though, when the person can give this house a personal character and when he there can experience a life of privacy.

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