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**From Institutional  
Life to Community  
Participation**

Ideas and Realities Concerning  
Support to Persons with  
Intellectual Disability

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## ABSTRACT

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The right for everyone with an intellectual disability in Sweden to participate in community life has led to the closure of residential institutions. To understand this issue three questions were formulated: 1) why did this occur, 2) which services provide the alternatives and 3) has this transition led to community participation?

The origin of this transition was found in the normalization principle of 1946. A new socio-political idea marked the beginning of a gradual shift from institutionally to community based services. To realize the closure of residential institutions, services which offered extensive staffing and personal support had to be developed. The character of the welfare society has been the context for this transition.

Empirical studies provide information about the ongoing development. One group had the concept of community participation as basis for analysis. The ambition of the other was to gain an understanding through the experiences of those concerned, primarily the persons, their families and staff. These studies show that participation in community life had been achieved for the persons but there were limitations as one did not fully avail of the new forms of support which had been created. The possibilities to achieve participation in community life is discussed as a matter of realizing a shift between two traditions of support.

*Key words:* intellectual disability, normalization principle, deinstitutionalization, institutional closure, institutionally based services, community based services

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## List of empirical studies

The empirical data presented in this thesis have previously been published in eight studies from the project “Two worlds of services” (see chapter 1). These studies are numbered and listed below. They will be referred to by their number throughout the thesis.

Ericsson, K., Bjernevall-Nygren, E., Thorsell, M. and Widman, E., 1981. *Behov av alternativa omsorger efter utflyttning från Carlslund och Klockbacka*. (The need for alternative services after having moved from Carlslund and Klockbacka.) Study 1.

Lerman, B., Ericsson, K. and Nilsson, I., 1986. *Vardagen inom två omsorgsvärldar. Om personer med begåvningshandikapp inom institutionella och integrerade omsorgsformer*. (Everyday life in two worlds of services. Concerning persons with an intellectual disability in institutional and integrated services.) Study 2.

Brusén, P., Ericsson, K. and Thorsell, M., 1986. *En uppföljning av personer som flyttar från institution under avveckling*. (A follow-up study of persons who move from a residential institution being closed down.) Study 3.

Thorsell, M., Ericsson, K. and Brusén, P., 1986. *Att bli synlig!* (Becoming visible!) Study 4.

Ericsson, K., 1993. *Efter att ha flyttat från vårdhem. En uppföljning efter ett vårdhems avveckling*. (After having moved from the residential home. A follow-up study after the closure of a residential home.) Study 5.

Gilbertsson, S. and Ericsson, K., 1995. *Vad säger dom själva?* (What do persons say themselves?) Study 6.

Tuvesson, B. and Ericsson, K., 1995. *Nära varandra igen*. (Close to each other again.) Study 7.

Ericsson, K. and Dahlgren, C., 1995. *Personal om sitt arbete på vårdhem och gruppbostad*. (Staff views regarding their work at residential homes and in group homes.) Study 8.

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The lack of well-being and adequate support for persons with intellectual disability is an issue of global concern. When attempts are being made somewhere to enable these persons to live a better life, attention ought to be given to documentation and analysis of experiences for the furthering of knowledge.

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Kent Ericsson

## Chapter 1

### Development and closure of a residential institution: Introduction to a problem

The establishment of Carlslund residential home

At the beginning of the 20<sup>th</sup> century Mrs. Maria Krantzson left her appointment at an asylum in the south of Sweden. Together with her family, 8 children with intellectual disability and 4 staff she moved to Upplands-Väsby, a village 30 km north of Stockholm. There she had received permission to start an asylum for 38 persons in a building which previously had been a carpenter's workshop. As the name of the carpenter was Karl Engström, the place was given the name Carlslund (Olsson 1989). As there was an extensive need for services in the Stockholm area, the majority of those who were to be provided with care came from Stockholm City.

After her death in 1925 the establishment was run by a private association founded to carry on her work. Because of their extensive interest in the institution, the social authorities of Stockholm took on a responsibility for its management through their involvement in the association. A plan for an extension was made in 1926, but it was not realized. Of the three buildings planned as an exemplary monumental institution, only one was built, the ward later on to be called "Minnet" (Olsson 1986).

At the end of the 1940:s the institution had been approved for 172 residents. Although originally started as an asylum, it had also been approved as an occupational home for 22 women. Residential accommodation was provided for 25 staff. The total establishment then included 10 smaller buildings, spread throughout the grounds. At this stage the same building could cater for several functions, containing a ward for residents as well as providing staff accommodation. A kitchen and dining room could be in the same building as facilities for daily occupation. By the end of the 1940:s the buildings were seen to be in need of renovation (Stadskollegiets sinnesslövärdskommitté 1951, p.40-46).

As the private association was unable to carry out the programme of renovation, ownership was taken over by Stockholm City. Although no legal responsibility was stipulated for the care of these persons, the social authorities did have an ultimate obligation by way of their duties according to the laws of the time. In addition, various state enquiries had indicated that future legislation would come to regulate the responsibility of Stockholm City for the education and care required by this disability group. This resulted in the appointment of a committee in 1946, which presented a report regarding the modernization of services for persons with an intellectual disability in Stockholm (Stadskollegiets sinnesslövärdskommitté 1951, p.40-46).

A modern residential home

#### *The 1951 plan for development*

In the report from the committee suggesting improvements for the care of persons with an intellectual disability in Stockholm it was said about Carlslund that "... the present

buildings are in no condition to be used as pavilions for the feebleminded ..." (Stadskollegiets sinnesslövärdskommitté 1951, p.90). It was therefore suggested that an extensive building programme should take place, the ambition being to turn Carlslund into a modern institution for persons with an intellectual disability.

One of the issues discussed was how the responsibility for these persons should be met. Should services be provided in one and the same institution or in several? The enquiry considered it desirable to have a differentiated system for education and care. It was therefore thought necessary that there be various types of institutions and that these be located to different places. For this reason a new residential school was built for pre-school and school age children who were regarded as "educable". For the "educable" adults an occupational home was to be provided. Carlslund was designated as the residential home for the children, youth and adults seen as "uneducable". It was estimated that Carlslund would in this way be able to offer facilities for 600 persons.

In the planning of this residential home a "system of pavilions" was introduced thus providing for the services to take place in 7 pavilions. Whereas those for children were to house 60, pavilions for adults were to provide for 100 persons. With 4 pavilions for adults and 3 for children, the residential home would thereby be able to provide for a total of 580 persons. These pavilions were to be built in two-storey buildings.

In addition a building for administration and medical staff was provided. A kitchen was built for the preparation of meals for the wards and for the staff dining-room. A laundry, a heating centre and a technical service station were also part of the establishment. The suggestion was that this development should take place in three stages, while none of the buildings from the original Carlslund were to be retained (Stadskollegiets sinnesslövärdskommitté 1951, p.85-104).

### *An ambitious modernization*

The ambition to provide a better life for these persons can be found expressed in information leaflets and in the speeches held at inaugurations. One finds there the thoughts then held about what the residential home was intended to represent, namely a miniature of the average community. The ideal was the normal life being lived outside the institution. This implied a development and an enhanced standard compared to that previously provided within the institution:

A happy community (p.5) ... a community in miniature (p.6) ... As in the community at large, life consists of leisure and work. Children go to their "school", adults to their "work" with energy and pleasure (p.6) ... They have the same right as all others to live a secure and full life (p.7) ... It is the duty of society to provide resources so that the life for each one can be as favourable as possible (p.7). (Mehr 1958)

The thought behind this institution was simple. In its simplicity it was revolutionarily new. To create a type of miniature community for these persons, who, because of an adverse destiny, had been forced to spend their lives in an institution. A community whose demands were adjusted to individual ability, whose daily and yearly rhythm corresponded to the normal variations of life. As in the ordinary community, life should include both work and leisure. It should be possible to leave one's home to go to a school or a job, to experience the pleasure of achievements which are appreciated and of contact with others. For leisure many different activities were provided, festivals to be celebrated, both private and those in which the whole neighbourhood participates, one has visitors and one takes part in various outings. (Carlsson 1965, p.2-3)

The intention with a "system of pavilions" was to counteract an institutional impression:

When planning it has been seen as especially important to avoid and counteract the character of institution. The pavilions have been placed on an irregular basis in the grounds and been concealed from each other by the use of plants and foliage. (Carlslund 1958, p.11)

The ambition to differentiate was also a principle which influenced the formation of Carlslund:

The more severe cases have, for reasons of supervision and nursing, been put together in the large pavilions. The pavilions for the pupils who can be occupied to some extent are considerably smaller and have a more homelike character. For the older pupils, who can care for themselves without so much supervision, pavilions with rooms for one or two beds are available. (Carlslund 1958, p.11)

Behind the endeavour to differentiate was the idea of separating persons in order to create a variation of wards. This differentiation also had consequences for the task to be performed:

Cases which previously had undoubtedly been described as "uneducable" could now be moved to the "educable" category. A goal for the future must be to reduce those categorized as "uneducable" and increase the extent to which the mentally defective be made capable of having a normal productive existence. (Stadskollegiets utlåtande och memorial 1951, p.708)

But there were financial limitations to the good will which undoubtedly existed among those who planned the institution:

Carlslund residential home ... will be too large if there are facilities for 600, even if it is planned as a system of pavilions. ... The financial view ... recommends however, a concentration to one area, in particular concerning the effective use being made of the administrative buildings. (Stadskollegiets utlåtande och memorial 1951, p.706)

The fact that economic issues also played a part in the structure of the institution being built, is illustrated by the discussion on the size of the rooms. The theme of either two or three beds towards each wall, became a question of four or six beds for each room:

The question as to whether there should be two or three beds in each row has been discussed from different aspects. Having two is not as suitable from a management point of view. Supervision is more difficult. The ward must also be longer, making for harder work. The advantage, that it makes the situation more homelike, has generally no significance with the clientele in question. The committee has therefore decided to have three deep, this also being a more economic alternative. (Stadskollegiets sinnesslövärdskommitté 1951, p.97)

The documents reveal an optimism over what one hoped to achieve through the institution. The development of Carlslund residential home, which represented a new approach and a willingness to invest in services for this group of persons, was at the time regarded as innovative. Those who previously had received so little attention as the "uneducable", had been limited to a life under meagre conditions. Through expansion, the needs of this group were recognized. At the same time, however, there were financial limits under which these ambitions were to be realized.

### *An expansion in three phases*

The building programme started according to the 1951 plan but was only followed initially. Only two of the seven planned pavilions were built, one for children and one for adults. The service buildings were also built. This first phase was officially inaugurated in 1954. During the 1950:s staff housing was also built in the vicinity. This was a way, in a time of staff and housing shortages, of ensuring recruitment of staff.

During the continued expansion, the second phase, the original plan was modified. Only one more pavilion was built in two-stories, however it was designed like a terrace house and was more homelike in character. Two successive pavilions were built on ground level. The corridors of the ward, which in the early two-storey building were on different floors, were now alongside each other on the same level. The rooms for the residents varied in size, some provided for 1 person while others provided for up to 6 persons. But even the model which these buildings represented was further modified when the following two wards were built. Each was formed as a separate building but half as large as previously. During this phase, which was completed in 1958, a special building for occupational therapy and leisure activities was also built.

The series of pavilions which were built during the third phase were further modified. In these the two corridors with rooms on each side were replaced as detached wings extending from a central building which contained common facilities. In this way the corridors, and thus the rooms, had been further removed from each other. This third phase was completed in 1965. By then the need for occupational facilities had been acknowledged. There had, admittedly, been "therapy-rooms" on some of the wards but now a sheltered workshop was built.

When the new buildings and the renovation work had been completed, the residential home consisted of a total of 33 buildings spread throughout the grounds. The area was surrounded by woodland and within there were many trees, shrubs and green areas, the ambition being that the buildings should blend into the surroundings, not seeming too dominant. However, the institution consisted not only of newly built buildings, but also of the older buildings from the old asylum which were still being used as wards.

### *Development continues*

During the 1960:s it was acknowledged that the first pavilion for adults was unsuitable as the care being provided there took place in too large groups. The 4 wards of this pavilion were therefore renovated so that persons could be cared for in 12 smaller groups. Some persons were also moved to the wards which had been built during the third phase so fewer had to be cared for in this building.

Persons were also moved to other residential homes which had been established in the county. One group was moved to a residential home in the southern part of Stockholm when it was opened in the latter part of the 1960:s, another group was moved when yet another residential home was opened at the beginning of the 1970:s.

As Carlslund was intended for the "uneducable" no plans had been made to provide a school. As a consequence of the 1967 Act, which stipulated that education should be provided even for this group of children and youth, a school was built in the grounds.

## Reactions against the residential home

### *Institutional critique*

Families wished to contribute to the development of the institution and therefore took initiatives to organize activities during day-time and leisure. As Carlslund was located some distance from Stockholm City it was found difficult to travel there and back. It was therefore seen as an important task to facilitate the desire of families to maintain and to develop their contacts with a son or a daughter, a brother or a sister. This was achieved primarily by providing travelling arrangements to simplify the journey to and from Carlslund.

Another ambition was to develop a more open and accessible approach, the institution being considered too isolated. The arrangement of leisure and holiday activities outside the premises is one example of changes that did occur. During the 1970:s more formalized contacts were established by way of regular meetings between families and the management. This practice was made use of to express views and requests concerning the improvement of the service. Amongst other things, demands were made for more resources and for the appointment of new categories of staff (Gunnarsson 1989).

The first years of the 1970:s was a period when the work carried on was criticized, questioned and challenged. Discussions began regarding new forms of organization at the institution. This was partially stimulated by the institutional debate in other parts of the country where the special hospitals and the form of care they provided, were subjected to increasing criticism (Axeheim 1972; Ericsson, K. & Ericsson, P. 1975; Ericsson, P., et al. 1973; Kylén 1972). This contributed to the forcefully expressed criticism of Carlslund and the low standards of the institution (Elwin 1976; Gunnarsson 1989).

Much of this criticism was formulated within the staff group. The strict hierarchical structure which existed was a cause for reaction and demands were made that staff who worked on the wards be given more opportunities to take responsibility. This was considered a basic requirement if the work being done on the ward was to meet the needs of those who were being cared for (Elwin 1976).

During these years increasing publicity was given to the shortcomings of the institution. Irregularities which were brought to light in the national press concerned, amongst other things, maltreatment and staff conflicts (Aftonbladet 1975, 1976; Dagens Nyheter 1974; Expressen 1974).

One of the contributions to this public debate was a collection of poems written by the medical doctor of the institution. In this form she expressed experiences from her encounter with a large institution with many persons with severe disabilities and unacceptable conditions of care. The picture she gave described the hopelessness of the situation, actions which all too often were destructive and emotions which often remained unacknowledged (Dahlin 1975). These poems gave rise to strong emotional reactions from staff, families and the general public and to a continued debate regarding conditions at the institution (Dagens Nyheter 1975).

The National Board of Health and Welfare, having responsibility for supervision of services, had carried out an inspection at the institution in 1971. Conditions were severely criticized, irregularities being apparent on 41 points. Apart from the criticism of the treatment of persons, the main objection concerned the size of the wards, the low

ratio of staff and the low level of resources. The criticism expressed in the report came "... as a storm from a clear blue sky. Carlslund became an out-dated badly equipped institution overnight" (Abrahamsson and Røren 1975, p.29). This led to demands for extensive improvements and restructuring of the institution. The criticism was acknowledged and explanations were given by the responsible administrator of the time in Stockholm County:

An institution for 450 persons is too large. But if they are to receive the sort of care which is possible, society will refuse. It would cost too much. In principle we should give them all that can be envisaged. Those are the norms which guide the National Board of Health and Welfare. The board assesses the needs, not the costs. (Citation from Abrahamsson and Røren 1975, p.26)

The organization of the institution was also criticized, a matter which led to a prolonged process in which more suitable forms of care were sought. During this period viewpoints differed as to how services for persons with an intellectual disability should be organized. Suggestions were made by central administration which favoured a traditional hierarchical organization, whereas staff groups supported a type of organization which gave as much responsibility as possible to those on the wards who worked directly with the persons receiving care (Abrahamsson and Røren 1975).

### *Community based services*

New conditions for a change of view of the institution developed as a consequence of the administrative merger of Stockholm City and Stockholm County in 1971, resulting in the creation of a county authority with responsibility for the entire Stockholm region (Fritz 1996). It was very soon established that services were in need of improvement. To commence this process and to clarify the type of future services, a survey of all persons with intellectual disability in the county was carried out and a plan for their development presented (Kjellgren 1996; Omsorgsnämnden 1977).

In this, community based services were recognized and it was considered desirable that they be developed in such a manner that they become available for persons with a more severe disability than had previously been possible. A programme was therefore presented suggesting housing in small groups, with support from a larger number of staff than formerly had been common. The study also included a programme for the development of daily activities at day activity centres. There were no plans for a new large institution but smaller residential institutions were, however, considered acceptable (Omsorgsnämnden 1977).

The residential home at the end of the 1970:s

### *The wards*

Table 1:1 accounts for the wards at Carlslund during the latter part of the 1970:s. In all 332 persons were resident there at the time. The table contains two sections. In part A the number of persons during 1978 is recorded, as is their mean age and sex. In part B one sees the number of persons who in 1980 shared a room.

Table 1:1. The wards of Carlslund. A: Information from 1978 showing the number of persons and their mean age. B: Information from 1980 showing the number of multi-bed rooms occupied with 2, 3 or 4 persons.

Ward	A: Persons and their mean age (1978).				B: Number of multi-bed rooms (1980).		
	Number	Age	Men	Women	Two-bed	Three-bed	Four-bed
The old institution							
EH	11	47.0	0	11	3	0	0
M	14	53.8	0	14	5	0	0
Phase one							
A1	30	33.2	23	7	3	3	0
A2	32	32.8	19	13	6	3	0
B1	20	25.5	11	9	3	3	0
B2	19	20.2	13	6	2	3	0
Phase two							
D1	20	50.3	4	16	2	4	0
D2	21	49.6	21	0	2	3	1
F	20	43.3	0	20	4	3	0
G	22	25.9	12	10	4	1	2
H1	12	34.1	11	1	2	0	0
H2	13	37.0	13	0	-	-	-
H3	12	43.7	6	6	-	-	-
Phase three							
O1	10	35.0	10	0	3	0	0
O2	10	33.0	0	10	3	0	0
P1	8	20.1	6	2	0	0	0
P2	11	22.9	9	2	0	0	0
X1	10	31.0	10	0	1	0	0
X2	10	30.0	3	7	1	0	0
Decentralization							
Pb	13	45.5	6	7	0	0	0
Sh	14	50.2	9	5	0	0	0
Sum:	332						
Number of rooms:					44	23	3

The wards are divided into four groups. Two wards fall into the category "the old institution", these having been established prior to the modernization of the residential home. "Phase one", "phase two" and "phase three" are the three stages during the building of the modern residential home. The category "decentralization" represents the two wards that had detached themselves from the main institution in order to work under more independent conditions. At this stage many persons had left the institution and ward C was no longer used for residential care, but as a place for daily activities.

The size of a ward depended partly on when it had been built. Those named EH and M belonged to the original institution. They were not numerically large in this context but they were, because of the limited space, overcrowded. Wards A and B, pavilions built during the first phase, were the large ones. In order to facilitate care being provided in small groups, each ward was divided into two sections. Those started during the second phase, D, H, F and G, were smaller and during the third phase wards were even smaller, as can be seen from the size of wards O, P and X. The two wards Pb and Sh, established during the change towards decentralization, were both small.

Table 1:2. Persons who left Carlslund between 1968-1978 according to the type of service they were receiving at the end of 1978.

Type of service	Number
Special hospital	15 (9%)
Residential home	62 (38%)
Local residential home	18 (11%)
Group-home	14 (8%)
Private home	16 (10%)
Miscellaneous	39 (24%)
Total	164 (100%)

There is also a difference between the ages of the persons. The average age was high on D, EH, M, Pb and Sh as these were persons who had lived in the original institution. Wards like B, P and X were pronouncedly for children and youth who had been admitted to the modern institution. At this period it was not regarded as natural to have both sexes on the same ward. Of the 21 units, 8 were dominated by one sex and on a few more, one of the sexes was clearly over-represented (Lycknert 1978).

It was not intended that each person should have his own room. In 1980 a survey was conducted which showed the extent to which persons shared rooms (Omsorgsnämnden 1981). This is shown as part B of table 1:1. Prior to that it was even more common that many shared rooms. The survey showed that 88 persons shared a double room, 69 persons shared a room for 3 and 12 persons were in rooms for 4, a total of 169 who shared their bedroom with someone else. At this time there were 301 persons in the institution as ward Sh had been closed. This meant that 59% of those at the institution shared their room with others.

### *Persons leaving the residential home*

As the institution was extended, following the three phases of expansion, the number of residents had increased to a total of 522 persons in 1965. As a reaction efforts were made to develop forms of care in smaller groups and this in turn resulted in persons having to leave. Table 1:2 shows a group of 164 persons who left the institution between 1968-1978, recorded according to the type of service they received at the end of 1978 (Borg 1980).

The category special hospital is represented by two special hospitals, large institutions with a distinct medical and psychiatric approach, located outside the Stockholm region. Persons were moved there when the provisions at the residential home were considered insufficient. Residential home is a category represented by two large residential homes in the Stockholm region with the same type of resources as Carlslund. One of the functions of these two residential homes was to enable persons to move from Carlslund, thus reducing the number of persons living there. The category local residential home was a smaller institution located in central Stockholm, offering a more limited amount of support than Carlslund. Persons who were resident there had a limited need for support so those who were moved from Carlslund were those

considered no longer to be in need of the resources of the large residential home.

Group-home is a category which covers a non-institutional residence, either for children or adults. Private home is the home of a family. Miscellaneous is a category including 24 institutions, both large and small, most of them outside the Stockholm region, usually for persons with a limited need for support.

When persons left Carlslund at this time they moved mostly to another residential institution, only a few, 18%, moving to community based services or a private home. The reason for this low number is of course that the services of that period were not available for those who were admitted to a residential home, as housing in the community did not provide adequate support.

## Closure of the residential home

### *Alternative futures*

By the mid-1970:s there was a well formulated demand that improved services be created for persons then at Carlslund residential home. This was also expressed as a political conviction publicly conveyed in the ongoing survey. The question of the future of Carlslund was also under discussion due to the pending decision of the National Board of Health and Welfare on the renewal of their authorization for the continuation of care (Socialstyrelsen 1975). Their decision was made in January 1975 and approval was granted only for the remainder of the year, allowing facilities for 328 adults and 59 children. In order to receive further authorization a long-term plan, including a reduction in numbers, was to be submitted.

In 1975 the county organization responsible appointed a working group for the task of drafting such a plan, "The future of Carlslund". The objective suggested was a total renovation to establish a modern institution for 200 persons (Omsorgsnämnden 1975). This would allow for that number to remain whereas a further 150 persons would have to move.

There was, however, another alternative. This suggested that persons presently at Carlslund should be included amongst those who were to gain from the general development of services being carried out in the county. This alternative implied that all should be able to avail of the new community based services being developed and therefore all must leave the residential home. With this alternative the institution would close. This was the alternative chosen by the Board of Special Services responsible for these services (Omsorgsnämnden 1976).

### *A plan of closure*

This decision heralded, for the first time, the closure of a residential home for adults belonging to the series of institutions which had been built throughout the country between the mid-1950:s and the mid-1970:s. As a consequence a number of new issues had to be solved if the decision was to be carried through. The task of preparing for the closure took place in a planning project, those taking part being representatives for the groups who were to be affected by the decision. Families to those living at the institution were included, as were representatives for the various staff unions

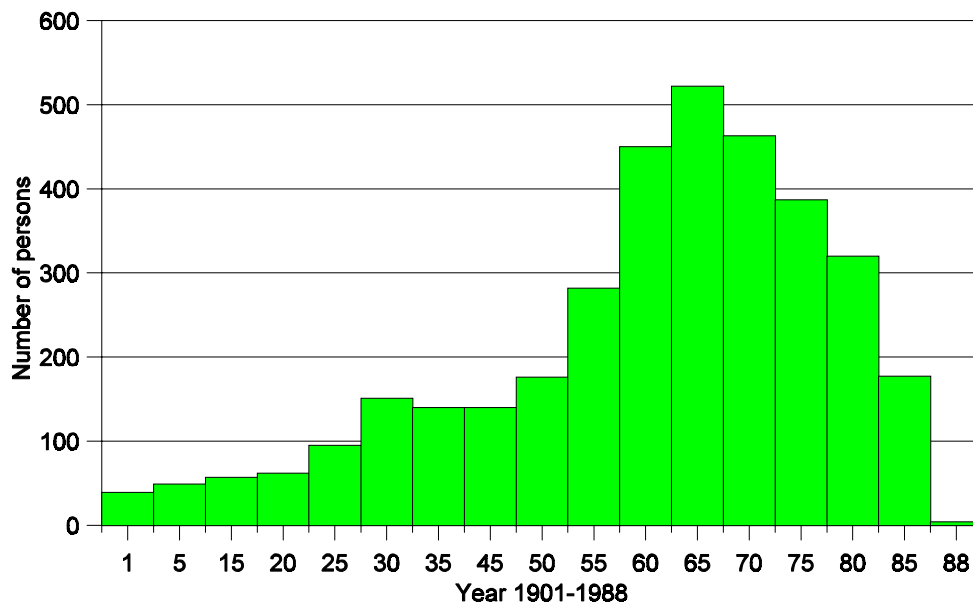


Figure 1:1. The number of persons at Carlslund residential home from 1901 when the home was founded until 1988 when it was closed down. The number of persons indicate the mean for each 5-year period.

concerned. The management of the institution and staff involved in the preparation of the closure also took part, as well as representatives from central management and its planning department. The project was headed by three politicians.

A working group was appointed to carry out the various analyses which were required for the plan of closure to be delivered. Persons were appointed to work with administrative and financial issues, with the question of community based services and for the analysis of staff issues connected with the closure. It was within this project that the debate took place concerning the terms on which the process of change was to be carried out. Families played a particularly active role in arguing for the quality of future services (Brunskog 1989; Gunnarsson 1989).

The question of which services would replace the institution was critical, closure being possible only if there were adequate alternative services for the persons to move to. The project started its task by carrying out a study, specifying each person's need of alternative services (Ericsson et al. 1981). A corresponding study of staff interests and opportunities for continuing to work in community based services was also carried out. These were included in the final plan presented by the project, which proposed the development of the community based services to which persons were to move and thereby the closure of Carlslund residential home (Omsorgsnämnden 1981).

#### *Realization of closure*

It is difficult to point to a particular year when work started on the closure of the institution. The number of places, 600, as envisaged in the original plan, was never

realized. Ever since the maximum number, 522 in 1965, persons were moved to other institutions and efforts were continuously made to reduce the size of the groups. After the 1976 decision to close the residential home persons continued to move and as a consequence the total number was gradually reduced. However, when the plan of closure had been presented in 1981 and a decision made concerning which conditions applied for the remaining last years, the process acquired a clearer sense of direction. During the years 1980-1988 systematic work took place to establish the new community based services required to replace the institution. Conditions were therefore created for the persons to leave the residential home.

The development and dissolution of Carlslund residential home can be summed up in the number of persons who have lived there. Figure 1:1 shows the number for each 5-year period from the establishment in 1901 to the closure in 1988. To begin with, up until 1920, the institution was relatively small with less than 100 places. In 1925 the numbers started to increase and by 1950 had reached 172. The larger numbers came with the modernization of the institution in the 10 year period between 1955 and 1965. After that it is quickly reduced in size, there finally being only 4 persons left during the first months of 1988, when it finally was closed down (Scharin 1993).

## Discussion

### *Development and dissolution*

The first 50 years, from 1901 and thereafter, constitutes the first era for this residential home which is characterized partly by an ambition to expand and improve the care being provided, but also by the reality of meagre financial resources which limited the extent to which these ambitions could be realized. This situation is well illustrated by the grandiose plans for new buildings made during the earlier part of the 1920:s, but which had to be abandoned because of the lack of resources.

At the beginning of the 1950:s, with the dawn of the welfare society indicating heightened social ambitions for persons with disability and increasing economic resources for the social sector, the extension of Carlslund as a modern residential home was begun and continued throughout the 1950:s and 1960:s. During this second era the aim was to implement the building plans in order to increase the number of places. But the number once envisaged was never reached as it would have led to an unacceptable environment for care. During a third era the building programme continued but now with new models for the wards which provided more positive environments. A school and premises for daily activities were also introduced as new components in the services provided at the institution.

Behind this change in direction for the development of the residential home one finds the recognition and acceptance of the view that the large institution, as once planned, would not have been able to provide a desirable service. This viewpoint was based to a large extent on the criticism being expressed by families and staff. The miserable conditions that persons with an intellectual disability had been forced to experience had led to increased public expressions of indignation and disapproval. Following the launching of the new programme for development of community based services in the county, criticism of Carlslund as a residential home became even more extensive. New groups outside the institution, also expressed the view that even the

persons at Carlslund should be given the opportunity to avail of the services being developed in the new programmes. The fourth era, covering the first half of the 1970:s, represented therefore a period of continued criticism and questioning of the services being provided.

The criticism was accepted by the responsible politicians who began planning for the future services required for the persons then living at Carlslund. At this point a choice arose, one alternative being a restructuring of the institution for a smaller number of persons, at the same time as a number would have to leave. The other alternative implied that all should have access to the community based services which would be made available through the development programme. The latter alternative was chosen, the consequences being that all should leave the institution and that it be dissolved as a place of care for persons with intellectual disability. This gave rise to an extensive planning task. The fifth era consisted therefore of the task of formulating the future services for these persons. During the sixth era which took place throughout the 1980:s, the task was that of creating new community based services. Hand in hand with their establishment persons were able to leave the institution and it, in turn, could be closed down.

### *The modern residential home*

The modern residential home, which Carlslund was intended to be, redressing the deficiencies in the care provided in the 1930:s and 1940:s for persons with severe disabilities, is well described in the 1951 enquiry regarding the future services in Stockholm. As this was the first residential home of a series which would later be built around the country during the period from the mid-1950:s to the mid-1970:s, the model on which Carlslund was based came to influence the others. One of the concepts which one finds is the idea of a differentiation within the services for persons with intellectual disabilities. It was intended to create a variation between institutions so that persons with a similar disability could be cared for at the same place, a specialization of the care being provided. As a consequence Stockholm City started a school specially for “educable“ children and an occupational home for the “educable” adults. Carlslund was to be the place for the care of the “uneducable”, those with severe disabilities who were not admitted to the other institutions. The system of pavilions, which had been applied in the development of Carlslund, represented the same idea of differentiation, but within the framework of the institution. In this way a variation between the wards was established, each one providing for a group of persons with similar disabilities.

Another idea which one finds is the ambition of allowing normal life, the life led by the general public, to influence the pattern of life at the residential home. Separation of housing from the school or place of work was one example as was the idea of allowing the normal variations of a day, a week and a year, also to effect the daily life of a person. This was an innovation which contributed to a new type of residential home.

However, in the document describing these ideas regarding the future development of Carlslund as a residential home, one also finds the group of persons who were going to be resident there being described in a rather degrading manner. These derogatory views were related to the financial arguments advocating cheap large-scale management, thereby denying these persons the services they required. The miserable conditions which were found at the home during the 1970:s can be more

easily understood in the light of these attitudes. Accordingly, in the plan for how it was intended that the institution should be run, one can find the key to an understanding not only of the positive development which this institution represented, but also of the problems which in the end led to its dissolution.

### *Normalization in everyday life*

The normalization of the person's daily life at the residential home contributed to the development of the institution. However, it was when normalization came to influence the community based services that criticism of institutions became more widespread and public. The living-standards and conditions of life which community based housing and daily activities offered were the starting point for the criticism of institutions generally around the country and especially in relation to Carlslund. This process also contributed to the conceptualization of the new models for services which were beginning to be formulated. The Stockholm model for community based services (Omsorgsnämnden 1977) later led to a general acceptance of these new goals.

Seen in this context the decision to dissolve the institution appears natural. The politically responsible board had recognized the need for improved conditions of living for persons at Carlslund at the same time as a general plan had been presented in the organization which meant that community based services had emerged as the desirable alternative. Thereby a political majority was created around the decision to close the institution.

During the years several steps had been taken at Carlslund residential home to better the lives of the persons. When housing and daily activities with support were provided in the community, outside the institution, the normalization of everyday life once again led to a development for persons. This time the persons left the institution, each to a new life.

### Problem and questions for research

#### *Institutional closure and its personal consequences*

After 75 years of providing its support Carlslund residential home was questioned as a service during the middle of the 1970:s. New ideas about standards of living and participation in community life for persons with an intellectual disability had been formed and had made new demands on the delivery of support from society. As these could not be met a situation arose when politicians responsible for services were faced with a choice. Either the residential home must be renovated or new forms of support outside the institution must be offered. The choice of the latter alternative was unexpected for those who were associated with the residential home. Up until then this had been a home for adults and seen as the only form of service which could be organized for persons with extensive needs for support. The closing of the residential home and its consequences for persons who were to move was therefore seen as a major problem

### *Three questions for research*

Three questions became central before, during and after the transition of services which has been illustrated in chapter 1. Even if this residential institution had been the subject of criticism, for the families, staff and others concerned it was not indisputable that it should be closed. The question of why this should take place was therefore one of the first issues to be addressed. This question was repeatedly asked, not just during the planning phase, even while closure was taking place. It has also been asked by some people long after the closure was completed. Today, when institutional closure has become an established part of current legislation, it is still of relevance to ask this question. The first research question is therefore: *why close a residential institution for persons with an intellectual disability?* The answer to this question is dealt with in chapters 2-3.

In order to close the residential institution it was replaced with community based forms of support, but the development of these took place within the framework of the planning of the closure. Those concerned therefore found themselves in the situation that they knew that the institution was to be closed, but did not know how it would be replaced. The question as to which services would constitute the alternatives was therefore relevant. Today there is knowledge, acquired from a follow-up study, regarding the alternatives to this particular institution. However, a discussion continues about the meaning of community based services, especially for persons with an extensive need of support. The second research question is therefore: *what forms of community based support are needed in order to replace the residential institution when it is to be closed?* This question is handled in chapter 4.

A further question concerns the consequences on persons after having left the institution. Beneath this question lies the worries felt regarding those who have moved, particularly as the majority had spent most of their lives in a residential institution. This issue was accentuated by the fact that information was generally lacking, the closure of Carlslund residential home being the first of its kind. At the time the change in the lives of persons was seen as a shift from an institutional life to participation in community life. The third research question is therefore expressed in this way: *do community based services contribute to an increase in persons' participation in community life after institutional closure?* The answer to this question is dealt with in chapters 5-9.

### *Project Two worlds of services*

Following the decision to close Carlslund residential home, I was invited to join the group whose task it was to plan the closure of the institution. My role was to handle the issues concerning development of community based services for the persons who were to move. This was the period when Study 1, the assessment of needs for community based forms of support, was carried out (Ericsson et al. 1981).

As a consequence of my earlier research experiences of services for persons with an intellectual disability, I was also asked to initiate a research project to analyze the ongoing process of change. Thus the project "Two worlds of services" was conceived in order to analyze the transition from institutionally to community based services (Ericsson 1980).

The expression "two worlds of services" was formulated in an earlier project

concerning the evaluation of community based forms of support. From this it emerged that these had a different structure and thereby provided a different everyday life to that of institutionally based services. A service organization with institutionally as well as community based forms of support thereby offers persons with a disability a life in one of two entirely different worlds. As there are variations in conditions for personal development in these, the choice of type of service made for a person has immense consequences (Ericsson 1981a).

In this project the problem has been the focus for a number of studies and analyses during the years. The material to be presented here is collected from this project and represents my position today in relation to the issue of “two worlds of services”. The documents which have been used are presented in the first part of the list of publications. There is also a presentation of projects and publications from project “Two worlds of services” (Ericsson 2001b).

### *Two fundamental concepts*

The concepts institutionally based and community based services have been used in this project. Practically and legislatively they comprise two different forms of support. A characteristic feature of the residential home is that within an institutional area one finds a facility for the care of many persons, all with an intellectual disability. In the series of residential institutions in Sweden of which Carlslund was one, the size of the institution varied from 200-600 places when they were originally built. The institution also represented a totality in that one found, within the institutional grounds, all the functions which it was thought that persons belonging to this group could require. They were also located to large areas set well apart from the local community. Carlslund residential home as presented earlier in this chapter is a good example of institutionally based services (Åhman 1976).

Community based forms of support have acquired their structure through the endeavour to contribute to the person’s participation in community life. They are therefore located to areas in the community where others lead their lives. Out of necessity these services must be small as housing with support must, for example, be comparable in size to other housing in order to be located to local housing areas. The place where the person has his activities during the day is also located to places in community where others spend their working day. As community based services are spread to different places in a neighbourhood, they lack totality. A model illustrating these services is presented in chapter 4.

### *The chapters to follow*

Chapter 1 has presented the transition from institutionally to community based services when a residential home is being closed. In chapter 2 this is related to the development of services in Sweden in order to clarify the presence and nature of this transition on a national level. In this chapter international aspects are also given. In chapter 3 the principle of normalization is presented and elaborated on. Chapters 2 and 3 give the basis for an answer to the first research question presented in chapter 3.

In chapter 4 the alternative services which replaced Carlslund residential home

are described. The planning process of these is accounted for, based on an assessment of personal needs of support (Study 1). A follow-up of which services came to replace the residential home is also presented (Study 5). This material is the background to the answer to the second research question given in chapter 4.

Chapters 5-9 accounts for the consequences for persons with an intellectual disability after they have left an institution which is being closed down. Chapter 5 introduces a series of empirical studies as well as the model for an analysis of participation in community life. In chapter 6 a cross-sectional study is presented (Study 2), in chapter 7 a longitudinal study is summed up (Study 3) and in chapter 8 the follow-up study (Study 5) carried out after the closure of the residential home is presented. In chapter 9 the analysis of community participation is summed up and commented on. Also in this chapter information is added from four studies which present how three parties concerned, the persons themselves (Study 6), families (Study 7) and staff (Study 4 and Study 8), account for their experiences of the process of transition. This forms the basis to an answer to the third research question given in chapter 9.

Chapter 10 contains a discussion of the transition of services and its context. Possibilities to further persons' participation in community life are also discussed against the background of a development of community based forms of support. Comments are given from a wider frame of reference which perceives the ongoing change as a shift between two traditions of support.

## Chapter 2

### Transition from institutionally to community based forms of support

During the latter half of the 20<sup>th</sup> century support from society to persons with an intellectual disability has gone through a transition from institutionally to community based forms of support. The development and dissolution of services in Stockholm County, described in the previous chapter, is therefore only part of a more general ongoing change. Some aspects of this transition, in Sweden and internationally, are described in this chapter.

#### Transition of services in Sweden

Up until the 1940:s there was no formal legislation in Sweden which regulated the type of services to be provided for persons with an intellectual disability. Since then five Acts of Parliament have been passed which regulate the provision of services. As such they make explicit the views of society towards this group of people, expressed through the political parties represented in Parliament. The Acts stipulate the responsibility of society to support these persons, thereby regulating the responsibility of authorities for the financing and implementation of the services. They also specify the group of persons for whom the service is to be made available and the nature of the relationship between the person receiving a service and the providing authority.

#### *The Act of 1944*

It was not until the passing of the 1944 Act on education and care of the educable feeble-minded (SFS 1944:477) that education for persons with an intellectual disability was based on legislation. The compulsory schooling, as stated in the Act, had a double significance (Wessman 1987). It became compulsory for society to provide education for all pupils seen as "educable" and it became compulsory for the child to avail of the education now provided by the special school. The education prescribed by this Act was institutionally based, non-institutional schooling being merely mentioned as a possible alternative. Earlier experiences had led to them being regarded as an inferior form of education to that provided by the residential school.

The 1944 Act gave rise to reactions on primarily two issues. One concerned the question of supervision over the residential home, the institution which housed the residential school as well as the occupational home and the asylum. Supervision of the residential home had up until then been a medical responsibility. With the introduction of compulsory schooling, supervision became an educational responsibility. This was seen by some as unacceptable and consequently gave rise to demands for new legislation. Another reaction concerned the fact that the 1944 Act only regulated support provided for some, not all, persons with an intellectual disability. Those adults termed "educable", and those seen as "uneducable", irrespective of age, were not included. The 1946 Enquiry on the care of the feeble-minded (SOU 1949:11) was therefore appointed,

their task being to suggest services for all persons with an intellectual disability.

Their report gave rise to a further discussion concerning which authority was to be responsible for the provision of services. This debate can be seen essentially as a question of differences in perspectives. The medical-psychiatric ideology, which had developed during the 1920:s and 1930:s, was now being questioned by an educational tradition (Söder 1973). The report of this committee was not accepted and the 1951 Enquiry on the care of the feebleminded (1951 års sinnesslövärdutredning 1952) was appointed. This led to the Act of 1954.

### *The Act of 1954*

The 1954 Act on education and care of some mentally subnormal (SFS 1954:483) regulated services for all persons with an intellectual disability. Compared to the provisions offered in the Act of 1944, this meant that the responsibility of society was now extended to include adults with a mild disability as well as children and adults with a severe disability. A distinction was, however, still made between those considered to be able to benefit from education or not, schooling being provided only for the former group.

The intention of this Act was to place the main responsibility for societal support in one organization. As this was a regional body, services were organized in a centralized manner, a Director of Care and a Director of Schools being responsible for allocating relevant services to the persons concerned. The organization was run by a political board appointed by the County Council, the regional parliament. This body also had responsibility for financing services through taxation. As this organization alone, with some minor exceptions, was responsible for providing special services to persons with an intellectual disability other services which provided support for the general public were exempted from responsibility for persons with this disability. In order to channel support to the group regulated by the Act, the county authority was compelled to identify and register all persons with an intellectual disability.

Institutionally based services were provided for education and care. The residential school was available for children and youth who could benefit from education, whereas the occupational home was provided for those who had left school. The asylum, now called a residential home, was to provide for children and youth with a more profound disability. This residential home also provided for adults. The care of some persons with a profound disability was seen as a state responsibility, provided through special hospitals at a national level.

In the same Act, however, it was prescribed for the first time that “open care”, the expression of the time, should be developed. Regarding education it was stated that teaching in non-residential schools should be the primary alternative available in towns with more than 25.000 inhabitants. When non-residential schools could not be provided, day-classes should be made available within the residential school.

The children who had lived with their families and gone to school in their local community required, in adulthood, some form of daily activity. As an alternative to placement in an occupational home the 1954 Act recommended that community based centres for work and occupation be provided.

With these non-residential services new objectives were introduced. A step towards a more normal life had been taken in that it was now possible for a child to

grow up in its parental home, while attending a local school on a daily basis. For adults, the non-residential occupational centre offered an opportunity to receive support within their home community. A distinction was, however, still made between persons according to the degree of their disability. Non-residential services were seen as adequate only for some persons, the children and adults previously seen as "educable". Those with a more severe disability were still referred to residential institutions.

To realize the idea of non-residential schooling put forward in the 1954 Act and to satisfy an increased need for schooling, classes were localized to various premises which were not in use during the day, for example those belonging to recreational organizations. A number of practical problems soon became apparent, for example the lack of educational equipment, teaching now taking place in premises not intended for this purpose. As a consequence steps were taken to locate these classes to the local school. In this way several practical problems were solved. This development also had unexpected positive consequences, providing new experiences which contributed to the localization of more special classes into ordinary schools. Parallel to this it was soon considered possible to locate the residential facilities of the residential school to ordinary housing in the community (Wessman 1983).

Even in the Act of 1954 children with a severe disability, those previously termed "uneducable", were still excluded from education. The problem of identifying whether a child could participate in education or not, that is if he was to be seen as "educable" or "uneducable", led to the establishment of practical classes for those who were not admitted to the special school. The teaching in these classes was less theoretical, the emphasis instead being put on practical and social aspects. The experiences gained from these classes revealed the beneficial consequences of practical activities and social education, the pedagogical debate about special schools being greatly influenced by these experiences. A new set of values grew out of the debate, based on the idea that every child with an intellectual disability should have the right to education (Wessman 1983).

Against the background of the pedagogical debate regarding the introduction of the comprehensive school in Sweden during the period after the mid-1940:s, a change in attitude towards the education of persons with an intellectual disability became noticeable. With an individualized approach to education in general, the idea of regarding some pupils as "uneducable" became obsolete. Even the child with a severe disability could benefit from education if it was adjusted to the potentials of the child. This individualized approach to what a child could achieve led to more process-oriented teaching methods. This provided an opportunity for an increased participation by the child in the learning process and put greater emphasis on social competence when cooperating, sometimes in smaller groups, in a classroom (Ahlström 1986; Wessman 1983, 1987).

As the 1954 Act had stipulated that residential care should be available this resulted in the building of a series of residential homes. This should be seen against the background of the extensive demands for support from persons with a severe disability, their needs not having been adequately met during the 1930:s and 1940:s. At this time many persons with an intellectual disability also lived in mental hospitals. Between the mid-1950:s and mid-1970:s a series of new residential homes was built throughout Sweden, in general one located to each county.

In the committee which proposed the 1967 Act attention was directed towards these residential institutions, the criticism mainly concerning the passive life to which

the residents were subjected (SOU 1966:9). The potential of residents to develop was also pointed out, as was their need for occupation or work. Demands were therefore made that educational staff be appointed and that occupational therapy, occupational training and sheltered work be made available. However, no criticism of the institutionally based system of care was brought forward.

### *The Act of 1967*

The 1967 Act on special services for some mentally retarded (SFS 1967:940) had basically the same character as the Act of 1954. A centralized organisation remained as provider of similar services. The responsibilities of the county was further emphasized as the special hospitals, previously run by the state, became a county issue. The major new feature of this Act was however, that all school-age children were to receive education. This was to be realized through the establishment of the training school, a new educational form within the special school. As much of the existing special education was provided in an integrated form in the ordinary schools, this applied even for the training school. Through this legislation the idea that some of these persons were considered "uneducable" was finally rejected.

Community based services for adults with a less severe disability were to be provided through housing in boarding-homes while daily activities were to be offered through occupational centres. However, the only form of service for adults with a more extensive degree of disability was still the residential institution.

By the middle of the 1970:s children who had previously grown up in their families and received their education through the training school started to reach adulthood. It was natural that the question arose as to what sort of adult life they would live. Should they be referred to a life in a residential institution or should a life in the local community be made available through community based services? Families in particular made demands that they be given access to housing and daily activities which would give them the opportunity, even as adults, to live a life outside the residential institution. From the experience that more normal patterns and conditions of daily life were possible through community based services, a greater awareness had developed regarding the alternatives to residential institutions which could be offered. These experiences also initiated a critique of residential institutions and the way of life they offered (Kylén 1972).

At the end of the 19<sup>th</sup> century state asylums had been demanded by those who were running residential institutions, these asylums being seen as a way of relieving the residential homes of financial responsibility for persons with an extensive need for support. These demands were met and realized in the early 1930:s in the form of special hospitals, institutions which remained and were later modernized during the 1950:s and 1960:s. However, by the beginning of the 1970:s the traditional practices being carried out there were confronted with new socio-political ideas. An intensive debate took place concerning the role of these institutions in an organization of services which was essentially based on community oriented goals. During the 1970:s a process of dissolution of the special hospitals gradually took place.

This reduction of the special hospitals had its impact on the organization of the remaining services. Persons who previously had lived at these hospitals were now provided with alternative services, primarily at the residential homes in their home

county. In order to provide facilities for them, it was often found necessary for those already living in these residential homes to leave them for the newly established community based services (Grunewald 1969). Parallel to this process, criticism of the life offered at residential institutions had led to demands that the number of persons receiving residential care should be reduced. Those who left the institution were often persons with a limited need for support whereas those who moved in had a more extensive need. This meant that the group of persons living in residential institutions not only had decreased in number but also had changed as regards to the character of their needs. The consequence for community based services was that they no longer only provided services for persons who had grown up in their family but to an increasing extent were also providing for persons who had grown up within an institutional setting (Ericsson, K. & Ericsson, P. 1980).

### *The Act of 1985*

During the 1970:s the open care which had been advocated in the 1954 Act had gradually been implemented. This became the starting point for the 1977 Committee on special services (SOU 1981:26) the work of which led to the 1985 Act on special services for mentally retarded and others (SFS 1985:568). In the report from the 1977 committee one finds a critical view of residential institutions. They were seen as settings with negative attributes which had detrimental consequences for personal development and were an obstacle to living a good life (Kylén 1981). This committee also referred to a "rights motive" for the closure of institutions, indicating that housing could be regarded as an issue of social rights and therefore be made available for everyone.

The introduction of the 1980 Act on social services (SFS 1980:620) stated that its area of responsibility was to apply to all citizens in need of support in order to lead a life of well-being, including those with a disability. When the Act of 1985 was formulated the 1980 Act on social services was already applicable. Persons with an intellectual disability had therefore the right to avail of the ordinary social services provided by the local authority, in addition to some specified special services provided by the county authorities.

A similar development took place with education. Regulation of education for children with an intellectual disability now became part of the Act on schooling (SFS 1985:1100). Likewise, legislation for health also became the responsibility of ordinary health services (SFS 1985:570). With this legislation steps had been taken away from a special organization and moved to the generic services which thereby became responsible for support to persons with an intellectual disability. The special legislation had become merely supplementary.

A feature of the 1980 Act on social services was the basic principle of social support being non-compulsory, the option to avail of a service being placed on the person with the need for support, together with his representative. This had consequences for the Act of 1985 because of its supplementary nature. All its services were also to be provided only on the request of the person concerned. In addition, in case of a dispute between the providing organization and the person, both parties had the right to have the decision judicially tried in an administrative court. One-sided decisions by the administration were, however, still permitted as long as residential institutions had not been dissolved.

With the elimination of compulsory measures in the 1980 Act on social services the use of residential institutions as a form of support was also prohibited. The residential institution was therefore no longer recognized as a service in the 1985 Act. The closure of residential homes, which had previously started on the basis of local initiatives, now became imperative.

### *The Act of 1993*

As a consequence of the 1985 Act the transferral of responsibility from the special county organization to local welfare authorities was begun and formally implemented by the 1993 Act on support and services for some disabled (SFS 1993:387). This Act also intensified the development towards an increase in personal control over the services being provided and the demand for the dissolution of institutions. Services prescribed by this Act were no longer intended only for those with an intellectual disability, groups with other forms of disability, in need of extensive support, were also included. These persons were not, however, identified by the disability itself, but rather by the degree and permanence of their needs (Ericsson, P. & Ericsson, K. 1993).

The 1993 Act stipulated that 10 categories of special support be made available, these being similar in character to those prescribed in previous legislation. There was, however, one additional form of support, personal assistance. This meant that the person could be provided with support in the form of a personal assistant. The financial subsidy towards this assistance could be paid direct to the person and his representative, through an organisation, for example a co-operative society, or through a public authority. The intention was, however, that the assistant be chosen and controlled by the person himself, thereby providing the opportunity for a more personal form of support.

The need for the further development of support from society to persons with a disability remains. A document concerning new legislation is presently available for discussion (Svenska Kommunförbundet 1998).

### *Two types of legislation*

In the four Acts of Parliament from 1954, 1967, 1985 and 1993 one finds a gradual development towards community based services. To begin with these were established parallel with the legislation advocating the use of institutionally based services. With the 1985 Act development of community based services continued and the dissolution of residential institutions was also endorsed.

These four Acts represent two different approaches concerning how support from society should be provided, those from 1954 and 1967 representing one type whereas the Acts of 1985 and 1993 expressed another type of organization. The 1954 Act reflected an organization which was natural at the time, whereas the 1967 Act represented a further development, with modifications based on experiences gained and the new conditions which had emerged during the 1960:s. In both these Acts a special organization, at a regional level, had responsibility for special services considered necessary in order to meet the needs of this group. Services were to be provided through institutions of various kinds, well differentiated so as to provide the variation of services required.

Persons with an intellectual disability received the care or education they were thought to be in need of, in that a representative for the regional authority placed the person in the residential institution considered most relevant. This procedure was consistent with the compulsory measures prescribed, the person being registered and admitted, according to a one-sided decision.

The terminology of the 1954 Act also illustrates how these persons were understood. By terming them “mentally subnormal”, focus was put on their deficiencies and their need for increased competence in order to participate in community life. The task for the services for education and care was to provide these special measures, thereby endorsing the view held of these persons as pupils (the “educable”) or as patients (the “uneducable”).

The Acts from 1985 and 1993 express a different way of looking at these persons and their support. The Act on social services of 1980 provided the foundation on which the 1985 Act was to be formulated, the 1993 Act being a further development of this legislation. The basic idea of these two was that persons with a disability should have access to the social services provided for general public welfare. This required that the welfare services developed their competence in order to meet the needs of those with an intellectual disability.

As this legislation was of a voluntary nature, new procedures needed to be developed in the process for application and admission to the support services. This process began with a request to the organisation for support, from the person himself, the service the person later received having been finally decided on in dialogue between the two parties. If necessary, the person or the representative for the service provider, could request that the decision be tried in an administrative court. As this procedure was an expression for these persons having been recognized as judicially responsible, persons with a disability had become recognized as citizens. The persons’ right to participation in community life became logical, as did their right to avail of the services provided for the public in general.

Some international experiences from the transition of services

### *Changing patterns in residential services*

This expression, as well as being the title of a book issued by the President’s committee on mental retardation in USA (Kugel & Wolfensberger 1969) coincides well with the transition which took place regarding support and services to persons with an intellectual disability. It captured the commitment of the 1960:s to the development which was to lead away from a life in the large all-inclusive institutions. This commitment is well illustrated in this book which starts with an extensive and powerful criticism of permitting persons with an intellectual disability lead their lives under unacceptable conditions (Blatt 1969; Kugel 1969).

For a change in patterns of residential services to become a reality, there is a need for alternatives. This book therefore also contains illustrations of the experiences from Europe and the USA in the 1960:s, concerning efforts to improve living conditions for these persons through the newly emerging forms for support in the local community. Denmark (Bank-Mikkelsen 1969) and Sweden (Grunewald 1969) contributed with some of their experiences which aimed at achieving improved living conditions. In this report

Nirje's (1969) article on the normalization principle was published for the first time.

#### *A declaration of rights by international disability organizations*

The International League of Societies for the Mentally Handicapped, today Inclusion International, a worldwide association representing a large number of national organizations promoting the interests of persons with an intellectual disability, published its Declaration of general and special rights of the mentally retarded in the 1960:s (International League of Societies for the Mentally Handicapped 1968). This was based on two declarations by the United Nations. The Declaration of Human Rights argues the right for all people to experience "... equal and inalienable rights of human dignity and freedom" (United Nations 1948) while the Declaration of the Rights of the Child "... proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education and care required by his particular condition" (United Nations 1959).

In seven Articles in this international declaration attention is given to the consequences of these UN positions for the person with an intellectual disability. Of particular interest is the thought expressed in Article V, which states "the right to live with his own family ... to participate in all aspects of community life". The declaration concludes by focussing on the right of the person with an intellectual disability to be met with respect.

#### *A global strategy for a global problem*

The years following the early 1970:s have been a period of intense action by the United Nations with regard to the disability issue. An early opinion of this organization is reflected in a declaration concerning the rights of persons with an intellectual disability (United Nations 1971). As work proceeded the interests of this particular group has been expressed within the same framework as that for all persons with a disability, irrespective of type or degree (United Nations 1975). This culminated in the 1981 International year of the disabled, to be followed by the Decade of the disabled which took place during the period 1983-1992.

One result of the work carried out during these years was the global strategy presented in Standard rules on the equalization of opportunities for persons with disabilities (United Nations 1993). This global programme for the well-being of persons with a disability is expressed in a number of "rules", all based on the social policy described as "Equalization of opportunities". There are three major sections to this document. One deals with the target areas for equal participation, the second describes the pre-conditions seen as necessary to achieve equal participation while the third describes a number of measures towards implementation.

The major goal of the standard rules is expressed in the term "equal participation" (United Nations 1993, p.17, p.22). This conveys the idea that the life which is led by families and peers in a given society, should also be the life available to the person with a disability. The strategy to achieve this is expressed as "Equalization of opportunities". The intention is that activities which are organized for the benefit of the general public should also be available to persons with a disability:

The term 'equalization of opportunities' means the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disabilities. (United Nations 1993, p.11)

There is also a value basis for this expressed as "Equal rights and obligations for persons with a disability". This underlines the person with a disability as a member of his community:

The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. (United Nations 1993, p.11)

It is important to point out that this is not a strategy valid only for countries seen as developing nations. Instead, this is a strategy with equal relevance for all, including those nations considered well developed. Such countries may appear to have very well developed systems of services for persons with an intellectual disability, but these can often be old-fashioned and based on obsolete forms of services.

The European Union has recognized the development by the United Nations of a policy based on the rights of persons with a disability to avail of the resources of the local community and to participate in the life it offers. It thereby adheres to the UN strategy of "Equalization of opportunities" for persons with a disability as a means of acquiring them. The work of the European Union on the disability issue began with the International year of the disabled in 1981 and has continued, throughout the 1980:s and 1990:s, to develop a "rights based policy" and to introduce it into the framework of its activities and projects (European Union 1996).

#### *A comparison between Britain, Scandinavia and the USA*

From an international comparison between Britain, Scandinavia and the USA (Mansell & Ericsson 1996a) it is apparent that there is an ongoing development from institutionally towards community based forms of support. A statistical comparison between England, Norway, Sweden, USA and Wales shows the same tendency, that the number of places in institutions declined during the period 1970-1995. There was an initial variation, Sweden having had a high number of institutional places whereas Wales and USA had a lower number. The figures for all countries have, however, fallen during this period and reached a comparable level at the end of the period. Norway was the only country to deviate, having under many years remained at the same high level, followed by a quick reduction in the number of places during the last year. This comparison clearly illustrates the dissolution of institutions for persons with an intellectual disability which has taken place in these countries (Ericsson & Mansell 1996).

One can also find many similarities in this movement away from institutions. It was during the 1950:s that steps were taken towards finding community based forms of support. While in Sweden one sees the advent of the welfare society as providing the necessary context, developments in USA were influenced partly by the parents' movement as well as actions for civil rights. In Britain various public enquiries, often

arising out of scandals concerning institutional services, provided early motivation to create community based services (Mansell & Ericsson 1996b).

## Discussion

The Swedish development of community based support to persons with an intellectual disability since the early 1940:s is rooted in a series of enquiries and in legislation, support to this group having been seen as a crucial task for society. When one looks more closely at the content of the various Acts of Parliament one finds that they not only seek to clarify the responsibility of society but also to regulate how support should be provided. They also illustrate the gradual development of community based services at the same time as the dissolution of institutionally based services takes place.

A transition from institutionally to community based services has taken place at the same time as the various Acts specified that both types of service should be provided. Part of the transition resulted in the reduction in the number of places at institutions, but also in the closure of residential homes for children and of institutional forms of schooling. Concerning institutions for adults, the number of places were reduced but their final dissolution was not yet seen as self-evident. With a tradition which differentiated between persons being termed “educable” and “uneducable”, where one group was to receive education while the other was provided with care, it was not seen as appropriate to dissolve institutions intended for those with the most extensive needs. Consequently, the first expression of a new public opinion that considered these persons as also having the right to leave the institutions for participation in the life of the community to which they belonged was not seen until the Acts of 1985 and 1993.

### *Factors contributing to development*

On several points in this account it emerges that development within Swedish services has been a response to impulses from other sectors of society. The introduction of the right to education for all children and youth, even for the persons with a severe disability previously considered “uneducable”, can be seen to have taken place as an outcome of the views which emphasised the importance of individualized education. The general pedagogical debate and the reforms of the public school, can therefore be seen as crucial for the change of the special school. As an increasing number of children with an extensive need for support gained this opportunity to education in a special school, which was being integrated into the public school, they were enabled to grow up within their own family. As a consequence a new generation emerged which expected a non-institutional life in adulthood. In this way the development of the special school contributed to the transition away from the institutionally based services.

In a similar manner there is a connection between the 1980 Act on social services and the Act of 1985. With social legislation stipulating the responsibility of welfare services for all, even those with a disability, the possibility of maintaining special legislation for persons with an intellectual disability changed dramatically. As it was required that an Act regulating disability support had to be coordinated with social legislation, this instigated the developments which led to the 1985 Act and later the 1993 Act being designed as supplementary in character.

A more intensive study would probably reveal additional development in society as promotive to the transition towards community based services. A general development towards improved housing and reforms concerning labour market issues such as full employment, could probably be found to be other incentives which spurred on the demand for better housing and forms of employment and day services for persons with an intellectual disability.

### *International developments*

The international development which is reviewed here is limited, as comparisons of development have only been made between Britain, Scandinavia and the USA. There one finds many international similarities, the same transition of services having taken place. Since the 1950:s there has been a common development, the focus being on finding new community based forms of support in order to facilitate the move away from institutions. In all countries which have been compared one finds that a dissolution of institutions has taken place. However, it is only in Sweden and Norway that this is statutory. Similarities between the countries compared, with regard to the ongoing processes of change are, however, surprisingly similar.

One finds an understanding of the character of the debate of the 1960:s concerning the shift from institutionally to community based services in Changing patterns in residential services for the mentally retarded (Kugel & Wolfensberger 1969) which argues for the necessity that these changes taking place. The criticism of institutions is comprehensive and powerful and is presented with commitment. One can also say that the forceful wish for change is an expression of the fact that the normalization principle, as formulated in the book, had received such far-reaching international interest.

The nature of ongoing international developments can also be found in the United Nations global strategy for improved conditions for persons with a disability. Here one advocates a commitment to the forms of support which lead to an equalization of opportunities. No reference is, however, made to residential institutions, either as a positive phenomena or in critical terms. On the other hand, one finds a formulation of the goals which advocate participation in society, based on the conception of the person with a disability as a citizen with rights.

## Chapter 3

### Persons with a disability in the welfare society

In an analysis of ongoing change from institutional life to community participation for persons with an intellectual disability one soon encounters the concept of the normalization principle. It has been central in the Swedish and Nordic, as well as the international discussion on how to channel support to persons with a disability. In my endeavour to understand the Swedish development of disability services it has emerged as an important task to clarify the significance of this concept.

My first contact with the concept, as formulated by Nirje (1969), was in connection with an early project (Ericsson, K. & Ericsson, P. 1971). The idea presented by Nirje was later tested during a project when normalization procedures were introduced on a ward of a special hospital for persons with an intellectual disability (Ericsson, K. & Ericsson, P. 1975). Following that, I made attempts to formulate how I understood its meaning (Ericsson 1981a).

New possibilities were given when I started to work on the transition of services in connection with the closure of Carlslund residential home. When searching for the background and history of Carlslund the notion of a normalization of everyday life for these persons was one of the ideas which had been introduced when the modern residential home was established (chapter 1).

A more comprehensive understanding came, however, in connection with my search for the idea behind the closure of residential institutions. In a public enquiry from the 1940:s I found the normalization principle of 1946, a socio-political idea which signified the beginning of a public recognition of a development towards a normalization of conditions of life for persons with a disability (Ericsson 1985a, 1985b).

To-day I can conclude that there exists an abundance of ideas which make use of the term normalization. I do not intend to embark on an analysis of these, but instead to examine further the 1946 principle of normalization. The result of this review is presented in this chapter. This thesis is devised to provide answers to three questions. The first one concerns the reason why closure of residential institutions took place and my answer is given in this chapter.

The normalization principle of 1946

#### *The Committee for the partially able-bodied*

In Sweden at the end of the 1930:s, persons with a disability and their organizations presented their demands for means of securing employment and welfare. The basis for their discontent were the disparities and inequalities which they experienced. A discussion as to how to improve their situation took place in a public enquiry. The Committee for the partially able-bodied was appointed in 1943 in order to

... create better opportunities for the utilization of the productive ability of partially able-bodied persons. (SOU 1946:24, p.13)

In a comment as to who was thought to belong to this category, referral was made to those who in England, at that time, were termed "handicapped". The group was defined as those

... who because of physical or mental occupational impediment, or social affliction have, or can be expected to have, more difficulty than others to acquire and maintain an employment. (SOU 1946:24, p.12)

The partially able-bodied referred to should belong to one of the following groups:

Group 1. Blind and partially sighted. Group 2. Deaf-mute and deaf. Group 3. Crippled. Group 4. Persons with tuberculosis. Group 5. Chronically ill and aged. Group 6. Others (insane, nervous disorders, subnormal, abnormal, drunkards, criminals etc). (SOU 1946:24, p.14)

In their recommendations the committee dissociated itself from the type of support which characterized the pre-industrial society. The philanthropic spirit and public protective intervention which had been common, was regarded as inadequate when establishing modern social services. Assistance for special groups, in the form of institutional placement and charitable organizations, was rejected. Even if these methods had been able to provide for the needs of some persons, the overall disadvantage was that this form of assistance merely reflected a society which was lacking in responsibility for the entire population. In addition, it was regarded as unsatisfactory that support to persons with a disability, such as medical treatment, vocational training, allocation of housing and employment, was provided through the auspices of charitable institutions. As a consequence, assistance offered was primarily intended for the needy who were already admitted, whereas those outside the sphere of responsibility of the residential institution were not eligible for its support. The institution as such was also rejected as it was considered too patriarchal in its outlook (SOU 1946:24, p.24).

#### *A new socio-political idea*

In their task the committee was faced with a situation which offered two alternative ways of providing support from society to these persons. One implied a continuation of the existing system and the building of new institutions responsible for the provision of support to persons with a disability. The alternative proposal had its origins in the social services which were to be developed for the implementation of a welfare society. If these were made responsible for all members of society, new possibilities would exist for persons with a disability. The committee chose to recommend this latter alternative.

The ambition of the committee was therefore that the support to be provided to persons with a disability should be in accordance with the social spirit of the time. All citizens in need of support were to be given the same opportunity to welfare. At the same time one sought to develop an organization of social work which could include measures of a preventive nature. In order to achieve this, the committee chose to take the position that authorities responsible for social services to the general public should also be made responsible for services to persons with a disability:

In full accordance with the ambitions of our work for social progress, it is apparent to this committee for the partially able-bodied, that 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 follows therefore, as a working hypothesis, that no special solution outside the general framework should be suggested, before the applicability of the general solution, even for these categories, be tried and before it has been proved that the general organization cannot within reason be adjusted for this, in certain respects special clientele.

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. The institutions of society must be adapted in order to justly and if possible according to the circumstances, include all individuals, irrespective of which category they belong regarding physical ability, intellectual capacity, economic resources etc. To exclude certain categories from the general plan and agree on special arrangements for them naturally cannot always be avoided, but it must be the exception, not the rule. Psychologically this "normalization" of conditions of life, education, employment exchange etc. of the partially able-bodied must be a great achievement. (SOU 1946:24, p.28)

In this quotation one finds three components which together express a new socio-political idea. What is specified is the principle that ordinary 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 considered to be a democratic right which 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 persons themselves should bring about a normalization of the conditions of life under which they lived.

Because of the expectation that the principle thus formulated would lead to a normalization of conditions of life for these persons, it was called the normalization principle:

The normalization principle, as proposed by the committee, implies, amongst other things, that special institutions for partially able-bodied, concerning education, schooling etc. should be an exception, not the rule. (Kommittén för partiellt arbetsföra 1949, p.21)

As the normalization principle became the socio-political concept which formed the basis for the recommendations of the committee, the normal life, instead of an institutional life, became an accepted objective within the area of disability. It was, however, an objective considered applicable only for the "partially able-bodied". Persons with a more severe disability, those who were termed "unfit-for-work" were not affected by the recommendations and would instead be referred to modernized institutions.

### *Motives for the choice of welfare services*

The appointment of the committee was a response to demands for a better life by persons with a disability and their organizations. But the formulation of this socio-political idea also had societal motives. The committee presented six reasons for their suggestions of more effective measures which would enable the partially able-bodied to be productive. One of these saw this as a way of contributing to a better life for these persons. The dominating motive however, concerned the needs of the labour force during a period of economic growth and the restructuring of economic life. This in turn

required re-schooling and increased competence in order for the persons to qualify for new forms of employment. The major proposal of this public enquiry was therefore the introduction of an organization for vocational rehabilitation.

Another motive was directly associated with the introduction of a welfare society with social insurance and economic social support as important forms of benefits. If the partially able-bodied were to become more productive and more able to support themselves, demands on financial 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 introduction and realization of the 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 being 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 a financial 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 financial task. One would not be able to build specially designed institutions for all. The only way to meet their need for welfare was, therefore, to open up the general welfare services which were being created.

## Swedish developments

A thorough analysis of how the normalization principle of 1946 was realized would lead to the numerous Acts of Parliament which, during a long period, have regulated support to various disability groups who, by the committee, were regarded as being partially able-bodied. Neither can a realization of this principle be found merely by looking at how the expression itself has been used, as this socio-political idea can be formulated in many different ways. This presentation with regard to the normalization principle is therefore only an illustration of how the expression can be found in a 50-year long discussion about support to persons with an intellectual disability.

The 1951 Committee on the care of the feeble-minded had a mandate to "... dissociate itself from so-called institutional thinking" (citation from 1951 års sinnesslövsutredning 1952, p.15) and instead to suggest open forms of care for persons with an intellectual disability. In its report, the enquiry presented an analysis on the subject (1951 års sinnesslövsutredning 1955) and in an appendix, Bergh (1955) presented the normalization principle as it had been formulated by the Committee for the partially able-bodied, as well as a proposal for measures which would facilitate the procurement of employment for partially able-bodied persons. Bergh who wrote this appendix was most active in advocating the normalization principle in the work to assist persons with a disability to get employment. He had for a long time been a proponent of this idea. When he was employed by the National employment commission this principle had been part of their work with the partially able-bodied. From there he

brought it with him to the Committee for the partially able-bodied, of which he was a member (Montan 1992).

In other public enquiries one can also find the concept of normalization being mentioned. In Enquiry into institutions reference was made to normalization, in connection with non-institutional day schools for special education:

... with the objective of normalizing the situation for pupils at special schools, in finding new ways ... day schools, combined with weekly boarding facilities ... a more normal environment for children during their school days. (SOU 1965:55, p.63)

In the enquiry prior to the 1967 Act ambitions concerning a development towards normalization were expressed:

... endeavours to provide the mentally retarded with as normal a life as possible must include increased help in the form of adult education ... (SOU 1966:9, p.83)

Other occasions when one finds the quest towards more normal conditions of life being expressed, is during the period of institutional development. As these institutions tended to become relatively large it was pointed out that the negative consequences of this could be alleviated by designing them in such a way that those being cared for should experience a normalization of their life. The plan for the modernization of Carlslund residential home, redesigning it as a miniature community (chapter 1), is one example of this. However, the concept of normalization used in this way pointed only to a restructuring of the residential institution towards a more normal life. It did not have the connotation that implied increased contact between persons with a disability and those in the local community.

#### *Formulations by Bank-Mikkelsen*

Bank-Mikkelsen's work in Denmark and his view of persons with an intellectual disability, had a major influence on Swedish and Nordic developments. Much of his original work was formulated during visits to Sweden. His partner and colleague was Nordfors, an educationalist who had been one of the experts in the 1951 Committee. A great deal of the preparatory work prior to the Danish legislation of 1959, was carried out by Bank-Mikkelsen and Nordfors in Upplands-Väsby (the municipality where Carlslund residential home was situated), as Nordfors was principal of the residential special school in the same area (Bank-Mikkelsen 1984; Nordfors 1984).

Bank-Mikkelsen was concerned with the undertaking of bringing about a normalization of life for persons with an intellectual disability. In connection with the 1959 Act in Denmark he let this idea express the objectives for services:

... to create a situation for the handicapped as near to the normal as possible, irrespective of whether it occurs entirely or partly within the institution or out in the community. (Socialministeriet 1959, p.7)

Behind these aspirations towards a normal life one finds a reaction against the protectionist view which had been characteristic of services in Denmark and which had led to the establishment of large institutions. For Bank-Mikkelsen the phrase "a normal existence" had become his way of expressing his objectives for the services for persons

with an intellectual disability:

The aim is to give the mentally retarded a normal existence, that is to say, to assist with treatment of any kind and ensure living-quarters and work in the ordinary community for as many as possible. (Bank-Mikkelsen 1964, p.3)

He also clarified the role of the person with an intellectual disability:

The mentally retarded individual is first of all a fellow human being and so he must from a viewpoint of equality have full rights as a fellow citizen. ... If an equality-viewpoint is not acknowledged, there is a risk of ending simply in sentimental pity, in theories of over-protection, in group-discrimination or in something worse. (Bank-Mikkelsen 1969, p.3)

According to Bank-Mikkelsen the person must be seen as a fellow human being, even if one with a disability. As such he is a full citizen who must be allowed to experience the same life and rights as the citizen without a disability.

#### *Formulations by Nirje*

During the 1960:s Nirje was involved in the parents' association in Sweden and participated actively in the debate and development which took place during a period of change. In an article he summarized some of these experiences by calling them the normalization principle and thereby expressed his views as to how a worthy life for persons with an intellectual disability should be formed:

... making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. (Nirje 1969, p.181)

What he meant by patterns and conditions of everyday life was given a concrete form in eight characteristics of the normal life. He meant that the normal rhythm of the day, of the week and of the year also should apply for the person with a disability, thus enabling him to avail of the experiences which a normal life provides. They should also have the possibility to experience the normal life cycle, from birth, childhood and adolescence, to adult life and old age, with the varying experiences which this offers. Respect for each person's needs, choices and wishes must, he thought, be a reality also in the lives of these persons. Society must also take the consequences of the fact that men and women live side by side and that persons with a disability must also be given the opportunity to live together with persons of the opposite sex. Normal economic standards and normal physical standards in their living environments, are also some of the characteristics of the normal life which a person with an intellectual disability should have an opportunity to experience.

Nirje also, in a discussion on the right to self-determination, expressed a viewpoint regarding these persons:

But when mentally retarded adults express their right to self-determination in public and in action and thus gain and experience due citizen respect, they also have something to teach ... something about the deeper importance of democratic opportunities, the respect due to everyone in a democratic society - and that otherwise, democracy is not complete. (1972, p.189)

For Nirje the normalization principle became a description not only of what the normal life could consist of, but also an expression of the view that these persons should be seen as citizens with rights.

#### *Some later applications of the concept of normalization*

When the 1977 Committee on special services carried out its enquiry it became clearer than ever before that the objectives of normalization of living conditions for persons with an intellectual disability were the guiding principles behind their directives. The committee, when it presented its recommendation for new legislation made clear that "... the principle of normalization is of fundamental importance ..." (citation from SOU 1981:26, p.89) and that there was political unanimity regarding this objective. This had not been expressed so explicitly in previous legislation or in preceding enquiries.

Studies of evaluation of services from the 1970:s and early 1980:s, concerning the establishment of the newly emerging community services and the closure of institutions, also gave reason for those involved in research and development to take a standpoint on the implications and expected consequences of this socio-political direction. It was predominantly Kebbon and colleagues who discussed this issue in terms of normalization (Kebbon et al. 1981).

#### *A summing up of the period*

The expressions of some earlier formulations of the idea of normalization are taken from documents which have been important for the development of services during the 25 years after the middle of 1940:s. The picture which emerges is that during this period there has been a general endeavour towards realizing a normalization of conditions of life for persons with an intellectual disability. Initially this took place within residential institutions which were the dominant form of support during these years. Later on normalization was achieved through these persons' participation in community life. Montan summed up the period 1945-1985 in the following manner:

The Committee on social care ... had taken up all aspects of social security for scrutiny. The Committee for the partially able-bodied ... had been set up in 1943. Our country was in the throes of tackling the problems of insecurity and poverty. The vulnerable groups of citizens, amongst whom one must include the handicapped, were benefiting from the wave of improvements which later followed. The society, which was later established, came to have many problems and many weaknesses, but could, nevertheless, make certain claims to being termed a welfare society. (Montan 1987, p.12)

But the period has not only been characterized by expansion, but even by restructuring:

During the period institutions and organizations have been dissolved and others have grown up instead. This should be seen as a healthy sign and as a normal occurrence. Institutions have their life-cycles and survival is in the long run only possible if they keep in pace with the needs of citizens. (Montan 1987, p.160)

The ideological basis for this development can be found, he maintains, in the move towards greater societal responsibility, away from a tradition of reliance on individual

contributions. A comprehensive view had also emerged which means that attention is not only devoted to the functions which contribute to disability but also to the social situation of the person, for example housing and employment. An objective like normalization had therefore, during these years, been a decisive condition, as also has been the increase of democracy. Organizations for persons with a disability have also been an important factor, as they have emerged into a well developed and differentiated disability movement. In addition to this, there has been a political willingness to see that the needs of these groups be met (Montan 1987; Montan et al. 1990).

When the ideas of the Swedish welfare society were discussed by Lindberg (1999) he points to the minister of social affairs of the time, Gustav Möller, as the key person regarding social reforms during the 1940:s. Lindberg (1999, p.76) sees him as a representative for the idea of the social rights of citizens in need of support. A person's basic social right should not depend on his achievements but on the very fact that he is a citizen of this society. This is seen by Lindberg as part of the fundamental democratic principle of equal value of all persons.

The normalization principle of 1946 can therefore be seen as a socio-political vision pertaining to a life for persons with a disability within the ordinary welfare society. When it was to be realized one considered, however, that it was only relevant for persons with a limited disability, the so-called partially able-bodied. As a consequence developments which took place during the 1950:s, 1960:s and 1970:s were only concerned with an increase of participation in community life for persons with a limited need for support. In the 1985 Act, all, even those with a more severe form of intellectual disability, gained the right to participation in community life. One can conclude that it was not until then that the welfare society and the normalization principle, was extended to all persons with an intellectual disability.

## International developments

The concept of the normalization principle has, in the international discussion, come to express an aspiration towards a life with more normal conditions than the life provided in the traditional residential institution. This debate permeated from the article contributed by Nirje (1969) to the book *Changing patterns in residential services for the mentally retarded* (Kugel & Wolfensberger 1969). It is not the intent of this short comment to cover the extent and content of this international discussion regarding normalization or to evaluate its role in developments since the beginning of the 1970:s. The purpose is merely to show that this discussion has been an expression of a broad international opinion which points away from institutional life.

One of the reasons for this far-reaching international debate is that Wolfensberger gave the concept a formulation intended for the North American public (Wolfensberger 1980). In the formulations of Nirje and in those of Wolfensberger, one finds two different sets of ideas both being called, and referred to, as the normalization principle. Part of the debate has therefore been concerned with interpretations of the meaning of the normalization concept. The extent of this international debate can be exemplified by a bibliography of material, most dating from the 1970:s. During the years prior to 1980, 241 references are accounted for (Nitsch, Armour & Flynn 1980). Since then several more articles and books have been added, as work proceeds regarding the meaning and consequences of the concept. These, Bothe et al. (1986), Brown and

Smith (1992), Stangvik (1987) together with Stratford and Tse (1989), are just some examples from a variety of countries. Flynn and Lemay (1999) provides a review over a 25-year period regarding the principle of normalization.

When looking back it is easy to understand why the writings of Nirje sparked off this debate. In a service which so consistently has been associated with an institutional system of care, the concept of normalization points to an alternative. This may have been vague in the beginning. But in the formulation of what a normal, non-institutional life could consist of and in expressing the social role of these persons as that of a citizen, the fundamental idea that these persons should be confined to an institutional life was challenged. Many perceptions concerning what can be considered as good services for these persons were questioned and this, inevitably, gave rise to debate.

Answering the first question

#### *Development and dissolution of services*

The objective for the dissolution of a residential institution is, of course, that it ceases to exist as a place of residence for persons with an intellectual disability. The question, which was initially asked in Sweden generally and in particular with regard to Carlslund residential home, concerned the reason why this took place. The 1946 principle of normalization puts this question into a wider perspective, the closure of institutions being seen merely as part of a wider process which involves a shift between two forms of support, community based forms of support being developed at the same time as institutionally based services are dissolved. Institutional closure can, against this background, be seen as part of an ongoing process which originated with the socio-political position formulated by the Committee for the partially able-bodied. Beginning with the 1954 Act, one sees a systematic shift from institutionally to community based services in the following three Acts of Parliament which regulated the support of society to this group of persons. This shift culminates in 1999 when the residential institution finally ceases to exist as a form of service for persons with an intellectual disability (SFS 1997:724).

The socio-political idea formulated by the committee in the 1940:s was, however, considered only of relevance for persons with a mild disability, the “partially able-bodied” and to begin with the transition from institutionally to community based services concerned only those who were considered to belong to this group. As long as this characterized the transition of services it was unnecessary to consider institutional closure, as the residential institution was still seen to be required for those with a more severe disability.

Institutional closure became an issue when one was faced with the question as to whether the ongoing transition of services should apply even for persons with a severe disability. The question as to who should be given the possibility of leaving the residential institution then came under scrutiny. An additional issue was the lack of non-institutional services for persons with a severe disability. The solution, easy to formulate but more difficult to realize, was an acceptance of the viewpoint that community participation should be possible for all, irrespective of the nature or degree of the disability. However, acceptance of this point of view required that services, which met the needs and wishes of all, be made available outside the residential institution.

### *The 1946 principle of normalization*

The change of orientation towards community based forms of support had gained formal recognition in the socio-political idea formulated by the Committee for the partially able-bodied. The components comprising this change in direction can be seen as a contribution towards answering the question as to why institutional closure takes place. Looking to the work of this committee, one finds that four conditions needed to be fulfilled if institutional closure was to take place.

The appointment of this committee was an expression for a commitment, from the disability movement and from representatives of society, to improve conditions for persons with a disability. Recognizing that there is a need for welfare and a *will to realize a better life* for persons with an intellectual disability, can be seen as one of these conditions.

A belief in the democratic right for persons with a disability to experience a normalization of their living conditions was also basic to this idea. This view is expressed in that persons with a disability are seen as citizens and accordingly as members of society. The idea of a *citizen perspective*, which gives a legitimacy to the idea of participation of these persons in community life, can thus be seen as yet another of the conditions required.

The discussion in the committee included several arguments which expressed a cogent socio-economic motive in support of community participation. The major economic motive was the ambition to create a welfare society for all, including people with a disability, in order to use the economic welfare resources in a common organization. If these were instead used to establish a special service, only for persons with a disability, it would disseminate financial resources and be a threat to the development of the general welfare society. An *economic interest* in the shift away from institutionally based services can be seen as the third condition to be fulfilled.

Unique to the situation in which the committee found itself was the possibility of choosing between two types of services, on the one hand the institutionally based and on the other the community based services which were part of the welfare services offered to the public. Even if they were not yet fully established, an idea of community based services, as an alternative to those offered by the institution did exist. The existence of *community based forms of support* can therefore be seen as a recognition of the fourth condition.

### *The closure of Carlslund*

As was seen (chapter 1) a formal decision was taken (Omsorgsnämnden 1976) regarding the closure of Carlslund residential home. This gave rise to a period of planning which, in 1981 resulted in a proposed plan for the realization of its closure. The question which can be asked is whether the four conditions, considered to be pre-requisites for the closure of an institution, can be seen to have been fulfilled in the case of Carlslund.

Criticism of this residential home, expressed in various ways, had finally led to the recognition by the responsible authority that an improvement of living conditions was necessary for the persons living at the residential home. The decision by the Board of County Special Services to close the institution and to establish alternative community based services, came as a final recognition of this critique. This official

adherence to the view that improvement was necessary can be seen as an acceptance of the condition that a better life for these persons had to be realized.

In the long-term plan (Omsorgsnämnden 1977) one also finds a well developed model for community based services which was to be made available not only for persons with a mild but also those with a more severe disability. In this one finds that plans did exist for the provision of community based services which could be used as alternatives to those provided by the institution. The condition requiring the availability of community based forms of support was therefore also considered.

It is unclear as to whether any clearly stated economic motive lay behind the initial decision to close the residential home. However, during the planning period an economic comparison was made between institutionally and community based services. This was based on the assessment of the personal needs of those at the residential home (chapter 4). This economic analysis showed that the renovation of the institution, if it was to be maintained and modernized, was more expensive than the community based services proposed to replace the institution (Omsorgsnämnden 1981). The conditions pointing to an economic interest in the closure of the institution were therefore fulfilled.

Could one find a citizen perspective in the closure of the residential home? The debate following the decision to close the institution was to a large extent concerned with the issue of whether housing was available in order that persons with a severe disability also could leave the institution. The political chairman of the Board when the closure of the residential home was initially suggested, was the one who most emphatically expressed a citizen perspective, maintaining that even persons with a severe disability had, like others, a right to housing.

The debate on housing which took place at this time reflects different views as to how housing for this group should be designed. An article which summarized the content of this debate found that two perspectives on housing could be identified (Ericsson, K. & Ericsson, P. 1980). The concepts clinical and social perspectives were used at that time to describe these different views. In short, the clinical perspective expressed a static view on housing, implying the provision of a number of standard solutions varied according to the level of resources provided. The only way for a person to gain access to more or less resources was to move to another house with a more suitable level of resources. The social perspective saw instead a possibility of providing the resources required in the house in which the person was already resident. This could be achieved for example through a flexible adjustment of staff resources of the house. With this perspective, the likelihood of providing housing for all becomes realistic and the idea of the right to housing for every person with a disability, including those who move from a residential institution, can thus be realized. With this perspective one finds the condition expressing a citizen perspective.

During the dissolution of Carlslund residential home one finds, accordingly, the same four conditions as these expressed by the Committee for the partially able-bodied.

### *The Act of 1985*

In the 1985 Act it became, for the first time, mandatory that the closure of residential institutions was to take place. Which of the four conditions for institutional closure can be found in this Act? A declared resolve to improve living conditions for the persons covered by the legislation, is expressed in the directives given to the 1977 Committee

and later in the proposal. This resolve is also found in the 1985 Act. The conditions expressing a will to achieve a better life for persons was therefore present.

This Act also stipulates what community based services are to be offered to persons, as the residential institution no longer is available. Even more important is the fact that the 1985 Act was supplementary to the current 1980 Act on social services, which specified the right of everybody to support in the municipality where they were living, thereby endorsing the right to avail of the public services provided there. The condition which stressed the use of community based services can therefore be found in this Act.

In the 1985 Act one finds the fundamental assumption that the person should personally apply for the service required, from the organization responsible for providing support. He is also given the right to request a judicial investigation of the service which the organization provides if he is not satisfied with what is being offered. These measures are an expression of the person having been recognized as a judicially responsible citizen. As a consequence, the use of compulsory measures, present in earlier legislation, had now disappeared, the current services being entirely non-compulsory. Accordingly, the citizen perspective can be seen as directly related to the decision on the closure of institutions.

In the public enquiry carried out during the preparation of the 1985 Act it is stated that no financial calculation of the cost of institutional closure had been carried out (SOU 1981:26).

When the 1985 Act regulates that the residential home no longer is a service and therefore should be dissolved, one finds that three of the four conditions dating from the Committee for the partially able-bodied have been taken into consideration.

#### *An answer to the question*

A spontaneous answer to the question as to why residential institutions are being closed would be to argue that better lives for persons with an intellectual disability can be found outside the institution. But after having looked into three situations, where decisions have been taken about a development away from institutionally based services, one finds that the answer is somewhat more complex. This analysis shows that four conditions need to be realized in order for a decision to close a residential institution to appear logical. Apart from the first and natural condition expressing an ambition to create better lives for persons, there is also a need for existing community based services in order to create alternatives to the support offered by the institution. Leaving the residential institution also becomes logical when seen from a citizen perspective, that is when one sees persons with an intellectual disability, even those with a severe form of disability, as citizens with a right to a life in the community among other citizens. However, this is not enough for closure to take place. The fourth condition, concerning the economical conditions related to the transition from institutionally to community based services, also needs to be seen as favourable in order to leave the residential institution.

## Discussion

Nirje's views in 1969 concerning a more normal way of life was stimulating to read as it envisaged a positive way forward for the development of disability support. But not only I held the opinion that the principle was hard to interpret at the time. The debate on the normalization principle which took place during the 1970:s should therefore be seen as an expression of the difficulties at that time, to comprehend this formulation.

It was first in my search for the background to the transition of services which were taking place at Carlslund residential home that I came in contact with the work of the public enquiry which was preparatory to the 1954 Act of Parliament. There I found reference to the Committee for the partially able-bodied and the normalization principle of 1946. The writings of this committee gave an account not only of a new socio-political idea as regards forms for support to persons with a disability. They also described the society of the time and the conditions from which such an idea could emanate.

While institutionally based services were the logical forms of support in the society of the mid 19<sup>th</sup> century, the committee describes the conditions of the mid 20<sup>th</sup> century in Sweden and show community based services to be the natural form of support in this society, 100 years later. From the normalization principle of 1946 one therefore gains an understanding not only of the reasons for the closure of Carlslund residential home and the development of its alternatives, but also of the transition away from institutionally based services in Sweden.

In the debate concerning the normalization principle many have tried to interpret the principle and to find ways of inventing new versions of something which could be named the normalization principle. My view today is that a discussion about the label of normalization is of limited value. At least three principles of normalization can be identified today, one dating from the 1946 Committee (SOU 1946:24), one formulated by Nirje (1969) and one by Wolfensberger (1980), each with varying content.

As the essence of the principle of 1946 is the introduction of a new socio-political idea, it should instead be the idea which is focussed on and of concern for our interest. One can, of course, find that the idea as such is discussed in other places, perhaps with another label. For example the person who, at the conference in Nairobi 1982, arranged by Inclusion International, presented a very articulate and vivid expression of this idea when he argued for the development of education for children with an intellectual disability in Brazil (Anon 1982). The normalization principle of 1946 was never mentioned, but the idea put forward was the same.

The best example, in my view, of its usage is the UN global strategy of equalization of opportunities (United Nations 1993). The same three components of the 1946 idea can be found in this UN policy (chapter 2). An understanding of the 1946 idea and the conditions which led to its formulation, contribute considerably to an understanding of the UN policy. When all persons with a disability are recognized as citizens and gain a right to welfare and a good life, their needs cannot be met by special institutions, neither in Sweden during the 1940:s, nor in other parts of the world in 1994. Such rights cannot be achieved without making available the welfare services provided for the general public.

## Chapter 4

### Community based services for persons who leave the residential institution

In order to close a residential institution persons who live there must leave. But such a decision does not mean that their need for support has ceased to exist. Instead this must be provided in another manner. Only when alternative services are available is it possible to move and the closure of the institution can become a reality. As persons have different needs of support, services provided to meet these needs must be varied. In this way the process of closure will progress in relation to the development and availability of alternative services. The key to dissolution and closure of a residential institution is therefore to be found in the provision of adequate community based services for each person who is to move.

Against this background, it is natural that the second research question raised in chapter 1 concerned the issue of which community based services replace a residential institution. The question is answered in this chapter in the form of a description of how community based services were created for persons who lived at Carlslund residential home. The Stockholm model for community based services is presented, as is the manner in which it was used at Carlslund in order to assess individual needs and to specify the nature of the community based services needed in the future. The assessed needs (Study 1) are later related to the services which actually were provided, as they were identified in the follow-up study (Study 5) which took place after all had left the institution.

#### The Stockholm model of community based services

##### *Housing in the community*

Community based forms of housing had gradually been developed in the Stockholm area during the 1950:s and 1960:s. These were mostly located to apartments in local housing-areas. Those living there received support from staff who made visits to them from their base in a service apartment. With such a distance to staff, housing of this kind required a certain degree of independence on the part of the residents which meant that it was mainly persons with a limited need for support who were able to live in this way. In the Stockholm model of community based services (Omsorgsnämnden 1977) this category of housing was formalized and extended so that persons with more extensive needs for support also could live in the community.

*Housing type A:* This form of group-home was located in a number of apartments, usually 4-6, spread over a housing-area. One of them had the function of a service apartment whilst the others provided housing either for one person or for a small group. If a group shared an apartment each had his own bedroom, while the kitchen, sitting room and bathroom were shared. The number of rooms of an apartment decided thereby the number of persons who could live there. Staff were attached to a service apartment from which support was available for those who required it, either by staff going to a person's apartment or he coming to the service apartment. Staff were

accessible around the clock, sleeping on the premises at night. Those who lived in this type of housing were expected to be able to care for themselves without close proximity to staff support. If a person was in need of more extensive support, he could live in a room of the service apartment, thereby having closer contact with staff.

*Housing type B:* In this type of group-home a group of five lived together in an apartment. Each had a room of his own but shared a common kitchen, sitting room and bathrooms. Staff responsible for providing support for this group was based in the same apartment. As this residence became relatively large it was usually necessary to have purpose-built premises. Five persons lived in this type of group-home, with a staff-group responsible for providing support around the clock, 7 days a week. Night staff were either awake or on hand to be woken during the night, this depending on the needs of the residents. Decisive for whether a person was to live in this category of housing was his need of proximity to staff and a more extensive need of the support, which was available.

*Housing type C:* This group-home was similar to type B as regards physical outline and staff support. As it was intended for persons with special needs it was characterized however by the availability of additional specialized staff, for example a psychologist, a psychiatrist or a social worker. The number of residents living there was also smaller being only four persons.

These three categories of housing were all based in the community. The Stockholm model did not, however, exclude the possibility of providing services in residential institutions, the establishment of new ones still being considered an alternative. It was emphasized, however, that these should be small.

#### *A cluster of group-homes*

The Stockholm model made use of the term cluster of group-homes. By this was meant that a number of group-homes could form an administrative unit in that one manager was responsible for running several group-homes. It was also thought that staff of such a cluster of group-homes should be able to work in different houses, without being bound to one particular house or apartment. The localization of houses making up these group-homes could also be chosen individually, either close to or apart from each other. The type of house, its physical layout and the size of the staff-group was dependent on the needs of the persons who were to live there. The intention of the cluster of group-homes was that within a geographical area, in different houses, one could provide support to all persons who lived in this community, irrespective of whether a person had a limited or an extensive need for support.

#### *Daily activities with support*

Participation in daily activities outside the residential institution had gradually been established, to begin with during the 1930:s and 1940:s but more intensely during the 1950:s and 1960:s, mainly for persons who lived in their parental home or in a group home (Ericsson 1991a; Eriksson & Engdahl 1986). In this way one had created a new service outside the home, providing support during daytime. With support through housing and daily activities being provided in the community, a more normal life could

be experienced.

In the Stockholm model these early experiences were acknowledged and the services further developed in order to be provided by way of day activity centres. A model for such a centre was developed, providing day services for 40 persons. This included premises, equipment and other resources needed for the provision of daily activities, including a staff-group with the sole task of providing activities during daytime. These centres were localized to those areas in the community where other daily activities for the public were taking place.

### *Support from consultants*

In order to make social, psychological or medical support available within the framework of community based services, these professional groups were to be found in teams run by the county services. In order to make these available throughout the county, it was divided into 16 districts, each with a team of consultants. In each team social workers, psychologists, recreational staff, physio- and speech therapists, medical doctors and nurses were to be represented.

In addition, support and service was also available from the ordinary services of the community such as health centres, dentists, pharmacists and the ordinary organizations for social welfare.

### *The Stockholm model in relation to the closure of Carlslund*

The debate about what forms of services were to be offered to persons who left Carlslund residential home took place mainly within the planning group. The Stockholm model of community based services (Omsorgsnämnden 1977), which already existed, provided a frame of reference. However, the families of the persons who were to move clearly stated that they could not accept another residential institution as an alternative, neither an already existent, nor a newly built one. To accept the closure they demanded that all be given the opportunity to move to community based services.

During this debate demands were also made that some be given the opportunity to move to a house with a garden, to be able to experience some of the positive aspects seen with the residential institution with its lawns, bushes and surrounding woodland. Within the framework of the community based services of the time, there was no possibility of providing such an alternative as the group-homes which were already planned were mainly located to apartments. The only form of service which gave access to a "green" environment was the residential institution. This debate gave rise to the idea of a group-home in a detached villa, thus giving access to a house with a garden. The type of housing here termed B came in this way to have two versions, one located to an apartment (BA) the other in a villa (BV). This differentiation was also applied to housing of type C (Omsorgsnämnden 1981).

### Assessing the needs for community based services

A planning group was appointed to prepare for the closure of Carlslund residential home

(chapter 1). Part of its task was to develop the community based services which would replace the institution. This made high demands on the task as this was the first residential home for adults to be closed. There was, therefore, no previous experiences of persons with a more severe disability receiving adequate support through community based services. In order to get a basis for planning the alternatives, an assessment of each person was carried out (Study 1). The purpose of this was to formulate which services, based on individual needs, were required in order to allow for everyone to live outside the institution (Ericsson et al. 1981; Thorsell 1982).

#### *A questionnaire to describe a person's need of support*

In order to provide a structured description of the needs of each person with regard to community based support, a questionnaire was developed (Ericsson et al. 1981). The first part contained questions of a general and introductory nature. In this way one got a short and informal presentation of how the person was perceived by those participating in the assessment, together with information about the care he was presently receiving. The person was also described with regard to his need for staff support in everyday life. It was also discussed whether he was in need of special support because of characteristics caused by personality disorders.

In the second part, a series of questions clarified the person's need of support regarding housing and daily activities. In order to estimate his need for these services the concept of basic and additional support was introduced. The purpose was to achieve a greater precision of description than that expressed in the relatively rough categorization into housing types A, B and C and the day activity centre. The basic support amounted merely to the support available in a house with a standard staff-group and forms of daily activities were presented merely as a place at a day activity centre, also with a standard staff-group.

Additional support indicated the type of supplementary assistance required by a person in order to enable him to avail of the service provided in the suggested type of housing or day activity centre. The categories of additional support chosen to complement the choice of housing for a person were the need for staff who could be awake at night, the need for extra staff in the home, the need for medical service in the home and special requirements in the "internal" and "external" physical environment. Examples brought up concerning the "internal environment" were housing on the ground level, physical lay-out, furnishings of the house and equipment in the bathroom. Regarding the "external environment" issues like the distance to neighbours, closeness to parkland and open space, the character of nearby traffic and the wish for close proximity to shopping facilities, were discussed.

Assessing a person's need of housing in a villa was related to whether it was thought that housing in an apartment would limit his freedom of movement in or around his home. This aspect was therefore discussed in connection with the issue of "proximity to neighbours". The suggestion of housing in a villa was intended to provide a greater degree of freedom because of a greater physical distance to other residents in the area. Another motive was that it was thought to be preferable for the shy or insecure person who might find that closeness to neighbours limited his freedom of movement.

Additional support concerning daily activities were extra staff in the group at the day activity centre, allowing for 2 instead of 1 staff per group of 5 persons. Demands

made on the "internal" and "external" physical environment during day-time were also discussed. The need for personal hygiene equipment and accessibility for wheel-chairs were issues seen as relevant. Opportunities for daily activities outdoors were also considered important, placement in a traditional day activity centre not necessarily being suitable for everyone.

In the third section of the questionnaire other possible needs were discussed, for example a person's requirements regarding recreational staff to provide special activities during leisure time or extra staff to assist the person to avail of this service. The need for the services of consultants was also an area described. One aspect discussed concerned social relations in a future group-home, whether there was any particular person with whom he wished to live or if there was someone he wished to avoid. The need for staff support during journeys was also a matter considered. The choice of localization of housing and of daily activities, preferences concerning particular areas of the county, was also an issue which was discussed.

### *Preparing for assessment*

Considerable care was put into the preparation of the meeting at which a person's need for services was to be assessed. The reason was that those who participated often had limited knowledge about the community based services to which the person was going to move, the existing experience of families and staff being mainly from the services of the traditional institution.

The meetings were arranged for one ward at a time. Prior to the assessment a programme of information was carried out. Together with the parents' association at the institution, the planning group invited families and other representatives for the persons concerned to a one-day conference. The term "family" was interpreted in a broad sense, the staff on the ward and the representative for the planning group deciding on who should be invited. Most usual was that parents and siblings were invited, but when there was no knowledge of such a family member another representative, either a guardian or someone else concerned with the well-being of the person, could be invited. The purpose of these conferences was to present information about housing and daily activities in the community. Six such conferences were organized and a total of 211 relatives, to the 322 persons then living at the institution, participated.

Parallel to the conferences for families, a one-day conference was arranged for staff on the ward concerned. Staff from schools and day activity centres were also invited. Altogether 20 such conferences were arranged and were attended by 450-500 staff of various categories.

The week before the assessment meetings were to take place on a ward, families and staff met for an evening together with representatives of the planning group in order to discuss the questions in the questionnaire. A total of 25 such meetings took place, 224 relatives and roughly as many staff participating (Ericsson et al. 1981; Thorsell 1982).

### *Meeting for assessment*

For each person at the residential home a meeting was arranged to which family

members and staff were invited. The objective of this meeting was to express and collect the views of the participants regarding the person's need for support and service in order to establish a life outside the institution. The discussion was led by one of three representatives of the planning group. There was a willingness to let the person with a disability also participate but it had to be admitted that the discussion which took place was most often too complex to partake in a meaningful way. However, at 20 meetings the person concerned was able to join in. Most of those who did so had also taken part in activities which, over a 2-year period, had been arranged to discuss the question of the closure of the institution. It was therefore considered appropriate that these persons be given the opportunity to contribute with their own views on their future life.

Staff from the person's ward always took part in these meetings, most often the staff member who was assigned to the person or someone else who knew the person well. When someone who represented the day services took part, it was a member of staff, the head of an activity-group, a teacher or a physiotherapist. This representation varied depending on the extent to which the person had access to daily activities, some lacking this day service entirely and others only participating to a very limited extent.

The extent to which families took part in these meetings also varied, depending on whether the person had contact with his family or not. Some persons had no family representation at all, for others many members of a family could participate. At 203 of the 322 meetings, 310 relatives participated.

An assessment meeting lasted on average 2 hours, a positive and constructive discussion usually taking place. An opinion concerning a person's need for community based services was not a mechanical evaluation, but rather the result of a discussion between those participating about what was considered the most adequate future services for the person. The number participating on such an occasion could vary from three to fifteen persons (Ericsson et al. 1981; Thorsell 1982).

#### *Assessed needs for community based services*

The results of this assessment were presented to the planning group (Ericsson et al. 1981). The outline presented here refers to the basic services, expressed in the assessed need for housing and for daily activities. In table 4:1 the four types of housing are given, each representing a physical type of house and the staff-group related to this house. The variation in staff support in daily activities has been expressed as two types of daily activities. Daily activities type I indicates that the person was assessed as belonging to a group of 5 persons, which would have access to support from 1 staff member, whereas daily activities type II indicates that the person was assessed as being included in a group of 5 persons, but with support from 2 staff members.

The type of housing for which there was greatest need was type B, either in an apartment (BA) or in a detached villa (BV). It was found that 212 persons (66%) required this. A much smaller group, 81 persons (25%), were assessed to require housing of type A. Even fewer, 29 persons (9%), were considered in need of housing type C. Regarding daily activities, the group was evenly divided between the two categories, 48% requiring daily activities type I and 52% assessed as in need of daily activities type II.

Table 4:1. Assessed need for housing and daily activities. Housing is expressed in terms of four types: A=small group-home, limited staff support, BA=group-home in apartment, extensive staff support, BV=group-home in villa, extensive staff support, C=group-home, smaller group with access to consultants. Daily activities are expressed in terms of two types: DA I=group of 5, 1 member of staff, DA II=group of 5, 2 members of staff. Percentage is given in parenthesis.

Daily activity	Type of housing				Sum:
	A	BA	BV	C	
DA I	70 (86,4)	48 (44,9)	34 (32,4)	2 (6,9)	154 (47,8)
DA II	11 (13,6)	59 (55,1)	71 (67,6)	27 (93,1)	168 (52,2)
Sum:	81 (25,2)	107 (33,2)	105 (32,6)	29 (9,0)	322 (100)

#### A follow-up study to describe services acquired

After the closure of the residential home, when all persons had left, a follow-up study (Study 5) was conducted (Ericsson 1993). In this thesis the results are presented in two parts, the intention being to address two issues. The organizational issue, regarding the types of community based services actually attained, is discussed in this chapter. The individual issue, concerning participation in community life by persons after having moved, is addressed in chapter 8. Information concerning the methods and procedures for the follow-up study is not provided here as it is presented in its entirety in chapter 8.

#### *Acquired housing and daily activities*

Table 4:2 gives an account of the services provided for the 266 persons included in the follow-up study (chapter 8). The types of housing and daily activities are the same as those presented in table 4:1 and in more detail in the early part of this chapter. There is however, one additional category "RH", as residential home was not mentioned in the assessment but became an alternative offered to a limited group. There is also a group of 33 persons, in the results called MIS (miscellaneous), living in group-homes where the level of support has not been possible to identify. For 6 of them information is missing as regards type of housing. Daily activities as presented here are those which are offered persons through a day activity centre. The extent of their access to activities is presented in terms of the number of hours per week. There is also an alternative for those persons who had acquired paid employment.

The most predominant form of housing is type B, either in an apartment (BA) or in a villa (BV). A total of 62% live in this manner, a majority, 40%, in detached housing (type BV), the remaining 22% in apartments (type BA). Only a small number, 11%, acquired housing in an apartment with limited staff support (type A). A group of 14 persons were provided with a place at a residential home (type RH). For 33 persons, group MIS, information about degree of support is not available.

Table 4:2. Housing and daily activities after persons have left the residential home. Housing is expressed in terms of four types: A=small group-home, limited staff support, BA=group-home in apartment, extensive staff support, BV=group-home in villa, extensive staff-support, RH=residential home. MIS is a set of group-homes where the level of support can not be identified. Daily activities are expressed in terms of number of hours per week during which a person is involved in activities. Employment means that a person has paid employment.

Daily Activities (hours)	Type of housing					Sum:	%
	A	BA	BV	RH	MIS		
01-09	0	2	2	4	0	8	3,0
10-19	0	7	9	4	1	21	7,9
20-29	8	22	44	2	11	87	32,7
30 -	15	36	30	0	19	100	37,6
Employment	2	0	0	0	0	2	0,8
info. missing	5	17	20	4	2	48	18,1
Sum:	30	84	105	14	33	266	100,1
%	11,3	31,6	39,5	5,3	12,4	100,1	

Regarding daily activities, a majority of 100 persons (38%), have activities for 30 hours or more per week. As 87 persons (33%) are occupied between 20-29 hours per week, this means that 71% of the entire group have activities at least 20 hours per week, that is to say, half-time or more. This is a minimum value as there are 48 persons (18%) for whom information is missing. A group of 10%, 29 persons, are occupied 19 hours or less per week. 2 persons have paid employment.

#### *Early changes of housing and daily activities*

Housing which has been accounted for here concerns the situation in 1990, but not all of these persons had moved directly to the housing shown in table 4:2. An analysis to clarify to what extent persons moved between different forms of housing was made for those who left the residential home during the period 1980-1987 (Ladefoged 1987). A total of 19 persons had, on leaving the institution, moved to another form of housing than that shown at the end of this period. 8 persons had moved between group-homes. Another 3 persons, who had moved from Carlslund to another residential home, had later moved on to community living when suitable housing had been found. 2 persons had moved from housing in the community to a residential institution and 1 had left a group-home for foster care in a family. The main reason given for moving had been to find a place with support thought better than that originally provided. Another reason had been to move to a more suitable group for the person concerned. In addition, there were also reasons like a family moving to another part of the country.

Housing and daily activities for a person were made available at different dates as a consequence of the structure of community based services. Housing was normally planned for 5 persons and could, therefore, be more easily established and organized than a day activity center. A centre was planned for 40 persons and was therefore more difficult to establish at the same time and in the same community, as new housing.

Persons changing between various forms of daily activities after having left the institution was therefore more common than a change in housing.

In order to guarantee that persons, when they moved, could as far as possible have access to both housing and daily activities, some provisional alternatives were sought. This could mean that the person moved from the ward of the institution to new housing, but retained the daily activities they previously had at the institution. It could also mean that the person received his activities through another day activity centre than that which was intended, while waiting for this to be built. Staff in the new house could also be given the task of providing daily activities while waiting for a place at a centre. Following a period of transition, which usually lasted around one year, it was common that the person had been provided with the daily activities which had originally been assessed as desirable.

### *Comments on housing*

Carlslund residential home was at the beginning designed as an asylum. Throughout its history it had been predominantly an institution for persons with a severe intellectual disability, often persons with one or several additional disabilities which contributed to their extensive need for support. This naturally meant that they were persons in need of extensive support from a community based service. This explains why the majority of housing in the community was of the type with a high staff-ratio, providing support day and night, during the seven days of the week.

The character of staff support available during the night provides information as to the need for proximity of the person to staff. Information is available for 237 persons in this respect. For 162 persons, staff are awake and on night-duty between midnight and 6 a.m., while 64 persons have staff on sleeping night-duty. A further 7 persons live in housing where sleeping night staff are on call outside the house and 4 have no staff support during the night (Ericsson 1993).

During the initial stage of the period of closure responsibility for these services lay entirely with the county administration. There was, therefore, no legislative requirement for the social services of a municipality to take responsibility for a person with an intellectual disability who was registered in that municipality. According to the 1985 Act, the provision of services remained the responsibility of the county but it was stipulated that cooperation should take place with local social services. Moving to one's home community was, therefore, neither a right nor an obligation when the decision was made as to where the person was to move. Housing was therefore localized to residential areas of the county and daily activities to areas where similar activities took place during the day, irrespective of the municipality to which the person belonged. At the same time attempts were made, as far as was possible, to meet the requests expressed by the family, for example that a person move to an area closer to the home of the parents or of another family member.

The institution had originally been intended for persons from Stockholm City. Of the 322 persons in the assessment study (Study 1) who at the start of the closure period received services at the institution, the majority, 271 persons (82%), had come originally from this area. Some, 50 persons (15%), came from other communities in the county and 11 persons (3%), came from outside the county (Lycknert 1978).

Table 4:3. Location of housing in relation to type of residential area (type of housing defined in table 4:2).

Type of residential area	Type of housing					Sum:
	A	BA	BV	RH	MIS	
Mainly apartment dwellings	19	81	0	0	0	100
Mainly detached dwellings	5	0	81	0	4	90
Mixed dwellings	4	0	12	0	0	16
Other	0	3	1	14	1	19
info. missing	2	0	11	0	28	41
Sum:	30	84	105	14	33	266

The county consisted of Stockholm City and 24 adjacent urban municipalities. In this study these have been grouped to form four regions. Only 21% of the total group moved to Stockholm City. The largest group (42%) were those who moved to the region northwest of Stockholm, one of the municipalities there being Upplands-Väsby, the place where the residential home was located. Only smaller groups moved to communities situated northeast (8%), south (6%) and southwest (8%) of Stockholm. A few persons moved to areas outside the county, primarily because of special requests from family members who had left the Stockholm region.

One reason why more people did not move to Stockholm City depended on the difficulty of developing housing suitable for persons with a severe disability in such a densely populated area. At the time it also seemed natural that most of the persons remained in the northwest region. In these communities there was a willingness to develop community based services and there was an easy access to experienced staff, those who previously had been employed at the residential home (Ericsson 1993).

From the questionnaire describing the character of housing provided, one also finds a description of its vicinity. Table 4:3 illustrates that housing is located to residential areas, both those with apartments and those with detached housing. This applies for 206 persons. The most common type of area is that with apartment dwellings. Of the 19 whose residential area was characterized as "other", 3 group-homes were in areas dominated by shops, post and bank facilities, that is to say in a commercial area. One detached house was localized to a country area dominated by woods and parkland. Housing provided for 15 persons was in an area dominated by social services and care facilities, this referring to the persons who had moved to other institutions (Ericsson 1993).

The cluster of group-homes was an organizational form which was utilized at the time of the closure of this residential home. In this way it was possible to localize apartments either to the same or adjacent buildings and detached housing could be placed in the same or different grounds. It was found that the group-homes, in which 206 persons lived, were located as such clusters. Of those 114 persons living in apartments, 22 persons had others with the same type of disability living in the same building, while 18 had persons with the same type of disability living in closely adjacent housing. 44 had persons with this disability living in the same neighbourhood, whereas 24 persons did not have any neighbours with a disability in the vicinity.

Table 4:4. Reasons why a person spends his days in his home.

Type of reason	Persons	%
A: Person has daily activities part-time	32	37,7
B: Person has a "day-at-home"	37	43,5
C: Day activity centre "closed" - person must stay at home	4	4,7
D: Person is "locked-out" from the day activity centre	2	2,4
E: The person has chosen not to participate in daily activities	10	11,8
Sum:	85	100,1

Of the 105 persons living in detached housing, 28 had others with an intellectual disability living in a house in the same grounds, 14 had persons with this disability living in adjoining grounds and 28 persons with the same disability living in the neighbourhood. There were 42 who did not have other persons with intellectual disability living in or near their housing area (Ericsson 1993).

The group living in residential homes includes 10 persons who were moved to a smaller facility for 30 persons within Stockholm County. One person moved to community housing but was later moved to a large residential home. A remaining 3 persons moved to other counties and were referred to an institution, as housing with adequate staffing was not provided within community based services of these counties (Ericsson 1993).

#### *Comments on daily activities*

Daily activities outside the wards was not something that could be taken for granted for persons at Carlslund residential home. The intention with the modern institution had once been that at least 40% of those living there should receive such a service (Carlslund 1958). In contrast to this, community based services were based on the idea that daily activities outside the home were a necessity. When the institution was to be closed it was, therefore, not just a matter of providing alternative daily activities outside but rather developing activities for the first time, for a large number of persons with an extensive need for support. For the day activity centres, previously used to providing services for persons with a limited need for support, this was a challenging task

It is therefore understandable that there is a considerable variation in the extent to which daily activities could be provided. The optimum time for one person may be less than 40 hours, for example if the person had an extensive need for support, 20 hours spent outside the home during a week may be found most adequate. Another person may request to have daily activities only half-time, in order to pursue some recreational interest the rest of the week. That a person chooses to refrain from an available activity can also depend on the non-compulsory nature of the service, entitling the person to choose whether to participate or not. This can be relevant when a person becomes older and wishes to spend more time in his home. The reasons for a person staying at home during the day, not attending the available activities, is expressed through one of the

Table 4:5. Environments where daily activities take place.

Type of area	Activities	%
A: Residential area	462	38,9
B: Industrial area	138	11,6
C: Commercial center	232	19,5
D: Green area	236	19,9
E: Other	121	10,2
Sum:	1.189	100,1
information missing	34	

questions answered by the residential staff, presented in table 4:4.

There are those who spend part of the week in their home (A), giving various reasons for this, thus making part-time participation adequate for the person concerned. The same concerns the category termed as "day-at-home" (B), that is, the person remaining at home during one day of the week, thus enabling him to receive more personal attention from staff than is usually possible. On a day like this there are opportunities to devote oneself to personal interests like caring for the home or to go shopping. Facilities for daily activities being "closed" (C) can depend on staff participating in a conference or a training-program, thus requiring that the person stays at home. That the person is "locked-out" (D) is more remarkable. It indicates that the person is prevented from a service, which he has a right to receive. Persons who have chosen not to participate in day services (E) are, for example, those who are elderly and wish to lead a life like an old-age pensioner.

The information in table 4:4 has consequences for the conclusions based on the answers to the questionnaire describing daily activities (table 4:2). There it was found that information about daily activities was missing for 48 persons. In the questionnaire describing housing and a home one finds that 12 persons do not participate in daily activities (categories D and E in table 4:4).

The task of the day activity centre is to organize activities during day-time for a number of persons. In order to describe this service it can be sufficient to describe a centre, for example its localization, size and the activities it offers. However, to acquire knowledge as to the consequences of this service for a person, one must analyze each of the activities in which the person participates during a period, for example a week.

The need to describe the activities in which a person participates, instead of merely describing the centre, has increased as daily activities no longer necessarily are located to a day activity centre but can also take place in other settings in the local community. The activities in which a person is involved vary, not only with regard to the type of activity but also to the environment where it takes place and the persons with whom one participates.

In the questionnaire which was sent to the day activity centre, staff responding were asked to make a list of the activities in which the person participated during a week. A maximum of 12 activities could be described for one person. No-one has, however, reported so many. In the two following tables all the activities, for all the persons, are presented. The 216 persons, for whom information was given, together represent 1.223 activities, that is 5.7 activities per person. Each of these are then

Table 4:6. Group size and client/staff ratio for daily activities.

Client/staff ratio	Group size				Sum:	%
	1-3	4-6	7-9	10-		
0,1-0,9	1	1	0	0	2	0,2
1,0-1,9	137	120	30	13	300	30,1
2,0-2,9	54	245	35	21	355	35,6
3,0-3,9	49	42	25	21	137	13,8
4,0-4,9	0	54	22	3	79	7,9
5,0-5,9	0	54	0	19	73	7,3
6,0-6,9	0	17	16	17	50	5,0
Sum:	241	533	128	94	996	99,9
%	24,2	53,5	12,9	9,4	100,0	

described in a number of aspects, for example the character of the activity or the localization and the size of the group participating. In table 4:5 the type of environment where these activities take place is presented.

Most common, 39%, is that these activities take place in a residential area. It is less common, 12%, that daily activities occur in industrial areas. "Commercial centre" and "green area", each representing 20%, are also common. This distribution may seem unfamiliar in relation to how daily activities usually are located (Ericsson 1991b). One could expect that the categories "commercial centre", "green area" and "industrial area" would occur more frequently and "residential area" less frequently (Ericsson 1993).

Day services are provided in activity-groups, each with its own staff. The size of a group involved for an activity and the degree of staff support, is not formally regulated as with housing. Instead, a day activity centre has a certain number of staff and financial resources at its disposal with which it has to provide activities for those for whom it is responsible. In table 4:6 group size and client/staff ratios are presented. The size of the group and number of staff, has been available for 996 activities.

The client/staff ratio is expressed as a mean of the relationship between the number of persons in a group and the number of staff for this group. The ratio 1,5 would, for example, indicate 1,5 persons to 1 staff member. This ratio is presented in intervals, 2,0-2,9 being most frequent and representing 36% of the activities. This, together with those with a lower client/staff ratio, account for 66% of all activities. The variation in size of these activity-groups is also given. The most common group size is 4-6 persons. This, together with even smaller groups, accounts for 78% of all activities (Ericsson 1993).

#### Assessed needs in relation to obtained support

Answering the question as to the extent to which the services obtained correspond to the assessed needs, table 4:7 relates the assessed need of housing in the community (table 4:1) with the results of the follow-up study (table 4:2). As the assessment was made in 1979 and the information of obtained housing was collected in 1990, there is an interval

Table 4:7. Assessed need of housing prior to leaving the institution (BEFORE) in relation to obtained housing after having moved (AFTER). Types of housing: A=small group-home, limited staff support, BA=group-home in apartment, extensive staff support, BV=group-home in villa, extensive staff-support, C=group-home, smaller group with consultants, RH=residential home, MIS=group-homes with varying levels of support.

BEFORE	AFTER					Sum:
	A	BA	BV	RH	MIS	
A	<b>27</b>	25	9	1	7	69
BA	3	<b>39</b>	31	2	9	84
BV	0	17	<b>50</b>	5	15	87
C	0	2	15	6	2	25
Sum:	30	83	105	14	33	265
information missing	0	1	0	0	0	1
Total:						266

of 10 years between these two occasions.

Of the four types of housing in the assessment study (before), three became available for the persons. The group-home, with a smaller group and with support from consultants, type C, was not realized. In the follow-up study (after) one finds, apart from group-homes A, BA and BV, 14 persons in residential homes (RH). This was a type of housing not available during the assessment. There is also a group, MIS, for which information is lacking regards type and level of support in the group-home.

When one compares the results from the assessment (before) with those of the follow-up study (after) one finds that the results correspond for 44% of the group. This could be higher because of the uncertainty of type of housing in group MIS. In table 4:7 these are the persons on the diagonal, that is the 27 persons who live in housing type A, the 39 persons in type BA and the 50 persons in housing type BV. These 116 persons are to be related to the 265 persons for whom information is available regarding housing on both occasions.

There is also a group who has obtained housing with more extensive support than that originally requested. In table 4:7 they are the persons above the diagonal, that is the 65 persons living in housing type BA (25) and type BV (40). There is also a group of 37 persons who obtained housing with less support than what was originally requested. These are the persons who in the table are found below the diagonal, those in housing type A (3), type BA (19) and type BV (15).

As mentioned housing type C was not made available. But it is not possible to state that these persons have not obtained this type of support as it can be made accessible in other ways, for example from the consultants in the teams of these special services or from services responsible for the general public.

Summing up, one can say that for persons where a difference occurs between their assessed needs and the housing obtained the greater part have acquired housing which provides more support than was assessed. The process which has developed is towards an increase in the two group-homes, termed BA and BV, these being the dominating housing alternative which came to be used. The major difference can be

seen to apply to the persons who had been assessed as having a limited need of support, housing type A.

To understand these differences would require a more precise analysis of this part of the process of transition. The differences cannot be seen as a question of making correct or incorrect assessments but are rather consequences of the development which took place during the period from the time of the assessment to the time of the follow-up study. During these years one finds a significant increase in knowledge regarding housing issues. Economic factors and tactical steps taken by various groups involved also have contributed to this process of change. The needs of the persons themselves also changed during these years. One can express the relationship between the assessment and the following course of events as being the result of the debate about community based housing in general and for each person, which started with the decision on closing down the institution. Accordingly, one finds that more factors than those which were considered in an assessment have contributed to finding a new home for these persons.

Answering the second question

#### *Community based services - a new structure*

The second of the three initial research questions was concerned with the services which were to replace those at the institution. The follow-up study has shown that persons left the residential institution and moved to community based services. If support is provided in the community, which corresponds to the needs of persons, there is no longer any reason for persons to receive the services at the residential institution.

There was, however, a group of 14 persons who still lived at a residential institution at the time of the follow-up study. For those who moved to another county there is an explanation to this, as there were no community based services to be offered to them. That persons were offered institutionally based services in Stockholm County, is more difficult to explain. This does not, however, change the earlier conclusion as even these persons left later, as all residential institutions in the county were eventually closed down.

The account presented has shown some of the characteristic qualities of community based services and how these have been realized for persons who moved from Carlslund residential home. Support provided through housing and daily activities has emerged as the most important aspects of a community based service. As such these have provided a platform for participation in community life.

Persons have, of course, also made use of other services which contribute to a good life for them. The services of the teams with consultants who were part of the county organization, were also used by persons. There is yet another group of services available, those for health and social well-being, these being part of the ordinary services, those used by the general public. In the follow-up study reference is made to how these services were availed of, for example the pharmacy, the dentist, the chiropodist and the health centre (Ericsson 1993).

### *Persons with extensive needs*

Within services to persons with an intellectual disability there has been a long tradition of treating those who are regarded as “educable” in a different manner to those seen as “uneducable”. Ever since this field was developed during the 19<sup>th</sup> century the “educable” have had access to education and a service with a favorable standard, whereas the “uneducable” were referred to a passive life with an inferior standard. As was seen in chapter 1, institutions like Carlslund residential home were opened as an establishment for the latter group. With the closure of such a residential institution one is therefore faced with the major challenge of creating community based services for persons with extensive needs of support.

This calls for new knowledge regarding the types of services required if one is to satisfy the demands of a group whose needs have not received adequate attention at the institution. As this is a group which had previously been referred to residential institutions with inadequacies regarding resources and who have now gained the right to community based services, demands are also made that resources be made available in order to meet their needs.

Moving from a residential institution and beginning a new life among others, requires that all concerned share values which express an acceptance of and a determination to follow this course of development.

### *A diversity of personal needs*

As persons living at the residential institution represented a large variation of disability, high demands were made on describing and responding to each one’s personal needs. The small groups which are characteristic of community based services, in this case usually a group of 5 persons or smaller, is one way of meeting such a diversity.

A consequence of recognizing this variation in personal needs was to develop an assessment procedure which took place at an early stage of the planning process, this being the basis for the establishment of the community based services. This was possible to carry out even if it was an extensive task for the planning project, including the families and staff. 10 years later, half of the group had received the services which were assessed as suitable, while another group had more extensive support than had been assessed. The method used can therefore be seen as a constructive way of starting a process of meeting the diversity of personal needs of persons at a residential institution.

### *The cultural context*

A single answer to the question of which services are needed to replace the residential institution is difficult to give, as one can perceive these as culturally determined and therefore relative in their nature. The type of support which can be created on one occasion is dependent on the circumstances which exist at the time. When conditions change, new possibilities emerge. The development of community based services, which took place in connection with the closure of Carlslund residential home were those which were then possible to establish, with the conditions which prevailed in the organization, in that county and at that time. When other institutions in the country have

been closed, at a later date, other circumstances have existed and it has been possible to develop other forms of community based services.

The best example of alternative services during institutional closure is the group-home. The model which has been accounted for here was based on a family-like situation where a group lived together and shared a common home. The model which was developed at a later stage was instead designed as a house with 5 small apartments. In this way the person has access to a larger personal home. As a consequence the building in which these apartments are located becomes quite large and therefore has an appearance which deviates from the surrounding buildings.

Daily activities have also been developed through the emergence of new models. A common feature has been to create greater opportunities for a more personal planning of daily activities. This has been made possible in that the organization which provides daily activities no longer is seen as a day activity centre, but as a series of activity-groups, each one having its own characteristics depending on the needs of the persons who participate in the group. With differences in needs between groups, their character will vary (Ericsson 1991b).

The process of change which has been accounted for here took place during the period 1976-1988. As shown in chapter 2, legislation changed during this period, the 1967 Act being replaced by the 1985 Act. Later on the 1993 Act was introduced. As was shown (chapter 2) this legislation represented a new relationship to persons with an intellectual disability. With the right for all to participation in community life, not only residential institutions were closed. The county organization for special services was also dissolved, handing over some of their tasks to the social services of the municipalities. In that the municipality acquired responsibility to respond to the needs of housing of all citizens, new conditions were created for housing for persons with an intellectual disability (chapter 10). The development of services which started with the Stockholm model and which continued throughout the early phase of the transition process has continued, while the new Acts of Parliament have given a new context for the services.

## Discussion

This chapter has described the key task, the establishment of community based services when a residential institution is being closed down. The special circumstances on this occasion was the fact that no other residential institution for adults had been closed prior to this one. This meant that the task was a new one. One consequence of this was the high degree of uncertainty as to the outcome with regard to both the type of new services to be developed and the quality of life they offered.

Aspects of the planning of the new services have been described here. The basis for this was the Stockholm model for community based services, with the extension it was given by the planning project. The contributions of families and staff during the assessment of personal needs for community based forms of support were also important factors for the final plan. This had also been accepted by the political Board of the organization and by the County Parliament and thereby given the necessary economic foundation. The plan therefore provided the framework for the process of change throughout the period which ended when all persons had left the institution.

This chapter also describes, through the follow-up study, the services which

were provided for the persons when all had left the residential home. This presents the variation in housing, as well as in daily activities, the two main forms of community based services. The main conclusion is that it has been possible to create community based services for all persons to leave a residential home. However, there was a smaller group who were offered a place at a small residential home. The reason for the choice of this service is unclear. As this institution has now also been closed this alternative service does not negate the possibility of creating community based services for all who leave a residential home.

A comparison shows a difference between needs for services as assessed while at the residential home and those which were received after having left. Should this be seen as a problem? The function of the plan was to facilitate planning, laying the foundation for the services to come. The results show that one half of the group received what was seen as desirable during the assessment. Of the other half some received more, others less, extensive services. Based on these facts there is no way of concluding whether this result is right or wrong. The plan can instead be seen as a basis for the process which came to follow. During this some have argued for more support, others less, than was assessed. In the end there must be an accurate evaluation, made by responsible people who assess the needs for support of a person at the time when he actually leaves the institution. It is this final assessment which must be the basis for a decision about what forms of community based support to offer.

Many were concerned and involved in the transition towards community based services and during the period, from assessment to follow-up, more than 10 years, there was time to exert influence. A number of groups were important for the realization of the closure of this residential home. Families of persons who were to move and the staff of the institution were two groups which expressed concern. But also staff in the existing community based services had views about persons with a severe disability coming to use existing non-institutional services. Other influential groups were the administrators and the members of the political Board of the organization, as well as the members of the County Parliament. The general public in the county, those who would receive the persons from the residential home as new neighbours, also expressed concern about the ongoing transition of services. There were also members of national organisations and authorities who showed an interest in the ongoing process of change. These groups were not neutral with regard to the ongoing transition but often expressed severe doubts about the wisdom of closing a residential home. There were however, also groups who were supportive, even if these were only given limited attention during the ongoing process of change.

An important consequence of the fact that change takes place during such a long period is that persons in the organization, those responsible for realizing this transition, seldom stay for the number of years this will take. People change positions and organizational restructuring occurs. A number of elections to Parliament also took place during these years, with a shift in the political majority of the Board and as a consequence new members at the County Parliament. There was also a change of Acts of Parliament during these years, the 1985 Act being introduced. The context in which the process from institutionally to community based services takes place must therefore be seen as a most important factor.

## Chapter 5

### Personal consequences during institutional closure: Introduction to empirical studies

In the final part of chapter 1 the project “Two worlds of services” was introduced. Within this empirical studies were carried out to analyze personal consequences during the transition from institutionally to community based services. These studies are introduced in this chapter to provide an answer to the third research question, whether the closure of a residential institution contributes to an increase in community participation for persons who leave. The present chapter gives the model for an analysis, while chapters 6-8 present information from three studies. In chapter 9 the conclusion regarding participation in community life of persons is presented together with information from other studies which give a wider view of personal consequences during institutional closure.

A series of empirical studies

#### *Seven studies of personal consequences*

At an early stage during the closure of Carlslund residential home a study was carried out the purpose of which was to compare community participation of persons living at this residential home with that of a group who received support from non-institutional services. In this cross-sectional study (Study 2) groups were chosen from both types of services and described concurrently. It was initiated as a response to questions and doubts from families and staff concerning whether persons with extensive needs for support could live outside the residential institution and there participate in community life (Ericsson, Lerman & Nilsson 1985; Lerman, Ericsson & Nilsson 1986; Nilsson 1985).

This was followed by two studies carried out after persons had begun to leave Carlslund (Ericsson, Brusén & Thorsell 1986). In a longitudinal study (Study 3) a group of persons was described, the first time as regards community participation at Carlslund residential home and again two years later, after they had left (Brusén, Ericsson & Thorsell 1986; Brusén, Ericsson & Thorsell 1988). In an interview study (Study 4) staff provided information regarding the type of personal development they could see among persons after they had moved to community based services (Thorsell, Ericsson & Brusén 1986; Thorsell, Ericsson & Brusén 1988).

After persons had left Carlslund residential home a follow-up study (Study 5) was conducted. In this, those who had left were described two years after the closure with regard to their participation in community life (Ericsson 1992a; Ericsson 1993).

In the middle of the 1980:s planning had started to close residential homes in Skaraborg County. One of them, Johannesburg residential home, was large and had a similar character to that of Carlslund residential home, while the other were small institutions. Of the studies from Skaraborg County, three in particular, can be seen as complementary to the ones from Stockholm County and are therefore referred to here

(Ericsson 1992b; Ericsson 1995a). In one of them (Study 6) persons who had moved from a residential home were interviewed regarding their opinions about the new life (Gilbertsson 1992; Gilbertsson & Ericsson 1995). In another (Study 7) families were provided with an opportunity to describe how they perceived the process of transition for their family members who had moved and for themselves (Tuvevsson 1992; Tuvevsson & Ericsson 1995, 1996). The opinions of staff were described (Study 8) by means of a questionnaire to compare their views on working conditions in institutionally and community based services (Dahlgren 1995; Ericsson & Dahlgren 1995).

The reason for bringing together these seven studies from Stockholm County and Skaraborg County is that together they provide extensive information regarding the process of transition during institutional closure. All studies were conducted with the same purpose and within the same frame of reference.

### *Two groups of studies*

These seven studies constitute two groups. In one, consisting of the cross-sectional study (Study 2), the longitudinal study (Study 3) and the follow-up study (Study 5), the aim was to analyze whether this transition of services did contribute to an increase in community participation for persons. They took place during the early work of project "Two worlds of services". They were mainly oriented towards gaining knowledge as to whether a new life could be created for persons after leaving a residential institution.

In the other group studies describe the process of transition from institutionally to community based services, as this was perceived by the persons themselves (Study 6), by their families (Study 7) and by staff (Study 4 and Study 8). Three of these were conducted at a later stage during project "Two worlds of services". As studies from the early phase had shown that persons were able to leave a residential home which is being closed down, the latter studies were oriented towards issues relating to the various groups involved and their experiences of the process of change.

### *Studies in two counties*

There were variations in conditions for services between Stockholm County and Skaraborg County. While Stockholm is the capital with a dominating urban character, Skaraborg County is a geographical area which is more rural. Another difference concerns the community based housing offered. As the closure of Carlslund was early, the development of housing had been planned by the county. The transition which took place in Skaraborg had begun later and they could therefore use the specially formed group-homes which national authorities had been given time to design.

Experiences I have gained from having taken part in this transition of services in several places throughout the country indicates however, that the character of the process of change and its consequences are very similar, irrespective of where the transition has taken place. The reason for this is that the residential homes which were being closed were very similar and had a common structure, all having been established according to national plans following the introduction of the 1954 Act. Likewise, the alternatives to the residential home, the group-home and the day activity centre, are similar as they are also based on nationally designed models. The general characteristics

of the services of which these persons avail do not therefore vary around the country.

Conditions under which the studies were carried out

### *A short period*

Residential institutions were established during the latter half of the 19<sup>th</sup> century which means that they had existed for more than 100 years. In Sweden the institutional problem was publicly recognized in the middle of the 1970:s, when the closure of Carlslund residential home was decided upon in 1976 and when the directives for the 1977 Committee on special services were issued. This means that the long period of institutional dominance in intellectual disability services came to an end during a short period, the 25 years between 1975-1999. When one looks at this change from a formal point of view the period was even shorter, as it was in the Acts of 1985 and 1993 that this development away from residential institutions became imperative (chapter 2).

The analysis of this last stage of an institutional period in Sweden is important as it provides a unique opportunity to study the full transition from institutionally to community based services and its consequences for the persons concerned. A group of special interest are the persons with an extensive need for support, those who once were called the “uneducable”, persons whose only form of support was considered to be the residential institution. This transition meant that the task of providing adequate forms of community based support had to commence.

As community based services are the alternatives to the residential institution, the future for non-institutional services were formulated during this period. Knowledge as to what took place during this transition is therefore an important ingredient in the further development of community based services.

This is also a period when unique knowledge can be found as persons who lived at the residential institution start new lives among people of the local community where they now reside. The issue of how persons respond to these new living conditions extends the knowledge about intellectual disability and the lives of these persons.

However, it was a short period during which one could document and analyze the final phase of a residential era. When one wants to document and analyze consequences for persons who leave an institution when it is being closed, the period is limited during which it is possible to carry out studies. In the case of Stockholm County studies were carried out during the years 1980-1990. Several suggestions for studies were made but the four which have been referred to were those which could be realized.

A new opportunity to analyze the transition of services and its personal consequences was given when the residential homes in Skaraborg County were closed. A project to document the process of change was initiated and against the background of experiences from Stockholm, the new project could be developed further to analyze a wider set of issues (Ericsson 1995a).

Apart from the studies on personal consequences in these two projects a number of analyses were carried out, mainly on issues related to the socio-political change and on models for the new forms of community based services.

### *Formal conditions which prevailed*

The studies which have been commented on were commissioned by Stockholm County and Skaraborg County. Three of the studies in Stockholm were financed by national research grants while the follow-up study was financed by county funds. All of the Skaraborg studies were financed by the county. This meant that during a study a formal relationship existed between me as a researcher and the county concerned. A representative from the county was always appointed to be responsible for the commissioned study.

Each study was designed as a project. Attached to such a project a reference group was selected, comprised mainly of families and staff, together with those employed to carry out the study. In these projects the ongoing work was discussed, this contributing to the quality of the study. Such a group was also used as a forum for discussions of ethical issues. When a project was completed the product was handed over to the representative of the county who reported it to the board and made it public.

### *Choice of source for information*

It was easy to choose the source of information for the Skaraborg studies, the intention being to let three groups represent themselves. Interviews were therefore carried out with the persons themselves and with their families. As the working conditions of the staff was to be described, it was natural that they were also a source of information.

When describing participation in community life in the Stockholm studies, choosing the source of information required some consideration. At a residential institution for persons with an intellectual disability there are only a limited number of persons who use the spoken word to communicate with others. Someone must therefore speak on their behalf. Those who do this are usually the staff who provide them with services, members of the person's family or an official representative, for example an appointed guardian. The choice of source of information is not, however, something which is self-evident as these sources naturally have different relationships with the person.

When describing community participation, information is required about the everyday life of a person. As these persons receive staff support day and night, either from the residential home or from a group-home and a day activity centre, the choice which finally was made was to let staff be the source of information. They were interviewed in the cross-sectional (Study 2) and in the longitudinal (Study 3) studies. They were also the ones who responded to the questionnaire used in the follow-up study (Study 5). In the early follow-up study (Study 4) based on interviews about everyday life, staff were the source of information. In this study an attempt was made to let the persons themselves and their families also give their views, but the information collected in this way was limited.

## Community participation of persons

### *Choice of concept for analysis*

As can be seen in chapter 3, in the formulation of the principle of normalization from 1946, there was an aspiration towards a normalization of the conditions of life. There is reason therefore to examine whether this goal has been fulfilled. Regarding the general concept of normalization it was developed further by Bank-Mikkelsen and Nirje. Bank-Mikkelsen used it when he advocated the person's right to a normal existence and a more normal life. Nirje also used the normalization principle in referring to what normal patterns of everyday life meant for the person with a disability (chapter 3).

During the 1970:s, in analyses of daily activities of persons with an intellectual disability, the concept of community participation was formulated in order to evaluate whether day activity centres did contribute to a life in the local community for these persons (Ericsson 1981b). Community participation was a concept which was chosen at the time of these studies in order to describe personal consequences on leaving the residential home. As the closure of the residential home can be seen as these persons entering into the welfare society, to a life among others, the concept was defined from a welfare perspective. As such it focussed the right to housing and employment, access to commercial services, recreation, to services for social well-being and health.

Today the concept of participation can be found in studies from the 1980:s and 1990:s. The most noticeable current use of the concept is however, found in the UN policy of equalization of opportunities (chapter 2). There it says quite simply that the basic objective for support to persons with a disability must be their equal participation in community life.

### *Three studies on community participation*

Studies 2, 3 and 5 which have analyzed community participation of persons in connection with the transition of services from Carlslund residential home to community based services, have all been carried out in a similar manner. The main question has been whether an increase of community participation takes place when community based services are being used. This has been described by the use of structured methods in the collection of information, by way of interviews and questionnaires.

The studies have been designed so as to give a broad description of personal consequences. During the early stages of the process of change there were still many ambiguities regarding which personal consequences could be expected. Many questions were therefore formulated, covering a wide field. The information collected in a study was later used in many ways, for example to answer questions at staff meetings, as information to families, in reporting to administrators and politicians and in scientific presentations. The material that has been presented on each occasion has always covered a limited part of the available information, just as this presentation is limited.

The result on community participation which will be presented in the following chapters is based on studies carried out during three phases of the period during which persons left Carlslund residential home. The cross-sectional one (Study 2) was carried out prior to the actual closure taking place. This had, as its main objective, a comparison

Table 5:1. Model for analysis of community participation. With the 24 fields of the model, information will be collected from the studies in chapters 6, 7 and 8.

COMMUNITY PARTICIPATION	STUDIES		
	Study 2	Study 3	Study 5
1. Platform for community participation			
1.1 Housing	x	x	x
1.2 Daily activities	x	x	x
2. Everyday life with a personal character			
2.1 Housing	x	x	x
2.2 Daily activities	x	x	x
3. Participation in local community			
3.1 Housing	x	x	x
3.2 Daily activities	x	x	x
4. Quality in everyday life			
4.1 Housing	x	x	x
4.2 Daily activities	x	x	x

between daily life at the institution and the life lived by others, who already were receiving support through community based services. The longitudinal one (Study 3) was carried out during the process of change. Community participation of a group was described twice, the first time at the residential home and the second time after having left. The follow-up study (Study 5) was carried out after all persons had left the institution.

When the transition began there was an earnest ambition that the goal for this process of change would be realized. Yet at the same time there was a considerable lack of clarity as to the nature of the coming process regarding which services would replace those at the institution. There was therefore also an uncertainty as to what sort of life persons would be offered and what personal consequences could be expected. This of course influenced the interpretation given to the concept of community participation in the first study. Later on the concept had gained more specific meaning as knowledge about the process of change had increased.

#### *The concept of community participation in this analysis*

As mentioned the concept of community participation was used for the first time in a study aiming at the evaluation of day activity centres (Ericsson1981b). In the three studies to be presented (chapters 6-8) the concept was extended and used to create the instruments with which to collect information. After the closure of these residential institutions work has continued to develop the idea of community based services and its personal consequences (chapter 10). Today there are four areas of a person's life which appear as important in community participation. They supplement each other and give a broad understanding of the life of the person. These are also chosen because they are seen as critical in a change from institutional life to community participation.

The first area, “platform for community participation”, conveys the idea that a person has access to housing and to daily activities outside his home. To live where others live and to have daily activities where working life of the community takes place, can be seen as a basic aspect of participation in a community. This is also the platform for the person’s further participation in the community in which he lives.

The second area, “everyday life with a personal character”, is an expression of the fact that services should be personal and satisfy the needs and requests of the person. When housing becomes personal, the person will have a private home. When daily activities are chosen so as to relate to requests, the person will experience a purposeful week.

With housing and daily activities as a platform, availing of commercial services, recreational activities and services for well-being and health, contributes to a wider life. The third area, “participation in the local community”, therefore points to participation in activities in local community.

The fourth area, “quality in everyday life”, expresses the idea that a person should experience an everyday life which has quality. This can apply to the material conditions he is living under, but also his relations to others. Integrity and influence over one’s everyday life are two aspects which emerge as important in terms of quality for the person who has left an institutional life.

With these 4 areas, each described as regards housing and daily activities, a structure with 8 aspects of community participation is created. Information for an analysis is collected from chapter 6 (Study 2), chapter 7 (Study 3) and chapter 8 (Study 5). With information about the 8 aspects of community participation from 3 studies, a model with 24 fields has been created. This is presented in table 5:1. The results presented in chapters 6, 7 and 8 will be compiled in chapter 9 and presented in table 9:1.

## **Chapter 6**

### **The cross-sectional study**

#### Method

##### *Persons in this study*

Two groups are compared here (Study 2) regarding their participation in community life. One received its support from institutionally based services (group IBS) and the other from community based services (group CBS). Group IBS was chosen from persons living at Carlslund residential home while group CBS was chosen from persons living in group-homes in Stockholm County.

Groups IBS and CBS are also compared as regard to level of support. This was possible as support was provided through two types of community based housing (chapter 4). Staff-support in housing type A was limited and could therefore only provide support to a lesser degree. This was therefore the group-home which provided for those with a limited need for support (level L). Staff-support attached to housing type BA was more extensive, this being the group-home for those who were in need of extensive support (level E).

As Carlslund residential home was considerably older than newly built group-homes a recently built residential home in the county was included in the comparison. It had the same basic physical structure as Carlslund but at the time of the study it had only been in use for a period of five years. Apart from providing a more modern standard, it was also smaller. In the presentation to follow Carlslund is termed institution I while the modern residential home is termed institution II (Lerman, Ericsson & Nilsson 1986).

In order to be included in the study a number of criteria had to be met as the ambition was to minimize differences in community participation related to other factors than a person's need for housing. The person had to have been living in community housing for at least six months prior to the study, experience having shown that it takes time to get established and to avail of the opportunities provided by the new house and the local community (Thorsell 1983). Another ground for selection was the age of a person as only adults of active age, between 20 and 50 years, were included. Some forms of additional disability are of such a nature that they are a hinder for participation in community life. Therefore persons with such disabilities were not included. The three forms of additional disability were blindness, use of a wheel-chair and pronounced psychiatric or behavioural problems (Lerman, Ericsson & Nilsson 1986, p.11).

As the selection of persons to group CBS was to be made from existing community based housing, such services were identified. Regarding housing type A it was found that in the community at the time there were 36 group-homes, with a total of 74 residents. There were 13 group-homes, with a total of 54 persons, living in housing type BA. From these 24 group-homes were randomly chosen, 15 of type A and 9 of type BA. Persons living in these and who met the criteria for selection, were included in the

Table 6:1. The five groups of the study as regards their size. (IBS=institutionally based services, CBS=community based services, L=limited need for support, E=extensive need for support, I=institution I, II=institution II)

IBS-I/L	IBS-I/E	CBS/L	CBS/E	IBS-II/E	SUM
n=29	n=30	n=29	n=30	n=30	n=148

study. If someone declined to participate he was replaced by a person randomly chosen from a previously prepared list. In this way 29 persons were chosen for group CBS, level L, while 30 persons made up group CBS, level E (Lerman, Ericsson & Nilsson 1986, p.12).

At the time of the study a total of 276 persons lived at institution I. Information was acquired concerning persons who had been assessed as requiring housing type A and type BA. A group of 31 persons were seen as being in need of housing type A, while 73 persons were considered to be in need of housing type BA (chapter 4). From among these the selection of persons to the groups was made randomly. In order to create groups of the same size as those already living in community based housing, the group in need of housing type A was made up of 29 persons whereas the group in need of housing type BA included 30 persons.

At this time 164 persons lived at institution II. As the majority of these persons were in need of extensive support, only a group representing housing type BA was chosen. A survey which was carried out resulted in 83 persons meeting the criteria for this type of housing. Of these, a group of 30 persons was randomly selected to take part in the study (Lerman, Ericsson & Nilsson 1986, p.8).

Table 6:1 presents the five groups of the study. Group IBS is represented by three groups, two from institution I and one from institution II. Group CBS is represented by two groups. In two of the five groups there are persons with a limited need for support, while there are three groups with persons in need of extensive support. The table also shows the size of these five groups, which together make up the 148 persons of the study.

When presenting the results comparisons will be made between group IBS from institution I and group CBS. Two subgroups will be shown for each type of service, one representing level L and the other level E, indicating the variation in need for support. The fifth group representing persons from institution II will be included in the comparison only in the form of a comment to a table. Full information is given in Appendix (available from the author).

In order to understand the nature of the participation in community life in which these persons took part, information regarding the services which provide them with support is necessary. In chapter 1 Carlslund residential home is described. In the report presenting the Swedish version of this study (Lerman, Ericsson & Nilsson 1986) the residential home is presented in more detail. One sees clearly that this was a traditional institution for persons with an intellectual disability, most of the services being located to its grounds. Institution II had a similar physical structure although it was smaller and with a more modern material standard. Community based housing referred to in this study was located to residential areas in the municipalities of Stockholm County while daily activities were located to areas where employment and other forms of daily

activities for the general public took place (Lerman, Ericsson & Nilsson 1986, p.16).

There was a difference in the size of the group in which a person lived. In the 17 units where persons in the study lived at institution I, the average size was 13,1 persons whereas it was 8,8 at institution II. In the 24 group-homes the average size was 3,2 persons in a group (Lerman, Ericsson & Nilsson 1986, p.16). When one looks at staff quotas during evenings and at week-ends, the time of the day when it is likely to participate in the life of local community, one finds a difference as the number of staff generally is lower in institutionally based services (Lerman, Ericsson & Nilsson 1986, p.20).

In community based services a day activity centre provides support to persons during the day by arranging various kinds of activities. Group CBS had access to their daily activities from 17 centres. These varied in size from 10 to 59 persons with an average of 38. Support in the form of daily activities was originally not a natural part of a residential home, the ward being the place where all care was to be provided. When daily activities gradually become a part of the residential institution, they are difficult to specify. A day activity centre comparable to those of community based services did, however, provide a nucleus. But there were also other activities taking place outside this centre, but within the precincts of the institution. Persons at institution I and institution II were therefore provided with some daily activities, located to various places within the area of the residential home. Regarding the size of groups and the number of staff, there is no clear difference with regard to daily activities between institutionally and community based services (Lerman, Ericsson & Nilsson 1986, p.21).

It is important to note that the basis for comparison between groups IBS and CBS is their need for support in community based housing. A consequence is that persons, with the same need for support, may show a variation in personal characteristics. When one looks at the conditions when these persons grew up one finds that nearly all within group IBS and nearly two-thirds in group CBS have lived most of their lives in an institution. One also finds that there are more men than women in the groups. Concerning age the average lies within the interval 32,3-38,9 years for the five groups. Group CBS has, however, a somewhat lower average age (Lerman, Ericsson & Nilsson 1986, p.24).

Regarding the intellectual disability it has been described in a number of aspects. Additional disabilities regarding hearing, sight and mobility have also been described. A summary shows that there is no real difference between the two groups. When a description was made of behaviour usually described as problematic, it was found to occur more often in group CBS than in group IBS. When need of support in everyday life was considered one finds a difference between group IBS and group CBS in that the former group needed more support than the latter (Lerman, Ericsson & Nilsson 1986, p.26). In a separate analysis (Nilsson 1985) a comparison was made on 19 variables to see whether there were differences between group IBS and group CBS. The result shows that on most of them no differences were to be found. On seven variables there were significant differences on the 5% level.

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Table 6:2. Dimensions of community participation in the cross-sectional study.

1. Localization of housing	8. Extent of daily activities
2. Standard of housing	9. Purposeful daily activities
3. A personal home	10. Daily activities with community orientation
4. Participation in household duties	11. Material standard
5. Leisure at home	12. Social relations
6. Leisure outside home	13. Influence over personal life
7. Use of general public services	

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### *Instrument for collection of information*

As the concept of community participation had been chosen to describe the everyday life of a person, it had to be elaborated on. It was therefore given an interpretation which at the time of the study was seen as suitable. Accordingly, thirteen dimensions were found to be relevant (table 6:2). A dimension was described by one or more variables (Lerman, Ericsson & Nilsson 1986, p.5).

"Localization of housing" (1) describes aspects of the local municipality where a person is living. "Standard of housing" (2) gives an expression of the size of the home where he lives, while "a personal home" (3) describes whether it offers a place with a personal character. "Participation in household duties" (4) gives an account of whether a person is involved in the common tasks of a home. A person's leisure is spent both within and outside his home. Therefore "leisure at home" (5) characterizes what takes place within the home and "leisure outside home" (6) gives an account for leisure taking place in the local community. "Use of general public services" (7) presents the extent to which a person, for his well-being, utilizes services also used by the general public.

Aspects of daily activities are covered through "extent of daily activities" (8), which describes the degree to which a person participates in daily activities outside his home and "purposeful daily activities" (9), which refers to whether activities chosen are related to personal needs. "Daily activities with community orientation" (10) describes the extent to which activities are taking place in the local community.

Three qualitative aspects of everyday life are described. "Material standard" (11) refers to the economic resources and personal belongings of a person, thereby describing an aspect of his living standard. "Social relations" (12) expresses the range of social contacts occurring outside the service organization, while "influence over personal life" (13) covers the extent to which a person has control over his life and is able to influence its course.

In order to collect information, interviews were carried out during visits to group-homes and day activity centres. To achieve this a questionnaire containing three sections was constructed. A section covered some of the 13 dimensions. The dimension was described through a number of questions. For each of these categories of answers were provided. Some of them also had an open part where additional information could be given.

The first section consisted of 19 questions which provided a personal background. These were put to the member of staff who was interviewed in the home of the person concerned. The second section of the form gave a description of the person's home and the life lived there. This part included 55 questions. These were intended to

cover dimensions 1-7. Dimensions 11-13, designed to describe the qualities in everyday life, covered aspects which were related to the home and were therefore included in this second section. The third section described the person's daily activities, dimension 8-10, by means of 30 questions.

During the construction of the questionnaire a conscious endeavour was made to choose and formulate questions in such a way that the person's degree of disability had a minimal effect on the issue being described (Lerman, Ericsson & Nilsson 1986, p.13).

#### *Procedure for collection of information*

As very few of the persons with a disability had speech as their means of communication, information was collected through interviews with staff. The staff member interviewed in the home was the one who had the best knowledge of the person concerned. Information on daily activities was obtained from the member of staff who was in charge of the activity group to which the person belonged.

Following the selection of persons for the study, contacts were taken by telephone to arrange interviews. At the same time written information about the study was sent to those concerned. In connection with this initial contact, three of the group-homes in the community refrained from participating. This related to seven persons, who were replaced by others, randomly chosen. The series of interviews was conducted by two psychologists. An interview in the group-home lasted between 1,0-1,5 hours, while an interview concerning daily activities took between 0,75-1,5 hours (Lerman, Ericsson & Nilsson 1986, p.14).

#### *Analysis of information*

The information collected in this way was analyzed and presented (Ericsson, Lerman & Nilsson 1985; Lerman, Ericsson & Nilsson 1986; Nilsson 1985). The analysis accounted for in this chapter is based on the formulation of the concept community participation as presented in chapter 5. The structure which it represents has been the starting point in the selection of information from the project report (Lerman, Ericsson & Nilsson 1986). The account here covers three areas from chapter 5, "everyday life with personal character", "participation in local community" and "quality in everyday life". As each is described as regards housing as well as daily activities, six comparisons are presented. The area "platform for community participation" is not presented as it was the initial basis for selection of housing when conducting the study.

The empirical information for this analysis is found in Appendix 1 (available from the author). Each of the six analyses is presented in three ways. The first is in the form of a figure with comments. The second is the result from the test of significance which has been carried out with the use of Fisher's Exact Test (SAS 2001). The third is an index which is an expression of the result. This is also presented in chapter 9, where the results from the analysis of community participation are summed up.

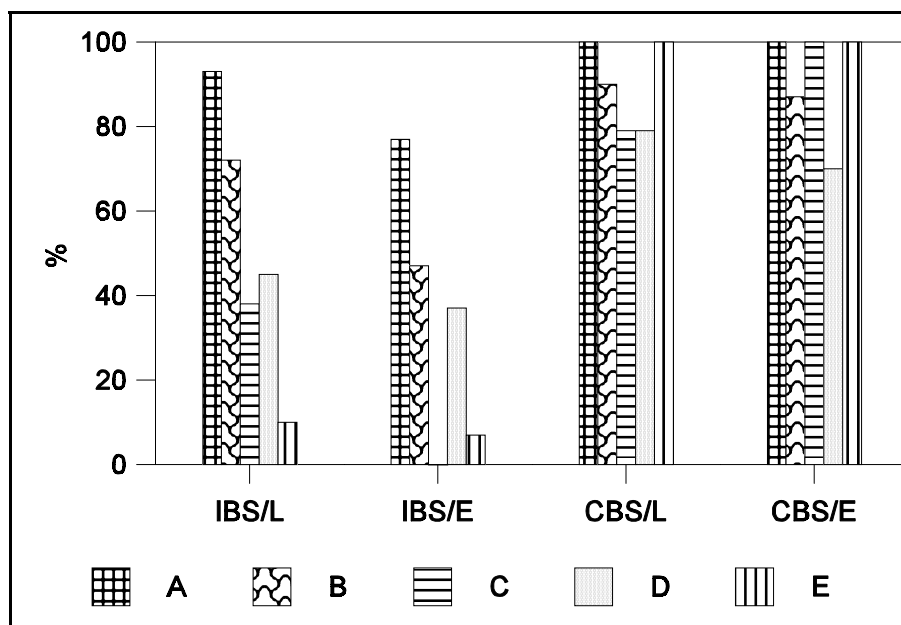


Figure 6:1. Use of personal belongings in the morning: A=clothes, B=soap, C=towel, D=dressing-gown, E=morning routine (IBS=institutionally based services, CBS=community based services, L= limited need for support, E=extensive need for support.)

## Results

### *Platform for community participation*

As type of community based housing was the basis for selection of persons to this study it is not relevant to give attention to this first area. Group IBS lived at institution I and II, while group CBS in group-homes in a number of places in Stockholm County. As regards daily activities there is no information at an individual level for the persons at the two residential homes, which enables one to clarify where these took place. Therefore it is not possible to make a comparison in this area (Lerman, Ericsson & Nilsson 1986, p.21).

### *Everyday life with a personal character*

The question as to whether housing provides a home and personal living is described by the occurrence of personal belongings. At the institution the person could use equipment which either belonged to the institution or which was commonly owned by all or several persons on the ward. In the ongoing change there was an expectation that such belongings would be entirely personal in the new services. In figure 6:1 results from this comparison are presented. Categories A-E describe whether the person uses only his own clothes (A), soap (B) and towel (C) when caring for his hygiene and if the person uses his own dressing-gown (D). Whether a person's morning routine and care of personal hygiene (E) takes place privately is also described (Lerman, Ericsson & Nilsson 1986, p.40).

The degree to which persons had a life with a personal character was throughout higher in group CBS than in group IBS. In spite of this it was not self-

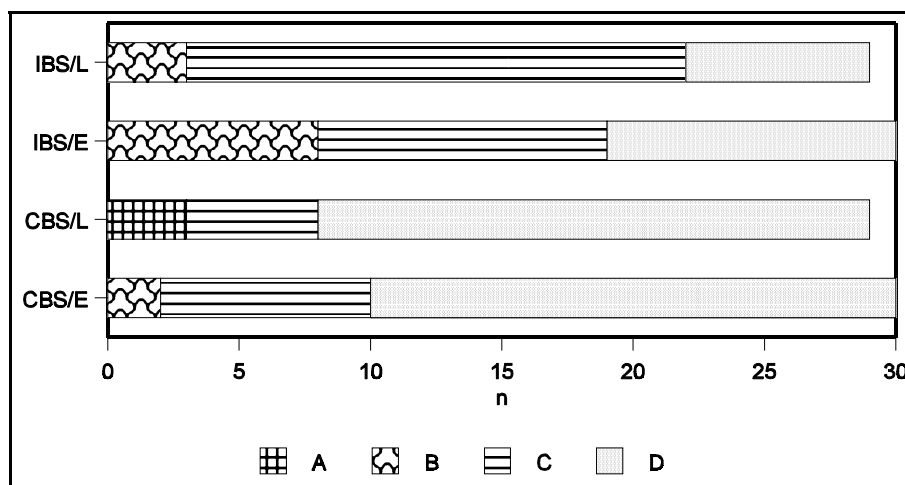


Figure 6.2. Day services with personal objectives: A=information missing, B=no daily activities, C=activities, no personal objectives, D=activities, personal objectives. (IBS=institutionally based support, CBS=community based support, L=limited need for support, E=extensive need for support)

evident that within community based services one used personal belongings in all the respects described.

When comparing the groups with a limited need for support (level L), the differences between group IBS and group CBS is significant on 1% level on one occasion, “E: Personal morning routines”. For “C: Private towel” the difference is significant on 5% level. For persons with an extensive need for support (level E) four of the five categories are significant on 1% level. The one not significant is “A: private clothes”. When comparing group IBS from institution II with group CBS, there are significant differences for three on 1% level, “A. Private clothes”, “C: Private towel” and “D: Private dressing-gown”. For the two other there is a significant difference on 5% level (Appendix I). The result from institution II is more comparable with institution I than with the community based services. Within community based services one found no real difference between persons whose need for support differed. At institution I there was a difference, those with more extensive needs being to a lesser extent attended to under conditions of privacy.

The results show that there is a difference between these two types of services. For group CBS the mean of privacy is 90,5% regarding these five categories in both sub-groups. This value is 42,6% for group IBS. The difference in community participation is therefore 47,9% (Appendix 1, table 1:1).

When receiving disability services it is not adequate merely to have access to activities during the day. If they really are to provide support, the content of these should be related to the needs and wishes of the person. A way to achieve this is to plan activities on the basis of personal objectives. In figure 6:2 the existence of this form of planning is presented.

There are four categories which describe this. The first indicates when information is missing regarding daily activities (A), the second that the person has no daily activities (B), the third that the person has activities but without any specific objective (C) and finally that the person has activities and that planning based on personal objectives has taken place (D). Here an objective is given a broad implication, from a general principle to specific goals and that these are known to the staff in charge

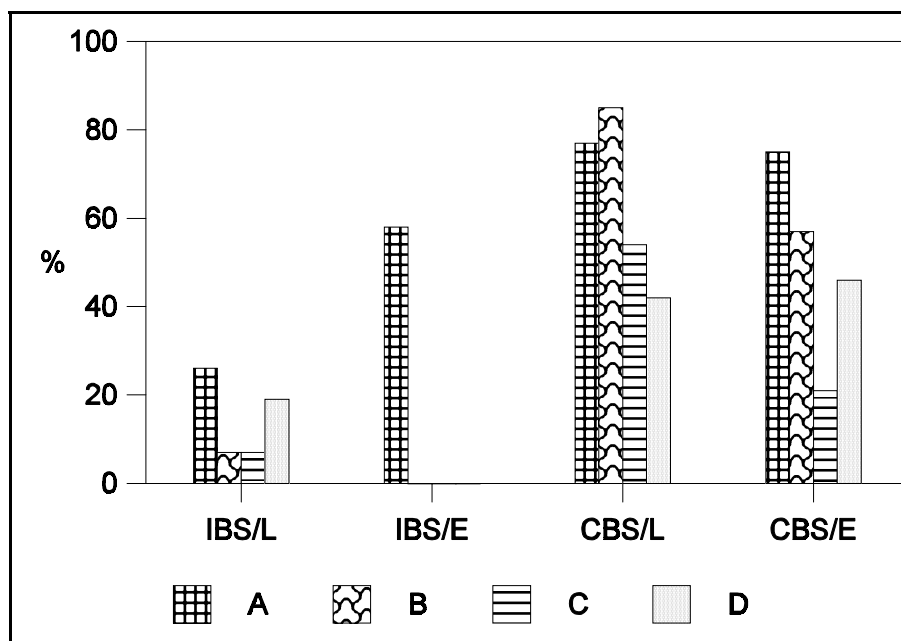


Figure 6:3. Daily activities with participation in local community: A=activities with community contacts during a week, B=productive activities with relation to community, C=regular lunch at public restaurant, D=visits to places of work (IBS=institutionally based services, CBS=community based services, L=limited need for support, E=extensive need for support.)

of the activity group (Lerman, Ericsson & Nilsson 1986, p.63).

When persons have access to activities during the day, categories C and D, one finds the larger proportion with a personal goal within group CBS. At the same time one can see that not all of this group have a personally formulated goal. When personal objectives do occur in group IBS, it is only to a limited extent. When those with a personal goal are related to the person's need for support, one finds no difference within group CBS. In group IBS this form of personal planning is somewhat more common for persons with an extensive need of support.

The difference between group IBS and group CBS for persons with a limited need for support (level L) is significant on 1% level. Comparing the two groups for those with an extensive need for support (level E), the difference is significant on 5% level. The comparison between institution II and group CBS is significant on 5% level. Institution II is therefore more comparable with institution I.

Community participation in this comparison, expressed through the proportion of persons in category D, is 69,5% for group CBS, whereas it is 30,5% for group IBS. The difference is thus 39,0% (Appendix 1, table 1:2).

### *Participation in local community*

The third area regarding housing concerns whether the person for his well-being avails of health and social services used by others in the community. To describe this the personal needs for each person were ascertained. Thereafter it was clarified whether the needs of a person were met through general services or through special services intended only for persons with an intellectual disability. For each person attention has been given to ten possible needs, five of these are general in character whereas five are personal. The general needs are dental care, hairdressing, travelling in connection with commercial service, purchasing of food and common articles for private consumption. Needs

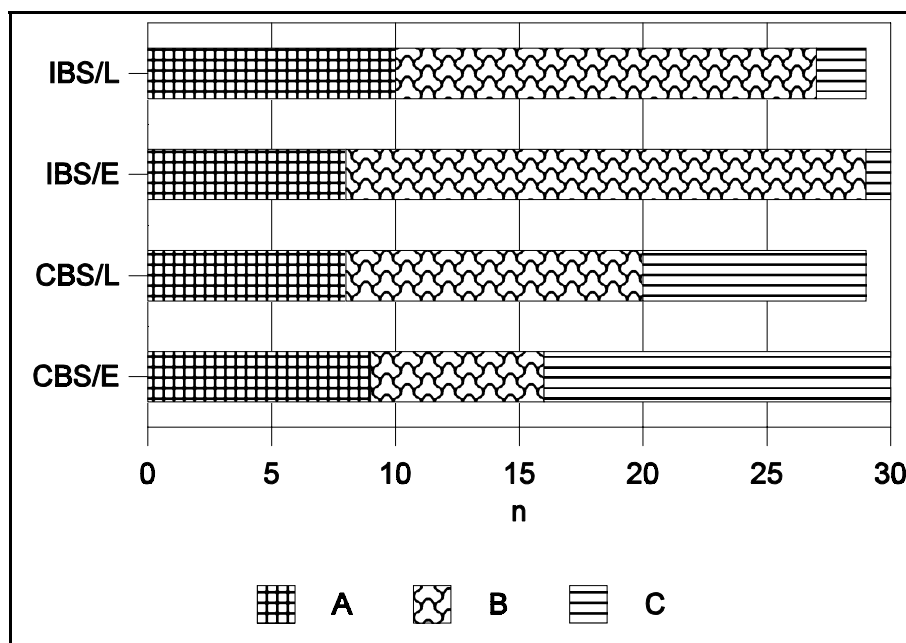


Figure 6.4. Influence over support in the home through participation in conference: A=no conference, B=conference, no representation, C=conference and representation. (IBS=institutionally based services, CBS=community based services, L=limited need for support, E=extensive need for support.)

of a personal character are medical care, physiotherapy, purchase of medicine, chiropody and lunch in connection with participation in activities during the day (Lerman, Ericsson & Nilsson 1986, p.57).

Because needs vary between persons, the answers have been expressed in relative terms so that a person has been categorized with regard to whether his use of a service has been limited or extensive. When 50% or more of a person's needs have been met through general services, it has been considered as extensive. The result shows that all within group CBS have availed of general services, whereas all belonging to group IBS have used services provided at the institutions. There is, however, one exception in group CBS. Results from institution II coincide with those from institution I.

The extent to which general services were availed of in group CBS is 98,3%, while it is 0,0% in group IBS. The difference with regard to community participation in this comparison is therefore 98,3% (Appendix 1, table 1:3).

Daily activities for persons are provided through the day activity centre, premises specially designed for this purpose. The extent to which this centre uses environments, activities and members of the general public outside the centre when offering its services, is an expression of whether participation in community life takes place during the day. In figure 6:3 four types of contacts with the local community are accounted for. Activities with community contacts (A) indicate that the person has availed of some form of resource or service in the neighbourhood. Productive activities with community contacts (B) indicate that activities, leading to some form of product, take place within the day activity centre but are carried out in cooperation with bodies outside the centre. Regular lunch at a public restaurant (C) implies that the person, rather than having lunch as usual at the centre, instead eats his lunch at a public restaurant. By regular is meant that this occurs at least once a week. Visits to places of work in the neighbourhood (D) indicates that the person has participated in such a visit during the previous six months (Lerman, Ericsson & Nilsson 1986, p.66).

It is within group CBS that this form of participation in the local community occurs. Many,

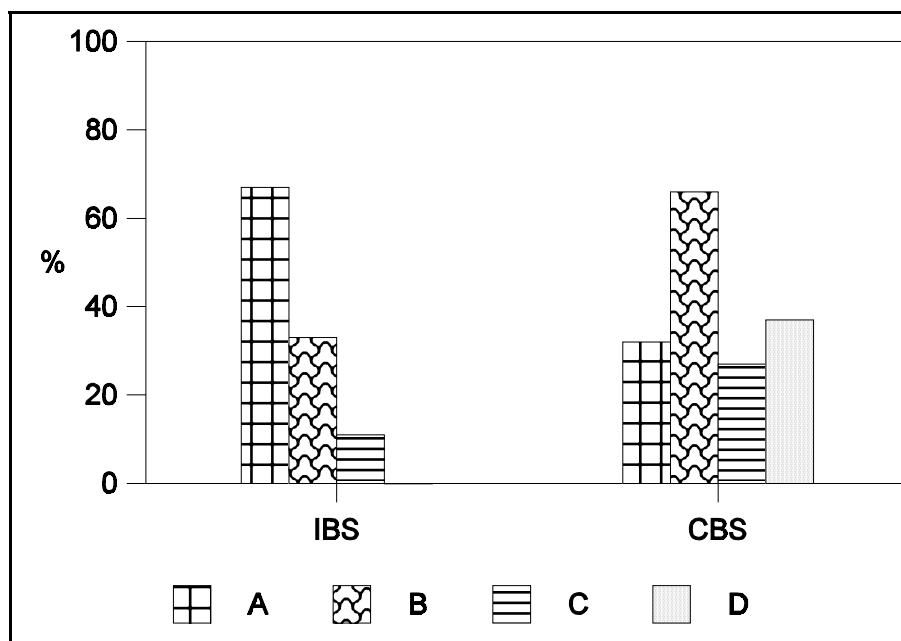


Figure 6:5. Contribution to planning of daily activities through participation in conference: A=only day service staff, B=other staff, C=social worker/psychologist, D=the person and/or representative. (IBS=institutionally based services, CBS=community based services.)

though not all, have experienced these community oriented activities. In group IBS there are very few who experience such contacts outside the centre. Regarding differences in level of support, one finds no clear tendency other than that there are somewhat fewer among those with extensive needs who experience this form of participation. The pattern at institution II is similar to that of institution I. There one finds only 2 persons (7%) who have had any form of contact outside the day centre.

When comparing groups IBS and CBS, persons with a limited need for support (level L), differences in three areas are significant on 1% level. For “D: Visits to places of work” there is significance on 5% level. When comparing persons with an extensive need for support (level E) two differences (“B: Productive activities with relations to community” and “D: Visits to places of work”) are significant on 1% level. One is significant on 5% level (“C: Regular lunch at public restaurant”) while there is no significance for “A: Activities with community contacts during a week”. When comparing institution II with group CBS, three of the differences are significant on 1% level. For category “C: Regular lunch at public restaurant” there is significance on 5% level.

The mean for this form of community participation is 57,1% in group CBS while it is 14,6% in group IBS. The difference is thus 42,5% (Appendix 1, table 1:4).

### *Quality in everyday life*

A person’s influence over his everyday life is considered to be an important aspect of being able to live a life with quality. A description is therefore given of the extent to which a person’s needs and wishes are expressed at a conference where staff plan the support which is being offered.

Participation in such a conference can take place either through the presence of the person himself or through his being represented by someone else. Figure 6:4 describes whether the person has been represented either by his own presence or through someone else, at a conference concerning support in his home. The three categories accounted for indicate that no such conference has taken place (A), a conference has taken place but the person was not represented (B) and a conference has taken

place and the person was represented (C) (Lerman, Ericsson & Nilsson 1986, p.65).

It is not always the case that the support being provided is planned in this manner. In group IBS as well as in group CBS there were 8-10 persons for whom no such conference had been arranged. When a conference had taken place and the person was represented, one found a difference between the groups. The person is represented to a considerably higher extent in group CBS. Even if it is more usual in this group there still were many, 19 persons, who were not represented. Regarding group IBS there are few, 3 persons, who were represented at such a conference. No clear tendency was found when the degree of support was considered. One finds, however, that some are more often represented among those with an extensive need for support in group CBS. The situation at institution II is most similar to that at institution I.

The difference between groups IBS and CBS, for those with a limited need for support (level L), is significant on 5% level, while the level of significance is on 1% level for persons with an extensive need or support (level E). The difference between institution II and group CBS is significant on 1% level.

The difference in community participation is 33,9%, there being 39,0% in group CBS for whom this form of participation did occur, while it is 5,1% of group IBS who are represented at a conference for the planning of support in the home (Appendix 1, table 1:5).

The contribution of daily activities to "quality in everyday life" is described in terms of whether the person has any influence over the activities in which he participates during the day. This influence can be exerted either by the person's own participation or through representation by another in the forum where decisions are made concerning the choice of his activities. Those who are considered as possible participants at such a planning conference can be the person himself or his representative, staff from the person's home, a social worker or a psychologist. Thus four alternatives are accounted for in figure 6:5.

At this conference participation can take place by staff from the daily activities (A), other staff for example from the person's housing (B), a social worker or a psychologist (C) and participation of the person himself and/or his representative (D). In the figure differences in the extent of the person's need for support are not considered, the comparison being only between institutionally and community based services (Lerman, Ericsson & Nilsson 1986, p.79).

This question was asked as a follow-up to a question on the occurrence of goal-related activities (presented in figure 6:2). Only the answers which describe the occurrence of goal-related activities are accounted for here. The groups are therefore small, with 41 persons in group CBS and 18 in group IBS. There are differences between these two groups in this comparison. The figure shows that it is primarily staff from the day activity centre who are responsible for planning in group IBS, whereas other groups are also represented in group CBS. In group IBS neither the persons themselves, nor their representatives, take part in the planning process. There is, however, an essential difference between institution I and institution II, as they differ in strategy regarding planning of daily activities. At institution II staff from wards, as well as social worker and psychologist, do take part to a greater extent.

When comparing groups IBS and CBS one finds only one occasion when there is a significant difference on 1% level and that is category "D: The person and/or his representative". On two occasions there are significant differences on 5% level, categories "A: Only day service staff" and "B: Other staff". There is no significant difference for category "D: Social worker/psychologist". Three of the differences when comparing institution II with group CBS are not significant. Only for category "D: social worker/psychologist", is there a significant difference on 1% level.

The difference in community participation is here 36,6% as 15 of 41 persons in group CBS are represented either by themselves or a representative at such a conference, while none is represented in group IBS (Appendix 1, table 1:6).

## Discussion

As the six comparisons show that the degree of participation in community life is higher for the group of persons who receive their support from community based services, the result points to a difference between institutionally and community based services. As regards housing and a home for persons with an intellectual disability, the comparisons show that the group-home offers a more personal life. The second comparison shows that the use of local welfare services is higher for persons who live in group-homes. In the third comparison it was found that the degree of planning of services, when the person was present or represented on these occasions, was higher for those living in group-homes. There is therefore a marked difference in the lives led in the home, depending on what is offered by the two types of services.

There is also a difference in the daily life of these persons. The first comparison shows that daily activities are more personal, as expressed by the higher degree of personal planning which takes place in community based services. The second comparison shows that participation in the life of the local community is higher for the group which receives its support from community based services. Personal influence over planning of daily activities, expressed as the person being represented at a planning conference, is higher in community based services.

It is also possible to study the degree of need for support of these persons and how this influences their community participation. Looking at the size of the differences one finds that this is highest for those with an extensive need for support, when it concerns a home with a personal character. They also have the higher degree of presence, themselves or through representatives, at conferences in their home when their support is planned. For persons with a limited need for support one finds that the development towards community participation is higher as regards day services. They have a higher degree of support with personal objectives. They also participate in daily activities in the local community to a higher extent. This raises the interesting question as to whether the home has meant more for those with extensive needs for support, whereas day services has been more meaningful for those with a limited need for support.

There is a difference between institutionally and community based services in that the latter are more modern, having been built fairly recently. In order to see whether a modern residential home has a structure which influences community participation of persons a comparison was made between community based services and institution II, the modern institution. As can be seen from this the pattern of life of persons there was comparable to that of institution I in five instances. Community participation did not increase through the establishment of a modern residential home.

At the same time as this is said one must also point to the fact that persons receiving their support from community based services do not experience full participation in community life. This is shown in the results where the variation indicates that there is room for an extensive development in community based services, if the service is to contribute towards participation of persons in the life of the community.

The information was collected by two psychologists through interviews with staff who had good personal knowledge of the everyday lives of the persons concerned. For those carrying out the interviews the situation could be adapted so that questions could be understood. It was also possible for staff to ask for clarification and explanations if this was found desirable. This created an interview situation which provided good possibilities for the collection of reliable information. One of these psychologists carried out a separate analysis of the reliability of this study. Her conclusion as regards reliability was that "The questionnaire showed in its entirety to have reliability in the sense of consistency." (Nilsson 1985, p.43). Her view regarding validity was "In this way one can also say that the result also had good internal validity ..." (Nilsson 1985, p.45).

This cross-sectional study concerns persons with an intellectual disability leaving a residential home. Either at the institution or in the community the persons are those with the most

extensive need for support for their everyday life. This makes them a heterogeneous group with a great variation of personal characteristics. The manner of describing their lives, in the form of a study, has been to select limited groups in order to grasp some aspects of the individual level of this process of transition. How general are the results of a study like this?

I find it difficult today to generalize the results in a narrow sense. They express the situation which was found for this particular group, persons who were selected because of their need for support in community based housing. This result is also a reflection of what was possible in Stockholm County at the time of the study. The process of transition was in its early phase and Carlslund residential home was the first institution for adults to be closed. The community based alternatives for this group were also among the very early ones.

The tendency in these results is, however, most relevant. The difference between institutionally and community based services, as illustrated here, is one which reflects the life of persons in these residential homes, not only those in this study but also throughout the country. One aspect of this tendency is the problem for community based services to achieve full participation. That community participation is a more general problem for institutionally based services is recognized by the fact that throughout the country these residential homes have been closed and that since 1999 are no longer recognized as a form of service.

The basic function of this study has been to collect information which made it possible to describe the lives of persons in institutionally and community based services. This has been achieved with the study. In several of the groups who have participated in the process of transition, in Stockholm County and elsewhere in the country, the study has provided information for an exchange of views on disability services and sometimes even created debate. As such it has fulfilled the original ambitions.

## **Chapter 7**

### **The longitudinal study**

#### Method

##### *Persons in this study*

The choice of 1985 as the first year when this study (Study 3) could be carried out at Carlslund residential home, was a consequence of the date when funds were made available for this project. The choice of persons to be involved was thereby given, as they were the 40 persons who were to move that year. The majority of this group came from a ward which was to be closed during the year, while some minor groups came from four other wards.

Of the entire group, 30 were men and 10 were women. Most of them, 32 persons, were between 30-50 years of age, 3 were younger and 5 older. Their need for support from others varied within the group. When one considers "need for support during meals" as an expression of this one finds that 12 persons coped with their meals themselves, 20 were in need of some assistance, whereas 8 required extensive support. A person's prospects for participation in community life can be brought about by personal characteristics, for example physical mobility. There was, however, only one person with severely reduced mobility in the group. Regarding vision, there were 6 persons with such severely reduced sight that it affected their daily lives.

##### *Instrument for collection of information*

Participation in the local community is described in three main areas of a person's daily life namely housing, daily activities and community. For each of these main areas a number of sub-areas have been used (table 7:1). Housing is described by 6, daily activities by 3 and contact with the local community by 6 areas. Each one of these is described by a number of questions seen as relevant. The questions are chosen to reflect occurrence as well as quality of a phenomena. Occurrence states the extent to which community participation takes place, while quality expresses the conditions under which it takes place. The three qualitative aspects considered are material standard, influence and integrity. Material standard describes the economic conditions, whereas influence describes the way in which the person has an opportunity to control his daily life. Integrity expresses whether the person is met with respect.

Housing is described in 6 areas. "A room of one's own" (A1) characterizes the life the person lives in his own room. "Personal equipment" (A2) describes the person's belongings, primarily clothing and articles for personal care, including what the person owns. "Social relations" (A3) describes the relationships in the home of the person. In the area termed "food" (A4) mealtimes and the eating habits of a person are described. "Household activities" (A5) illustrates how the person participates in the normal tasks taking place in a home. "Leisure" (A6) presents the person's recreational habits in the

Table 7:1. The concept of community participation in this study. Each of the 15 sub-areas are described with regard to occurrence and quality.

A. HOUSING	B. DAILY	C. COMMUNITY ACTIVITIES
1. A room of one's own	1. Activities	1. Neighbourhood
2. Personal equipment	2. Work place	2. Friends and relatives
3. Social relations	3. Social relations	3. Commercial service
4. Food		4. Public service
5. Household activities		5. Working life
6. Leisure		6. Leisure

home and the opportunities provided for carrying them out.

In the second main area aspects of daily activities of the person are accounted for. Here the character of the "activities" (B1) as well as the circumstances in which they take place are described. "Work place" (B2), the physical place where the person takes part in these activities is described, as are the "social relations" (B3) which are developed in and around his place of work.

The third main area, community, is described with regard to the "neighbourhood" (C1) in which the house of the person is located. This is mainly concerned with the character of relations to neighbours. "Friends and relatives" (C2) describes the circle of friends of the person and how contact with them is maintained. By "commercial service" (C3) it is intended to describe how the person does his shopping. "Public service" (C4) accounts for the person's use of local welfare services. By describing the relation between daily activities and a "working life" (C5) one gets an idea as to whether daily activities are associated with local working life. When "leisure" (C6) is described here, it is related to the question of whether it takes place where others are engaged in recreational activities.

Based on this way of structuring the concept of community participation a questionnaire was compiled to collect information for the study. In addition, it contained questions concerning the background of the person being interviewed, as well as questions on organizational issues concerning his housing and daily activities.

### *Procedure for collection of information*

Throughout 1985 persons moved from the residential home to housing and daily activities in new communities. Before this took place the community participation of persons while at the institution was described. In a preliminary follow-up study conducted during an earlier phase in the process of change (Thorsell 1983) it was concluded that a person requires at least 2 years to establish a new way of life after having left the institution. In order for 2 full years to pass, 1988 was chosen as the year when community participation was described when support was being received from community based services.

The collection of information took place at the institution as well as in the community, the home and the place for daily activities for each person being visited. All

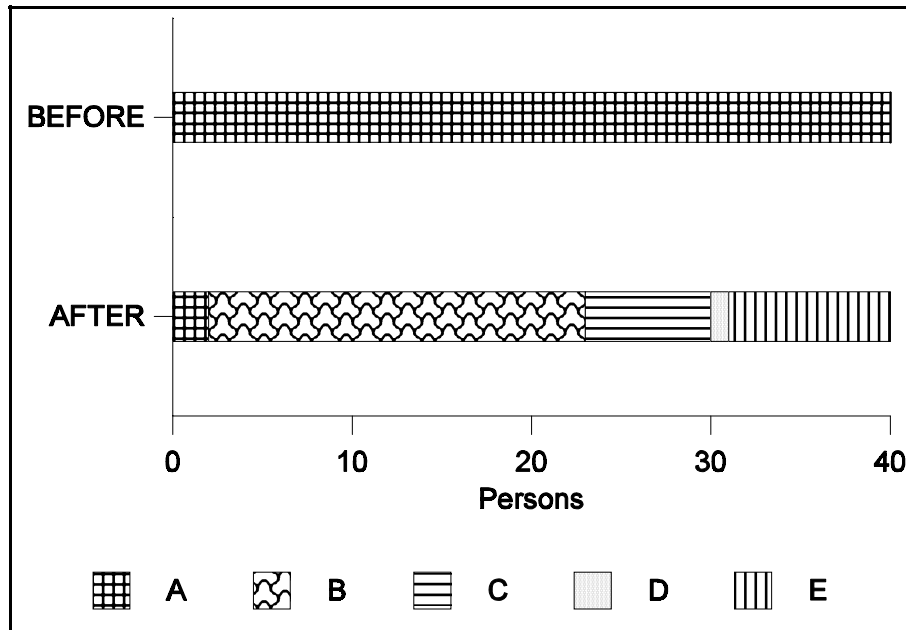


Figure 7:1. Type of house in which the home is situated. (A: residential institution, B: villa, special, C: villa, collective, D: villa, general, E: apartment building.)

interviews were carried out by the same psychologist. Each time the interview took place with the member of staff who had the best knowledge of the person. This meant that the interview, during the time the person lived at the institution, took place on the ward. Information was also collected during a visit to the place, most often within the grounds of the institution, where the person had his daily activities. After persons had left the institution the interview was carried out when visiting the person's new home. As daily activities of a person took place at a day activity centre outside the home, a visit was also made there.

### *Analysis of information*

From the database of the study, the results to be presented have been chosen on the basis of the model for analysis of community participation presented in chapter 5. In the account that follows 8 comparisons between institutionally and community based services as regards community participation are carried out. In each one the lives of persons at the institution ("Before") is compared with that which is lead after having moved ("After"). The first presentation of this difference expresses the degree of change in community participation for the group. These comparisons are presented as figures. The second is a comparison on an individual level which indicates the character of community participation for persons concerned. The degree to which the increase in community participation is significant has been tested with Sign Test (Blalock 1981). Community participation is also indicated numerically as a difference between institutionally and community based services in the category of the results which indicates the highest degree in present variable. The information which is the basis for this is presented in Appendix 2 (available from the author). Parts of this study have been presented on previous occasions (Brusén, Ericsson & Thorsell 1986; Brusén, Ericsson & Thorsell 1988).

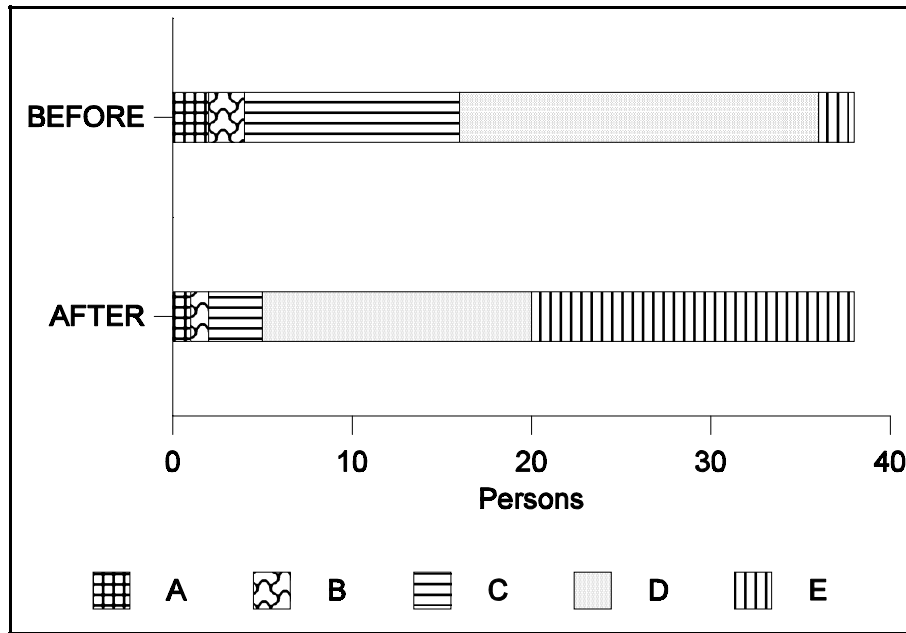


Figure 7.2. Extent of daily activities, expressed as number of hours per week. (A: no activities, B: 1-10, C: 11-20, D: 21-30, E: 31-40.)

## Results

### *A platform for community participation*

When these 40 persons were visited for the first time they were living at Carlslund residential home. On the second visit they were found to be living in a variety of housing (figure 7:1). Apart from living at a residential institution, “A: residential institution”, there are four types of community housing to which they had moved. One of these is the specially designed villa, “B: villa, special”, which was developed as a group-home when these persons were to move (housing type BV in chapter 4). That which here is called “C: villa, collective” is a house of experimental character which was built at this time in a new housing project for the general public. It contained a number of small units spread throughout the building in the form of single rooms, small apartments and common facilities. Housing which is called “D: villa, general” is an ordinary villa which was purchased on the open market. “E: apartment building” is housing with apartments in an urban environment for the general public, where a number of apartments are used as group-homes.

From figure 7:1 it can be seen that 2 persons now lived at a residential institution, though different to the one they had moved from. Most of them, 21 persons, lived in special villas developed to realize the ongoing transition of services. 7 persons lived in the collective housing which was used for this purpose. 1 person lived in a villa which had been purchased on the open market. 9 persons lived in group-homes located to apartment buildings. The high number of persons living in a villa indicates that this was a group who were seen to be in need of the extensive support provided in this type of housing. One must also note as surprising, that in a process the task of which was to close a residential institution, use was made of institutions as an alternative form of housing. On an individual level this change in community participation is significant on 1% level.

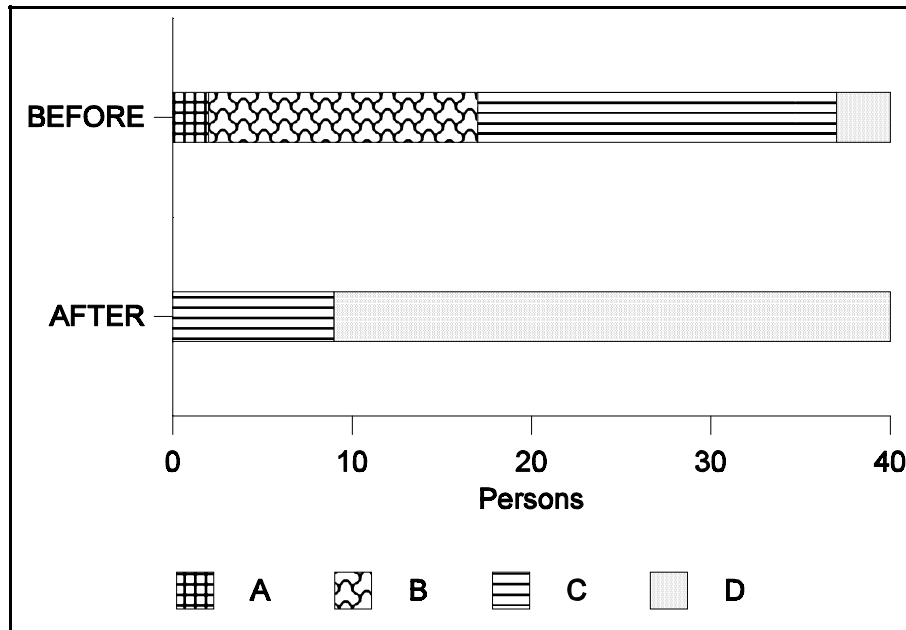


Figure 7.3. Privacy through the use of personal items. Categories show the number of privately owned soap, towel and dressing-gown being used. (A: none, B: 1 item, C: 2 items, D: 3 items.)

When one sees community participation as meaning that one lives outside a residential institution, one finds that no-one in the group had experienced a reduction in participation, for 2 persons it remained unchanged and for the remaining 38 persons (95%) it meant an increase in community participation (Appendix 2, table 2:1).

Daily activities are seen as a natural part of community based services the aim of which is a more normal life, a view which is not always part of institutionally based services. When a person lives in housing in the community it is assumed that he also has a place outside his home which he can attend for activities during the day. At the institution it was considered that the main part of the care should be provided on the ward. The activities which over the years came to be provided off the ward were merely seen as complementary.

A first step towards describing a person's daily activities is to look at the extent to which they cover his working week. The ambition of having access to a full 5 day-week is seen as a goal the purpose of which is to provide a number of activities which together make up a week which is meaningful for the person. However, for different reasons the extent to which a person will be occupied can vary. There are those who lack activities entirely, whereas others have full-time. In figure 7:2 the duration of activities during the week is categorized in 10 hour intervals. This describes 38 persons as information is lacking for 2. One finds that at the institution there was a variation from a total lack of activities to those who had full-time occupation, between 31-40 hours per week. One finds the same variation after they had moved. The difference, however, is that a larger group have activities to a greater extent, than on the first occasion. There were, for example, only 2 persons at the institution who had activities between 31-40 hours per week, whereas 18 persons had this extent of support after they had moved.

When one sees the information which is the basis for figure 7:2 (Appendix 2, table 2:2) one finds 23 persons whose duration of activities has increased, for 13 it is

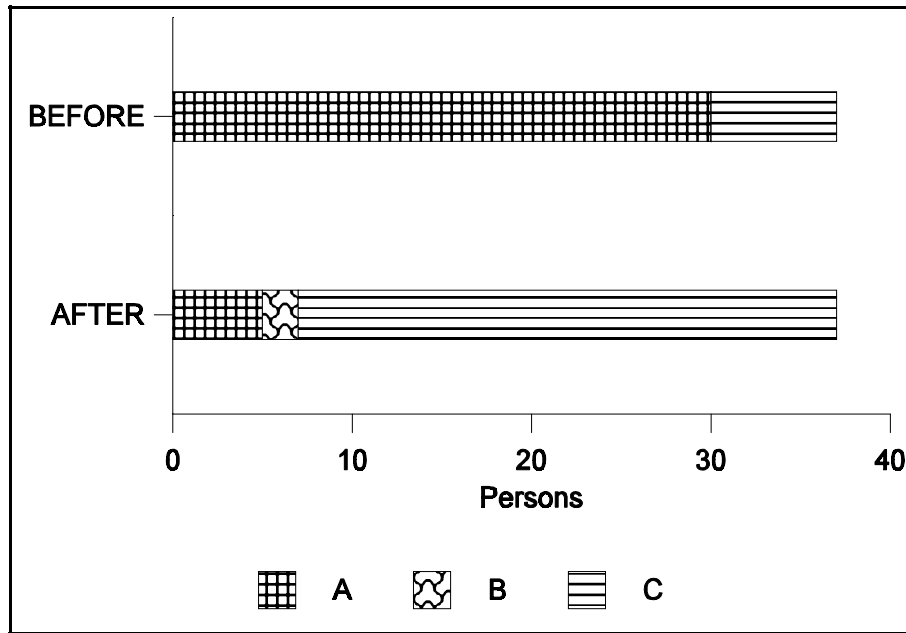


Figure 7:4. Daily activities with a personal character, expressed with the presence of a private place and a personal locker. (A: no private place, B: private place, no locker, C: private place and locker.)

unchanged and for 2 it is reduced, which is a significant change on 1% level. On the first occasion 5,3% had daily activities full-time. This proportion was 47,4% after they had moved. An expression for an increase in community participation is thus 42,1%.

#### *Everyday life with a personal character*

The basic task of the institution was to provide for all needs of the person. With this responsibility for the total care of the person provisions were available on the ward, but not necessarily on a private basis. Within community based services, formed with the ordinary life as the model, the person is provided with housing, which can be developed into a home with a private life. In order for this to take place the person needs to acquire the furnishings and belongings considered necessary for him.

The personal touch in home life is described by accounting for the extent to which a person uses his own belongings for his daily morning routine. There are three objects which are considered here, namely, having one's own soap, towel and dressing-gown. It is not self-evident that these are always personal. It does occur that those used are common property or that one borrows from some-one else with whom one lives.

As can be seen in figure 7:3, it was in no way natural that these are objects which were personal at the institution. 2 persons completely lacked any personal belongings, whereas for 3 persons these objects were all personal. After having moved these objects are seen as personal belongings for 31 persons. There are, however, 9 persons within community based services where only 2 of the objects are personal.

The information on which figure 7:3 is based shows that reduction has not occurred for anyone. For 8 persons this aspect of privacy is the same on both occasions, whereas there has been an increase for 32 persons. This is a significant difference on 1% level. The increase in community participation is here 70%. This is the difference

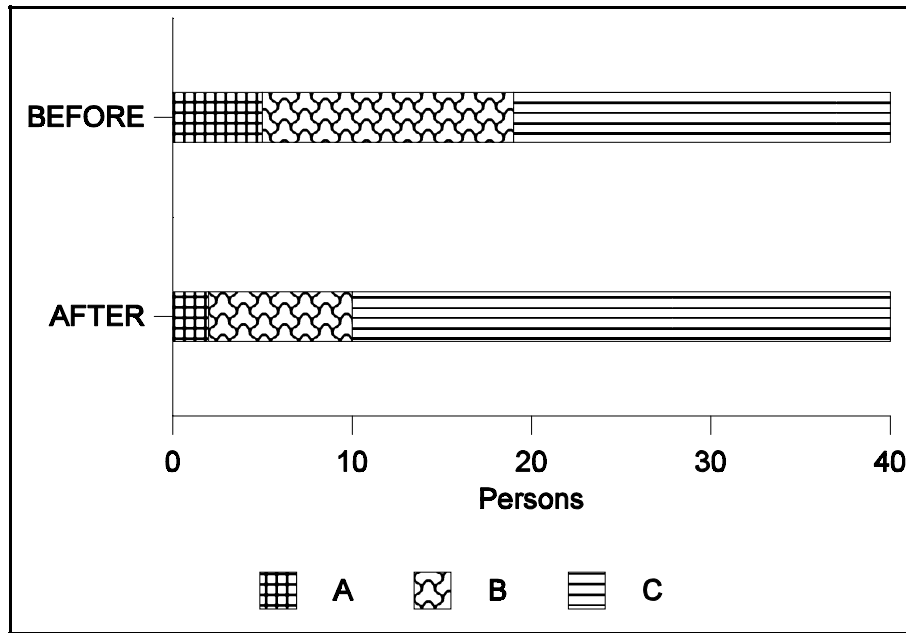


Figure 7:5. Type of hair-dresser when caring for the hair of the person. (A: staff in the home, B: staff/hair-dresser, C: local hair-dresser.)

between the 7,5% for whom all these objects were personal at the institution and the 77,5% who had these private belongings when living in community based services (Appendix 2, table 2:3).

When one spends 5 days of the week at premises outside the home, it is usual that there is a place which is considered more personal, a place for one's clothes and for other personal belongings which are used during the day. It was, therefore, natural to ask whether the person had such a personal place in the premises where he had his daily activities and if he had access to a cupboard for his personal belongings.

As seen in figure 7:4 it is not self-evident that one finds this type of personal character at the place for daily activities at the institution. Only 7 persons had a locker of their own. A private place is taken more for granted within community based services where 30 persons had access to a personal place of work as well as his own locker. There were, however, 5 persons who did not have this form of privacy. In this comparison information was missing for 3 persons.

The description of the change between these two occasions, based on the information for figure 7:4, shows that there is a reduction for 1 person whereas this aspect of everyday life is unchanged for 11 persons. For 24 persons there has been a development. This change is significant on 1% level. A probable explanation for this difference is that daily activities is a separate service within community based forms of support, whereas they were merely seen as an addition, of secondary importance, at the institution. An increase in community participation can be seen to exist for 62,2%, that is to say, an increase from 18,9% at the institution to 81,1% in community based services (Appendix 2, table 2:4).

#### *Participation in local community*

Attention to a person's hair, whether it is cared for by staff in the home or if one avails

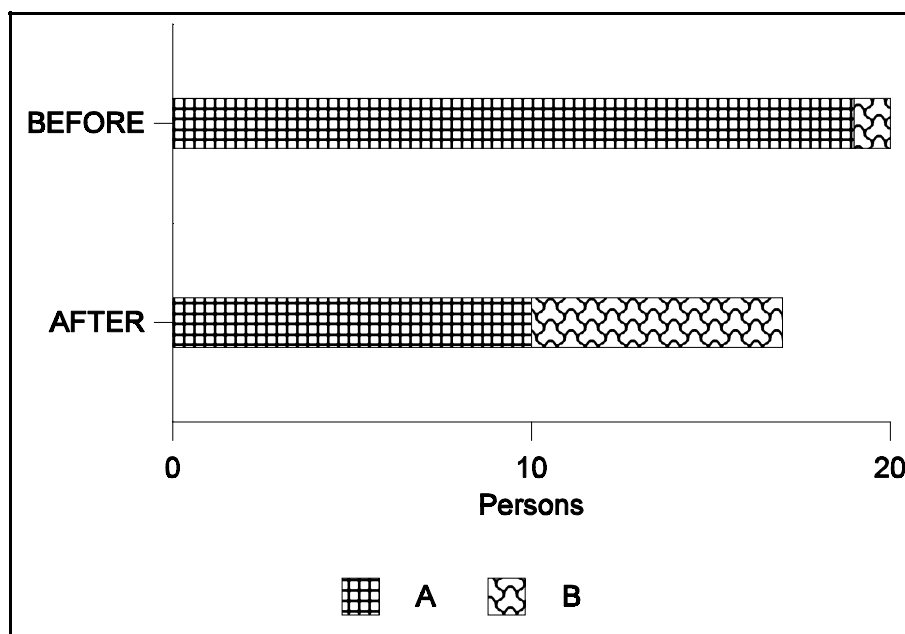


Figure 7.6. Participation in any of six types of activities in the local community, outside the day activity centre (A: once, B: twice.)

of a local hairdresser, was chosen as an expression for the extent to which local services were being used for one's personal well-being. In figure 7:5 three categories describe this service namely that staff in the home care for the person's hair (A), that it is always cared for by the local hairdresser (C) and a category which expresses a combination of these (B).

Here one finds (figure 7:5) that local resources are availed of before as well as after the person has moved. There are however fewer, 21 persons, on the first occasion than on the second when 30 persons used the local hairdresser. It is more usual that staff look after the person's hair at the institution this being the case for 5 persons. One could expect that all avail of the local service after having moved from the institution. There are, however, 2 persons who still have their hair cared for by staff in their home.

When one looks at the difference between the two occasions one finds that there are 6 persons for whom community participation has decreased in this respect. For 20 persons it is unchanged and for 14 it has increased. This change is not significant. This contact with the local community from the institution, which did take place for half of the group, can be seen as an example that the approach which had developed within community based services had influenced life at the institution. If staff caring for the person's hair in his home should be seen as an expression of institutional behaviour, the question that can be raised is why it occurs at all in community based services, after person's have moved.

A development of community participation can be seen to occur for 22,5%, as 52,5% used the local hairdresser while at the institution whereas 75,0% used this service after they had moved (Appendix 2, table 2:5).

To describe participation in the local community through daily activities a combination of 6 variables expressing various aspects has been used. For each variable a point has been given when participation has taken place. The resulting variable for each person sums up the degree of participation in a possible interval from 0 to 6 points.

The first of these six variables describes how the person spends his leisure

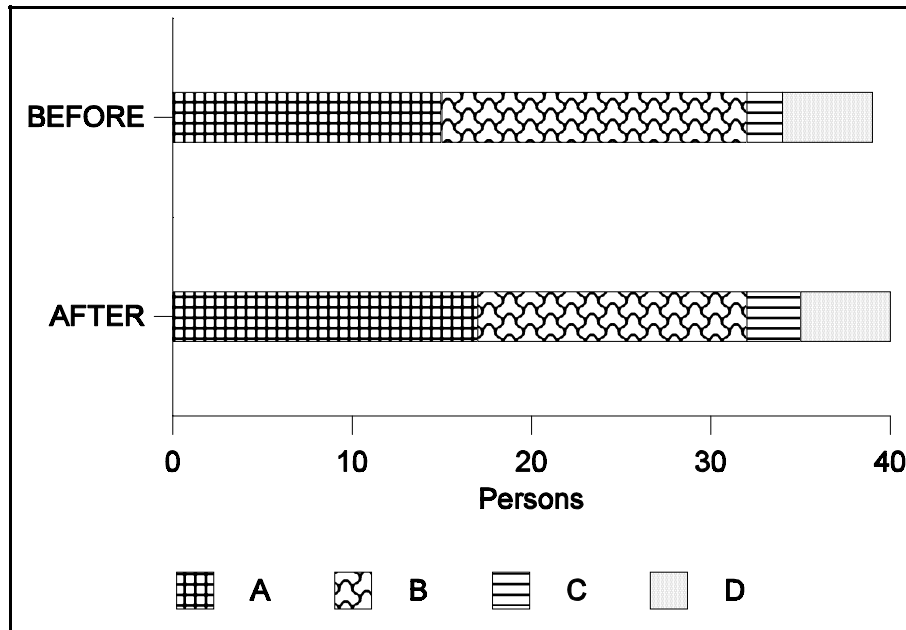


Figure 7.7. Representative attending conference in the home during the previous year. (A: no conference, B: conference, repr. not invited, C: conference, repr. did not participate, D: conference, repr. participated.)

during the lunch hour. This can be spent either in the home of the person, in the day activity centre or outside the centre. A point has been given if the person has spent leisure in community, outside the centre. A second variable describes whether the person has been visiting a place of work outside the centre. A point has been given if this has taken place. In the third variable a point has been given if an activity, arranged through the centre, has been going on at a place of work or other social setting, outside the centre. The fourth variable describes the extent to which the person has his lunch in a restaurant outside the centre. If this takes place at least once a month the person has been given a point. Occasionally a group makes a journey to some place or activity of interest, for example an exhibition. The fifth variable covers this type of participation in the local community. If a person has experienced this, he is given a point. The sixth variable describes whether a person has visited an employment agency. If this has taken place he is given a point. In table 7:6 the distribution of total points is presented. No analysis of personal change has taken place.

A reason for this low degree of community participation can depend on the fact that most of the activities carried out in this service are concentrated to and intended to take place inside a day activity centre. Consequently only a limited portion of activities do actually take place in settings outside the centre. In addition, if participation in the community is primarily intended for persons with a less extensive need for support, it is quite natural that the group with an institutional background, those with extensive needs, have few possibilities of experiencing any participation.

When one considers the changes which have occurred within the group one finds that the extent of such participation in community life has increased from 5,0% to 41,2%, that is to say, an increase by 36,2% (Appendix 2, table 2:6).

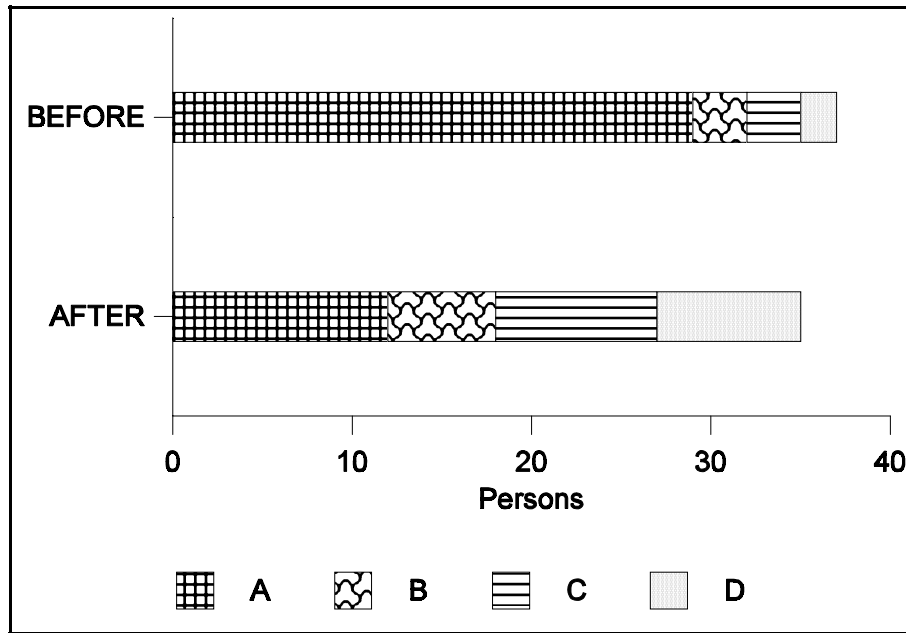


Figure 7:8. Influence over personal habilitation and planning of the activities of the group. (A: no planning, no habilitation, B: no planning, habilitation, C: planning, no habilitation, D: planning, habilitation.)

### *Quality in everyday life*

The habilitation conference was at the time of the study, the forum at which the formal planning of services received by the person was expected to take place. A group of staff, which varied in composition, met to discuss and decide on issues concerning the support provided to a person. In this area, which describes quality in housing, the person's influence over his life is seen as an expression of quality in everyday life. That the question is asked whether the person had a representative present on this occasion, indicates that it is presumed that the person, because of his disability, requires this support on such an occasion.

The first observation, figure 7:7, is that such a conference has not taken place for the greater number of persons. There are 15 persons for whom a conference of this kind had not taken place prior to moving, whereas 17 persons have not had such a conference after moving. When such a conference has occurred, prior to or after moving, no representative had been invited. For 5 persons there has been a representative present when it took place before moving and the same number have attended after persons have moved.

Even if the table shows that there are similarities between these two occasions, changes within the group have taken place. For 12 persons there has been a decrease, for 15 the situation is unchanged and for 12 persons there has been an increase. This change is not significant.

When development towards community participation is seen as an increase in whether these persons have had a representative who attends their conference, one finds a minor difference, less than 1% (Appendix 2, table 2:7).

Traditional day services consist of a number of organized activities carried out at and around a day activity centre. The choice of activities provided are decided beforehand and seldom change. The person is then allocated to the activities which the

organization considers most suitable and in this way a weekly programme is prescribed. In an organization like this influence for the person becomes limited, as is the likelihood of having a personally planned activity programme.

The issue of the person's control over his daily activities covers two aspects. One is concerned with influence over the planning which takes place in the activity group to which the person belongs. This can, for example, take place on a daily or weekly basis, in a forum where common issues of practical importance for the group are discussed. The other aspect concerns a person's habilitation, that is to say, planning of the activities in which the person will participate. This takes place at the habilitation conference where the person himself can participate.

The question here (figure 7:8) is concerned partly with whether the person, by participation in a conference, has influence over his own habilitation or not, and partly if the person has influence over planning in his activity group, in that he participates in a forum for this purpose. Based on this, four alternatives can be formulated. The person lacks influence over planning and over habilitation (A), the person lacks influence over planning but has influence over his habilitation (B), the person has influence over planning in his activity group, but lacks influence over his habilitation (C) and the category which indicates that the person has influence in both these respects (D).

The main result shows that persons lack influence over daily activities. At the institution 26 persons had no influence, whereas this group consists of 12 persons after having moved. This group is still the largest one. At the institution there were 2 persons who had influence over planning, including his habilitation, whereas this group after having moved consisted of 8 persons.

Regarding changes in the group between the two occasions, one finds from the information on which figure 7:8 is based, that influence has decreased for 3 persons, it is unchanged for 13 and it has increased for 18 persons. This change is significant on 1% level. Looking to the group one finds that community participation has increased for 16,6% after having left the institution, the group who had influence over both planning and habilitation being 5,6% at the institution and 22,2% after having moved (Appendix 2, table 2:8).

## Discussion

The four comparisons concerning house and home point to a development of participation of these persons in the life of the community. They have now received community housing. Some of this housing is located to areas where other people live, but the persons from the residential home still live in specially built housing. The degree of privacy has increased considerably and there is an increase in the use of local resources. But there is no real difference as regards participation in the planning of one's own life.

The four comparisons of participation in community life through daily activities also point to a development. The persons have now received a more extensive day service and they have also a higher degree of privacy in their daily activities. The difference is however small when one looks at their contacts with resources in the local community. There is nevertheless a higher degree of participation in the planning of their services.

These results describe changes for a group. As the same persons were described

on two occasions, it is also possible to describe differences on an individual level. One then finds that some persons experienced an increase in the variable being analysed, while within the group there were also persons who did not experience any change. A decrease in the aspect of life described by the variable was also found for some persons. The overriding objective for the transition of services which has taken place must be to offer better lives to these persons. One could therefore expect an increase for all persons, in all variables being described. Against this background it is surprising that a decrease in community participation has been identified. This points to a need for continued work by community based services if participation in community life is to be offered to these persons. The answer to the original question is nevertheless that an increase in community participation has taken place through the use of community based services.

To contribute to the reliability of this study information was collected with structured interviews, supported by a questionnaire. As a person was available to put the questions to the interviewee there was an opportunity to discuss a question in order to avoid misunderstandings. The same psychologist carried out the interviews on both occasions of the study, that is to say, while the person was still living at the residential home and after he had left it. This was therefore someone who was well informed about the issues being handled. In spite of this information is missing in these results.

The conditions for this study were the same as for the previous one (chapter 6). During the process of change at the residential home it was possible to carry out an analysis, the existing circumstances being those which had to be accepted. For example the persons in this study were those who were to leave the same year as funds for the study then became available. Thereby the group was dominated by the persons from the ward inhabited by those with an extensive need for support. It is most likely that this has been a factor explaining the limited degree of community participation which has been found. Another factor is that at this time these persons were seen as a “new” group receiving their support from community based services. Methods of organizing the work of staff were therefore not well enough developed to meet the needs of these persons.

But there are also organizational aspects of this transition. The procedures surrounding the situation when a person leaves the residential home for a group-home are not only an individual or local issue. The residential home, the group-home and the day activity centre are services with a basic structure emanating from national models. Consequently there are many similarities between procedures in the various parts of the country. The manner in which each single person moves from institutionally to community based forms of support is also prescribed by current national legislation. It can therefore be said this increases the generalizability of the results from this study.

## Chapter 8

### The follow-up study

#### Method

##### *Persons in this study*

The persons included in the assessment of need for community based services, which was part of the planning procedure prior to the closure of Carlslund residential home (chapter 4), constituted the group which was to move during the period 1980-1988. In order to describe community life for these persons, a follow-up study (Study 5) was carried out in 1990. The initial step was to identify those to be included in the study and to locate their housing and places for daily activities. It was possible to find all persons and the services they were receiving through the county organization responsible for the delivery of services.

The original group was the 322 persons who took part in the assessment prior to leaving the residential home (Study 1). As the suggestions from the planning group concerned the transition from 1980 and onwards, the 2 persons who left the residential home before 1980 were excluded. Of the remaining 320, 46 persons were deceased before the follow-up study was carried out, either at the institution or after having left. There are a further 6 persons who at the time for the study were living in their parental or other private homes. They are not included as the study was designed to describe the life which was lived as a result of the services which replaced the residential home. There is a further reduction of 2 persons whose representatives abstained from answering the questionnaire, with regard to housing as well as daily activities. The follow-up study therefore covers the lives of 266 persons (Ericsson 1993).

These 266 persons moved from the residential home between the years 1980-1988. A smaller group, 64 persons, moved between 1980-1983, while 197 persons moved during the following 5 year period (information is missing in this respect for 5 persons). The reason for a higher number of persons having moved during the latter period is related to the availability of services. As housing and premises for daily activities which were available at the early stage were localized to existing houses and buildings, it was only persons who could avail of such facilities who were able to move. Housing and premises for daily activities which had to be specially planned and built became available during the latter part of the period.

Persons in this study are described with regard to type of housing they acquired after having moved. Three forms constitute community housing, housing type A, BA and BV (chapter 4). While housing type A offers support to a lesser degree, the most extensive support is provided in housing type BV. There is also a group who moved to a smaller residential home (RH). There is also a group of 33 persons, in the results called MIS (miscellaneous), living in group-homes where the level of support has not been possible to identify. In this group there are also 6 persons for whom information is missing as regards type of housing. One finds a difference in age between groups in the three community based forms of housing, group A being older, 51 years, whereas group BV were 44 years on average.

Table 8:1. The concept of community participation and its main areas (MS=material standard, SR=social relations, II=influence and integrity).

	OCCURRENCE	QUALITY		
		MS	SR	II
1. Housing and a home	11	12	13	14
2. Daily activities	21	22	23	24
3. Local community life/housing	31	32	33	34
4. Local community life/activities	41	42	43	44

Regarding the ability to communicate, implying that one communicates with speech which is understood, one finds a variation between the groups. 93% show this ability in group A, whereas the proportion is 56% in group BA, and 34% in group BV. In group RH it is 19%. In the same way one finds a variation in the degree of support required by these persons. This is described by the extent of support needed in three everyday situations, namely “mealtimes”, “dressing” and “hygiene”. One finds that persons in group A are those with the least need for support, while it is most extensive for those in group BV. Group BA is in a medial position and group RH is found to be comparable with group BV (Ericsson 1993, p.12).

#### *Instrument for collection of information*

Four areas emerged as important when community participation of persons came to be described in this study. The two basic areas were the person’s housing and home and his daily activities. In addition the person’s contacts with the local community was seen as important. This has here been summarized by the concept of local community life. As this can emanate from the home as well as from the place for daily activities, two aspects can be described, local community life through the home and local community life through daily activities. 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. A description of community participation needs, therefore, to be able to characterize these four areas of a person’s daily life.

Daily life can also be described with regard to its quality. The three aspects of everyday life which have been found as most important in the frame of reference for this study are material standard (MS), the nature of existing social relations (SR) and personal influence and integrity (II). In table 8:1 the areas of community participation are described in schematic form.

The structure given to the concept of community participation in this study provides the framework for the questionnaire. Eleven areas have been chosen to be included. Each is covered by one or more questions (table 8:2). “Activities in the home” (1) describes aspects of the everyday life of the person in his home. Regarding “the person and the neighbourhood” (2), contact with neighbours is one of the areas described. “Recreation outside the home” (3) characterizes the leisure activities in which the person participates.

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Table 8:2. The 11 areas used to describe the concept of community participation.

HOUSING AND A HOME

1. Activities in the home

LOCAL COMMUNITY LIFE THROUGH THE HOME

2. The person and the neighbourhood
3. Recreation outside the home
4. Commercial services
5. Social contacts
6. Services for personal well-being

DAILY ACTIVITIES

7. The person's daily activities

LOCAL COMMUNITY LIFE THROUGH DAILY ACTIVITIES

8. Places and environments for daily activities
9. Social contacts in connection with activities

QUALITY IN EVERYDAY LIFE

10. Material standard
  11. Planning of support
- 

“Commercial services” (4) describes the extent of the person's participation in shopping, for example for food and clothes. Through “social contacts” (5) relations with persons outside the home are described. These can include relatives, representatives or others who play an important role in the person's life. “Services for personal well-being” (6) pays attention to whether the person benefits from services which contribute to his personal well-being.

When the person's life during daytime is characterized in this study a method is used which describes each one of the daily activities in which the person participates during a week. Together these provide a picture of the person's daily life for that week. In this way, each of the “person's daily activities” (7) can be described in organizational terms and with regard to “places and environments for daily activities” (8) and “social contacts in connection with activities” (9). Concerning “material standard” (10) this area is described by information regarding some of the person's personal belongings. “Planning of support” (11) describes some aspects of how the person can influence the character of the support received.

As a person receives support in the form of housing as well as daily activities, there are two sources of information concerning his everyday life. Section 1 of the questionnaire described the person's housing and home and the life he experienced in the local community. Section 2 described the person's daily activities. Section 3 contained questions about the person and his disability. This section was answered in the person's home. In addition to the questionnaire, material was added containing information about the study and the questionnaire.

### *Procedure for collection of information*

Sections 1 and 3 of the questionnaire, together with information about the study, was sent by post to the group-home of the person where it was received by the manager. Section 2, together with information about the study, was sent to the manager of the day activity centre which ran the daily activities in which the person participated. It was, however, the member of staff in the group-home and in daily activities who knew the person best, who was asked to respond to the questions.

There is a group of 266 persons for which information was received about life in the group-home. Regarding daily activities questionnaires were lacking for 35 persons. This does not, however, always indicate an unwillingness to answer. From previous results (table 4:4) it can be seen that 16 persons, for different reasons, did not participate in any daily activities. Formally they had access to this service but did not avail of it.

### *Analysis of information*

In the report where this study is accounted for (Ericsson 1993) material has been presented to provide a broad description of the results. Information from that report has been the basis for the analysis of community participation carried out here. The structure of the concept of community participation presented in chapter 5 is used to select the information from this report in order to describe eight aspects of participation in community life for the group which left the residential home.

The result in each of the eight aspects of community participation are presented here. The first step is to describe them in the form of figures. An analysis of significance using the chi<sup>2</sup>-method (SAS 2001) is then provided. Community participation is also summed up with an indicator expressing the degree of attainment of this objective by the group. The result from the analysis is presented in Appendix 3 (available from the author).

## Results

### *Platform for community participation*

In chapter 4 one part of the results from the follow-up study, the one concerning the new services, have been presented. Table 4:2 gives the distribution of housing and daily activities for the group. The categories of community based housing presented are the three types used during the planning of the transition of services. There are 30 persons (11,3%) living in housing type A, the group-home consisting of separate apartments where limited staff support is offered. 84 persons (31,6%) were living in housing type BA, a home for a group also situated in an apartment but with more extensive staff support. Housing type BV, the group-home located to a villa, was used by 105 persons (39,5%). As referred to earlier 14 persons (5,3%) were living at residential homes. The group which has been called MIS (miscellaneous), with 33 persons (12,4%), covers those group-homes where it was not possible to identify level of support offered. In this group there are also 6 persons where there was lack of information about the type of housing. This means that 246 of the 260 persons, about whom information exists

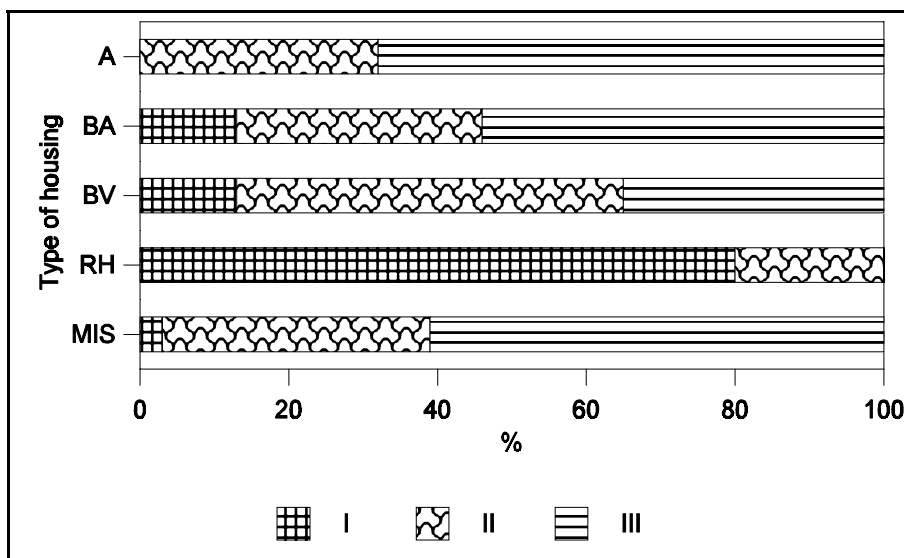


Figure 8:1. Extent of daily activities compared for different types of housing (I: 1-19 hours per week, II: 20-29 hours per week, III: 30 hours and more per week / A: group-home, limited support, BA: group-home in apartment, extensive support, BV: group-home in villa, extensive support, RH: residential home, MIS: group-homes with varying levels of support).

regarding housing, have acquired some form of community based housing. The degree of community participation attained can therefore be confirmed for 94,6% of this group.

As regards daily activities 35 questionnaires were not returned. There are also 2 persons who have paid employment, which means that they do not receive the support offered by daily activities. In addition, there are 12 persons who do not participate in any form of daily activity (table 4:4). These 14 persons minimizes the missing questionnaires to 21.

Figure 8:1 (based on table 4:2) compares degree of daily activities with the different types of housing. The first (I) category covers 1-19 hours per week, the second (II) 20-29 hours per week and the third (III) 30 hours and more. One finds that those who received daily activities full time, 30 hours or more per week, are related to the three types of community based housing. The proportion receiving full time is greatest for those in housing type A (68%) and this then decreases for the other two forms of housing, being 54% in housing type BA and 35% in housing type BV. A full week of daily activities does not occur for anyone living at a residential institution. The extent to which this day service is available varies therefore with the need for support of persons. Those with the greatest need for support are the ones having the least degree of daily activities. No analysis of significance has been made for this result.

The degree of community participation through daily activities for this group is 43,8%, that is the 102 persons with daily activities during the full week (including the 2 persons with paid employment) in relation to the 233 persons for which there is information in this respect.

#### *Everyday life with a personal character*

For persons with an intellectual disability acquiring a good standard of housing is naturally a major step towards living a life like others. But such housing must also

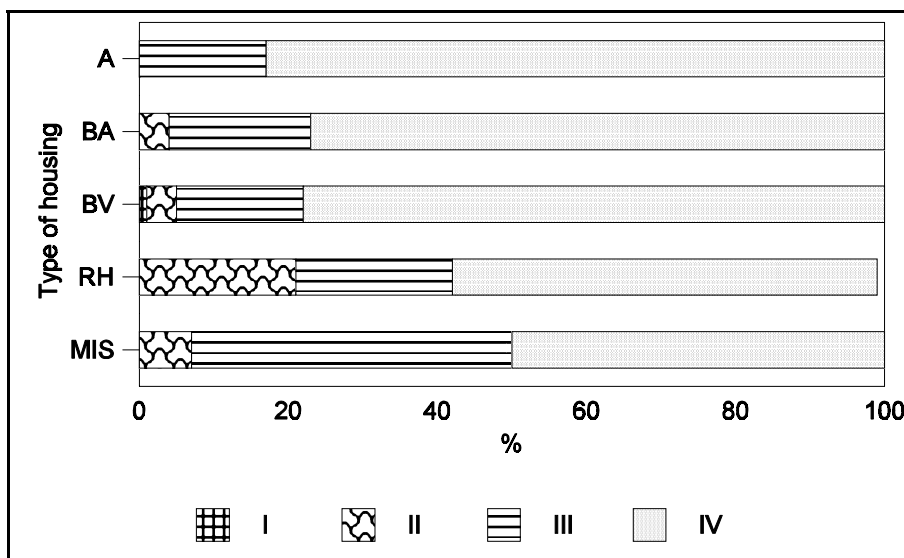


Figure 8:2. Housing as a home for the person compared for different types of housing (I: not at all a home, II: a home to a limited extent, III: a home to a rather large extent, IV: a home to a very large extent / A: group-home, limited support, BA: group-home in apartment, extensive support, BV: group-home in villa, extensive support, RH: residential home, MIS: group-homes with varying levels of support).

develop in order for it to become a home, a place with a personal touch to it, where one is able to live one's private life. In the questionnaire, this issue was covered by a question with regard to whether the housing of the person had developed into a home. The four categories of answers were "not at all" (I), "to a limited extent" (II), "to a rather large extent" (III) and "to a very large extent" (IV).

As can be seen (figure 8:2) nearly 80% of those in community housing are seen as having acquired a good home. The greatest proportion is found in housing type A. There are also 8 staff who consider, to a large extent, that a placement at an institution, also constitutes a home for the persons who live there. It is also interesting to see that among staff who answered the questionnaire there are 24% who consider that the housing the persons have acquired does not offer a home to a very large extent. There is, for example, one who decidedly maintains that this is not a home for the person concerned.

There are no significant differences as regards type of housing and the assessment of housing as a home for a person.

Community participation is seen to exist for 75,8% of the group, that is the 185 persons, of the 244 for whom there is information, who have been assessed as having a home to a very large extent (Appendix 3, table 3:1).

As the daily activities offered through a day activity centre are part of a person's support, they are intended to contribute to a good life, satisfying personal needs and requests. The same type of question as was asked regarding housing, was used. This time the question asked to what extent one considered that the daily activities in which the person participated, were purposeful for him. The four categories of answers were "lack of purpose" (I), "limited purpose" (II), "rather purposeful" (III) and "very purposeful" (IV).

Of the group 71% are thought to have access to very purposeful daily activities (figure 8:3). But there is a 10% difference between the groups. This is thought to apply

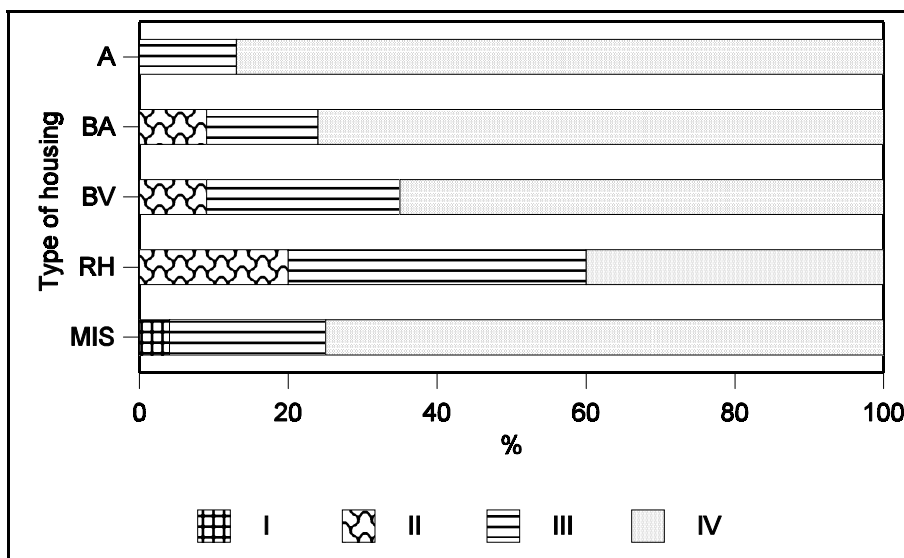


Figure 8:3. Extent to which the daily activities are purposeful for the person, compared for different types of housing (I: lack of purpose, II: limited purpose, III: rather purposeful, IV: very purposeful / A: group-home, limited support, BA: group-home in apartment, extensive support, BV: group-home in villa, extensive support, RH: residential home, MIS: group-homes with varying levels of support).

to 87% of those in housing type A, to 76% of those in type BA and to 65% of those in housing of type BV. It has been described already how these three types of housing vary in the amount of support provided and therefore one finds persons with different levels of need for support in these types of housing. The result indicates that those with least need for support, those in housing type A, are those who receive the most purposeful activities, while for those with a more extensive need of support, the activities are considered less purposeful. This pattern can only be called a strong tendency as the level of significance is only found on the 10% level.

Community participation is seen to exist for 70,7%, that is the 147 persons, of the 208 for whom there is information, which have been seen as having daily activities which are very purposeful (Appendix 3, table 3:2).

#### *Participation in local community*

The expression used here to describe participation in the life of the local community through housing, is the utilization of commercial services. The area which has been chosen is participation in the purchase of food. The four categories of answers are “never” (I), “seldom” (II), “monthly” (III) and “weekly” (IV).

Figure 8:4 shows that it is very seldom that persons participate in the shopping for food. The major group, 80%, never takes part in this, or does so seldom. When comparing the three types of housing, B, BA and BV, one finds that persons with an increased need for support, group BV, participates more seldom when shopping for food. This pattern is significant on 1% level.

Community participation is here seen as taking place if a person is involved in buying food monthly and weekly. This concerns 44 persons of the 241 for whom there is information and that is 18,3% of the group (Appendix 3, table 3:3).

One way to facilitate a person’s participation in the life of the local community

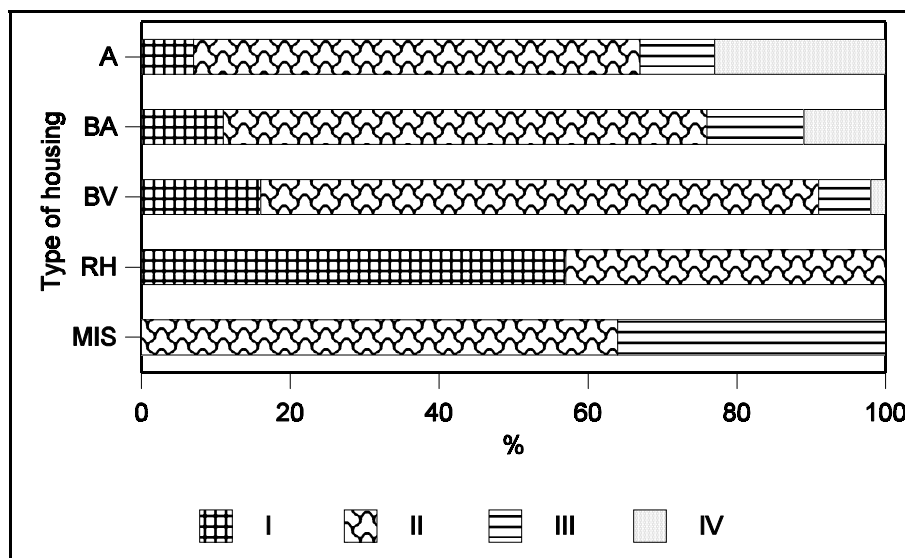


Figure 8:4. Participation when shopping for food compared for different types of housing (I: never, II: seldom, III: monthly, IV: weekly, / A: group-home, limited support, BA: group-home in apartment, extensive support, BV: group-home in villa, extensive support, RH: residential home, MIS: group-homes with varying levels of support).

is through localization of daily activities to premises and settings used by the general public. If the person during these activities develops relationships with members of the general public, his participation in community life can be strengthened.

To describe this it is required that one looks beyond the day activity centre as a unit and instead describe the various activities in which a person participates. Prior to this being done it is not possible to get a full picture of the everyday life of these persons (chapter 4). For this reason a description of all the daily activities in which these persons participated, has been carried out. Consequently 1.223 activities are accounted for in a number of aspects. One of these is the localization of the activities. In figure 8:5 these have been categorized. One group of activities take place in the person's home (I) while others take place in specially formed day activity centres (II). Others are located to facilities in the ordinary community (III). In addition there is a category termed miscellaneous (IV), where localization has not been defined.

It can be seen in figure 8:5 that the activities are predominantly located to the day activity centre, 70% taking place there. There are some, less than 20%, which take place in the community outside of the special premises which the centre represents. Very few activities, 2%, take place within the home. No real differences can be found between the groups A, BA and BV. No analysis of significance has been carried out for this comparison.

Community participation is here seen to take place for 19,0%, those 204 activities taking place outside the day activity centres, in relation to the 1.073 activities where information about localization is identified (Appendix 3, table 3:4).

### *Quality in everyday life*

As in previous studies the person's participation in planning of his services has been seen as an expression for quality in everyday life. The question asked here has been

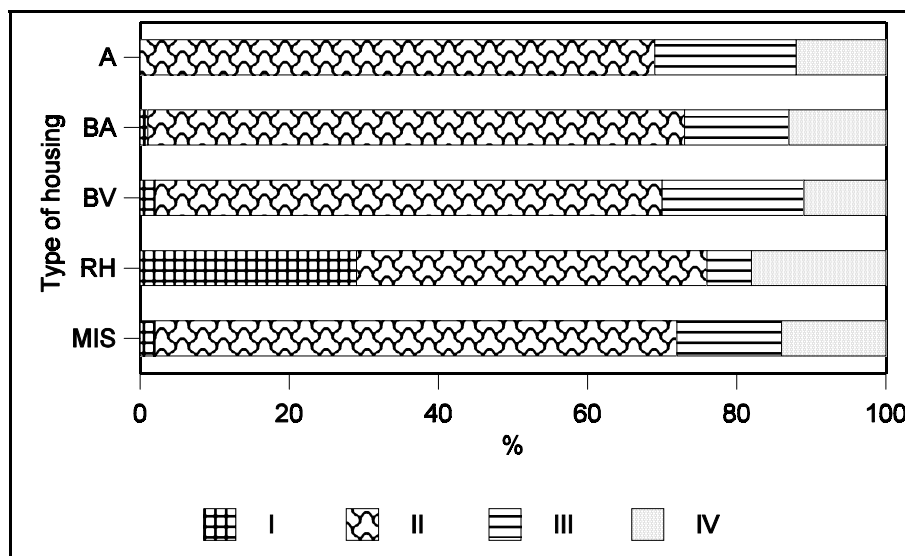


Figure 8:5. Localization of daily activities compared for different types of housing (I: the home, II: the day activity centre, III: a group in the local community, IV: miscellaneous / A: group-home, limited support, BA: group-home in apartment, extensive support, BV: group-home in villa, extensive support, RH: residential home, MIS: group-homes with varying levels of support).

intended to clarify whether planning has taken place and if so, to what extent the person himself has participated. The three categories of answers are “no planning” (I), “planning, no participation” (II) and “planning and participation” (III).

The most noticeable result (figure 8:6) is that there is a difference between the three types of housing. Planning where the person himself participates is fairly similar between groups, 33% for housing type A, 27% for type BA and 37% for housing type BV. The absence of planning varied between groups. In housing type A, planning did not take place for more than half of the group, 57%. This group is reduced for housing in type BA (38%) and BV (24%). This means that planning, irrespective of participation, takes place to the highest degree for persons in housing type BV and to the lesser degree for those in housing type A. Those with the more extensive need for support are therefore those for whom planning is taking place, but they do not participate more often than others in this process. This pattern of planning is significant on 1% level.

Community participation is seen to take place for 71 persons, those who experienced planning as well as participation, of the 231 for whom there is information, that is for 30,1% of the group (Appendix 3, table 3:5).

To understand this aspect of quality in everyday life as regards daily activities it must be realized that this is a form of support which must be planned for each person. For this to be purposeful it is presumed that the person concerned participates in the procedure. The categories of answers are the same as for housing, that is “no planning” (I), “planning, no participation” (II) and “planning and participation” (III).

Within services providing daily activities, individual planning occurs to the same extent (80%) within the three groups (figure 8:7). There is, however, a variation regarding the extent to which the person concerned participates on these occasions. In group A it is most usual that one participates, 41%, whereas it is only 13% in group BV, with group BA lying in between with 34%. Consequently, it is the persons with least need for support who participate most. This pattern of planning is significant on 1%

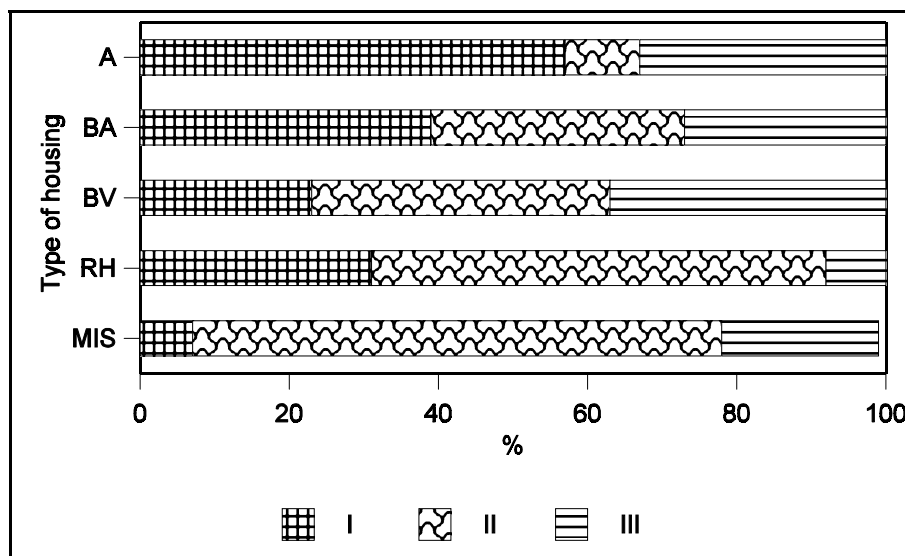


Figure 8:6. Participation in the planning of the person's support in his home compared for different types of housing (I: no planning, II: planning, no participation, III: planning and participation / A: group-home, limited support, BA: group-home in apartment, extensive support, BV: group-home in villa, extensive support, RH: residential home, MIS: group-homes with varying levels of support).

level.

Community participation is seen to take place for the 49 persons, of the 204 for whom there is information, that is for 24,0% of the group (Appendix 3, table 3:6).

## Discussion

For the persons who had left the residential home a new life had been established. With regards to housing and a home, this is characterized by the fact that new forms of support had been offered to 95% of persons, namely those living in community housing. However, because of the objective of offering support related to personal needs, there was a variation in type of housing. When asked whether this housing also could be seen as a home for a person, a majority of staff considered this to be the case. There was no difference in this respect between the three types of community housing. There was however a variation between types of housing as regards participation in local community life. It is uncommon to participate in shopping for food. If this does take place it is mainly those with a limited need for support who experience it. There is also a variation in how planning of the support of a person takes place in the home. This takes place more often for those with an extensive need for support but when it does occur it is less likely that the person is represented.

Persons have received day services outside their home and there is a substantial number for whom this takes place during a full week. When one looks at the persons' variation in need for support, it is more common that this service goes on less than full time among those with a more extensive need for support. Staff express that there is also a variation in the purposefulness of this day service. An increasing number for those with a more extensive need for support are seen to have daily activities which lack purpose. Participation in the life of the local community is not common when one looks to the localization of places for daily activities. Only a small proportion have their place

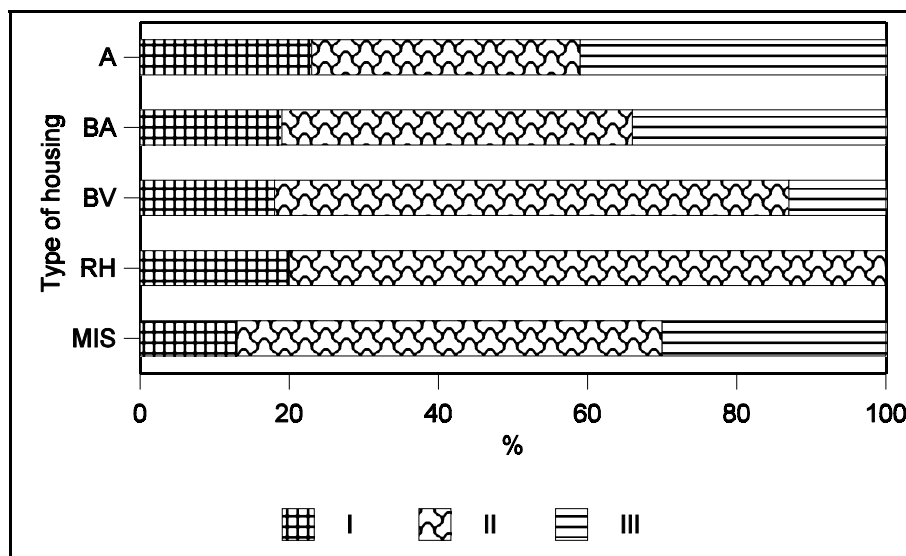


Figure 8:7. Participation in the planning of the person's daily activities compared for different types of housing (I: no planning, II: planning, no participation, III: planning and participation / A: group-home, limited support, BA: group-home in apartment, extensive support, BV: group-home in villa, extensive support, RH: residential home, MIS: group-homes with varying levels of support).

of activity in the local community, outside the day activity centre. In this aspect there are no differences between persons. As regards planning of day services there is a variation in the participation of persons. It is more common that those with a limited need for support take part in the planning of their activities.

A factor contributing to the high degree of interest for the follow-up study was the fact that staff from Carlslund residential home who had changed place of work, but still were supporting persons who had left the institution, had expressed a particular interest in participating in the study. Apart from the questionnaires not returned there are a number of questions where information is missing. It is possible that staff without the institutional background have been less motivated to respond to the questionnaire or that they found some questions difficult to answer. One cannot argue that there is a high degree of social desirability in these answers as the result gives a frank description of the lives of these persons. A higher degree of community participation than that found could have been expected.

The basis for the results are the conditions of this study. Persons moved from the residential home during a period starting in 1980 and ending in the year 1988, while community participation was described during 1990. It should be remembered that there is a variation in the experiences of community participation in this group. As was mentioned (chapter 4) the character of the alternative services determined when persons could leave the residential home. As a consequence those with a limited need for support were able to move during the first half of the period, whereas those with more extensive needs could leave during the second half. As the latter group had less time to experience participation, this could be a factor influencing the result. However, as was seen in the cross-sectional study (chapter 6) there was a tendency that community participation was limited among those with extensive needs for support.

An important factor influencing this issue is the way services are organized. The interpretation of the objectives for support and the working methods which have evolved in the new services does not always express support for the right for persons,

irrespective of degree of disability, to a community life. This has a background in a system of services which saw the “partially able-bodied” as being those who were given the opportunity to live a life outside the institution, something which was not given to those with more extensive needs (chapter 3), the intention being that they remain inside the residential institutions.

The conclusion put forward in the two previous studies is supported here, namely that more could be done by these services as regards participation of persons in community life.

## **Chapter 9**

### **Community participation of persons**

In chapter 5 a model for the analysis of community participation was presented. This was used to select information from studies where this concept had been used to describe personal consequences when moving to community based services. The results from these studies have been presented in chapters 6, 7 and 8. In this chapter the analysis is compiled and discussed. To provide a broad view of personal consequences during the transition to participation in community life, information from interviews and questionnaires with persons, families and staff is included. This provides the background against which the third research question, whether community based services contribute to an increase in persons' participation in community life after institutional closure, can be answered.

#### Analysis of community participation

The model for analysis which was presented in chapter 5 gave possibilities to describe four aspects of community participation as realized through two forms of services, housing and daily activities. In this way eight aspects of community participation could be described. With information from three studies a model with 24 fields was formed (table 5:1). The analysis of community participation was carried out with results from the studies in chapters 6, 7 and 8. This is presented in table 9:1.

The value in a field of this table is given as a percentage. Information concerning the calculation of this was presented in the previous chapter where the study was reported. The cross-sectional study (Study 2) compared institutionally and community based services regarding their ability to contribute to participation in community life of persons. Results are therefore an indication of the difference in this respect, between these types of services. The longitudinal study (Study 3) compared institutional life with participation in community life attained after having left the institution. The value in a field in this case indicates the difference in the degree of participation between institutionally and community based services. The follow-up study (Study 5) describes community participation of persons after they have left the institution. A value in this case expresses the extent to which participation has been fulfilled.

As can be seen in table 9:1 there is a difference between the four areas. This depends on their different character. The level of participation is highest regarding "platform for community participation". This is related to how housing and daily activities are administered. Formal decisions are made about building plans and the financing of them, thereby making it easy to decide how many persons will receive these types of support. The lower level for daily activities depends on the situation that only part of the group actually had acquired daily activities during the full week.

Table 9:1. Analysis of community participation based on results from three studies. A percentage in a field is an expression of degree of fulfilment of this objective.

COMMUNITY PARTICIPATION	STUDIES		
	Study 2	Study 3	Study 5
1. Platform for community participation			
1.1 Housing	-	95%	95%
1.2 Daily activities	-	42%	44%
2. Everyday life with a personal character			
2.1 Housing	48%	70%	76%
2.2 Daily activities	39%	62%	71%
3. Participation in local community			
3.1 Housing	98%	23%	18%
3.2 Daily activities	43%	36%	19%
4. Quality in everyday life			
4.1 Housing	34%	00%	30%
4.2 Daily activities	37%	17%	24%

The degree of participation in the area “everyday life with a personal character” is also influenced by the physical structure of services. A private bed-room and a private bathroom are examples of conditions which must exist for a private life. But this is not enough. The philosophy and working methods of the service also influences the extent to which physical conditions are used and how tasks in everyday life are carried out. It is therefore not self-evident that well planned services are given an orientation that insures that an everyday life with a personal character will be realized.

“Participation in local community” and “quality in everyday life” are areas more concerned with the content of the new services. Participation is related to how objectives are introduced into a service, translated into working methods and implemented in everyday life. As this area relates to everyday activities which assist the person in availing of environments and services in the community in which he lives, working methods with a social orientation are necessary. Development of such methods becomes a critical task during the transition from institutionally to community based services. The problem of developing these new methods may explain the relatively low level of community participation found in this area.

“Quality in everyday life” is concerned with relations between staff and the person with a disability, this being primarily related to the issue of the person’s influence and control over the support he receives. As this area is based on the view that the person should have a formal say over the planning of his life, one must conclude from these results that this is only met for a minor part of the group in these studies.

The main picture which emerges shows, as all the values are positive, that persons have, by means of the community based services to which they have gained access, been able to experience an increase in community participation. However, at the same time as this is observed one must also note that participation is not total in any of the separate analyses. Development needs to continue if this objective is to be attained. There is also a variation in participation between these four areas. A previous comment

pointed out that activities emanating from the central level of the organization resulted in a higher degree of participation. The low degree of participation was found when the local level had responsibility. One can also find a difference between the two services, housing and daily activities. In the 11 comparisons one finds that participation through housing is higher on 7 occasions. In the discussion in chapter 6 the question was raised, and this is supported here, whether new housing had meant more than daily activities for persons who leave the residential institution.

### *Generalization of the results*

The work presented in this thesis concerns Carlslund residential home from its establishment in 1901 to its closure in 1988. But the topic does not end there as the group in the follow-up study carried out in 1990 (Study 5) are the persons who once lived at the residential home. The question of how to enhance participation in community life for these persons is discussed in chapter 10, particularly with respect to the new conditions created after the Act of 1993, which pointed out the responsibility of the social authorities in the municipalities for the welfare of these persons and after the Act of 1997, which clarified that all residential institutions be closed after year 2000. The thesis thereby spans a 100 year period, the main issue being the same, namely how to organize support from society to the benefit of these persons. This work can therefore be seen as a case-study of an institution and the persons living there.

The ambition of project “Two worlds of services” was to document and analyze the process of transition which took place in Stockholm County when Carlslund residential home was closed. The studies which were realized were those which it was possible to carry out and most of them have been reported here. The organizational analysis of the residential home (chapter 1) illustrates the initial idea of the residential home and the process when it was dissolved. The assessment of the need for community based forms of support for all persons who were to move (Study 1), became the basis for the transition and for the analysis which followed.

The three studies carried out during the process of transition had, for practical reasons, to be based on selected groups. The group in the cross-sectional study (Study 2) were those in institutionally as well as community based services who could make up comparable groups. Those who were excluded were persons with more extensive needs for support as they could only be found living at the institutionally, but not in community based services. Persons included in the longitudinal study (Study 3) were those who were to leave during the year when funds had become available for the study. That year a ward was to close and the main group of those who participated were those who left that ward. As this originally was organized for persons with extensive needs for support, personal consequences are the ones experienced by these persons. A follow-up study (Study 4) was carried out during the process of transition when staff in community based services were interviewed about the well-being of a limited group of persons. The follow-study (Study 5) after the closure of the residential home concerned all who on the day of the census lived in community housing with support.

These studies give a comprehensive view of the transition from institutionally to community based services for this particular residential home in Stockholm County. A question can be raised concerning to what extent one can generalize these results to the process of transition in the country? In Sweden there are large geographical differences

between the 25 counties. Stockholm County is the largest as regards inhabitants and is also characterized by the fact that the capital is situated there. This would argue against these results representing this process on a national level.

But there are also similarities. When services for persons with an intellectual disability were part of the special organization run by a county, as during this process of transition, these were highly centralized and dominated by national bodies which specified models for the services being offered and made recommendations concerning the content of the services to be provided. This led to a homogenous service with residential homes, group-homes and day activity centres looking very much the same throughout the country. I also have personal experiences from this type of project in various parts of the country, not only Skaraborg County, which support the general trend of this study. My conclusion is therefore that these results are to a high degree representative in relation to the process of transition on a national level.

#### Transition as seen by the persons, their families and staff

The four studies which follow give additional views on the transition as these are seen by three groups which were deeply involved in this process of change, namely the persons themselves, their families and staff.

#### *Study 6: Interviews with persons who started a new life*

In a work which aims at an understanding of the change from institutionally to community based forms of support it is naturally desirable to listen to those persons who left in order to hear their views about the events which have taken place. But this is difficult as many of those who lived at the residential home were persons with extensive disabilities. This meant that several lacked speech as a way of communicating with others. Many also had a severe intellectual disability which made it difficult to express the significance of the change which had taken place. The way of getting an understanding of these persons' own thoughts in this series of studies was to interview the relatively small group who had speech, regarding what it meant to start a new life outside the residential institution. This study was conducted as part of the project which documented and analyzed the transition of services which took place in Skaraborg County (Ericsson 1992b; Ericsson 1995a). 18 persons were interviewed by a member of the Skaraborg project, Sirkka Gilbertsson (Gilbertsson 1992; Gilbertsson & Ericsson 1995).

As an interview was to relate the views of a person on his life after having left the residential home, a number of issues concerning everyday life, housing and a home, daily activities, leisure and relations to others, were to be covered. To make a person feel free to talk about his experiences, interviews were open but care was taken to cover all issues. The interview was carried out during a visit to the home of the person. From each interview quotations were collected, by writing them down during and after an interview, which were indications of the person's views of his new life. All interviews resulted in a collection of 307 quotations which expressed these persons' perceptions of their new lives. As the quotations were the material for this study, these were sorted into categories and together with comments, presented in a text.

It is a positive picture of their new lives which emerges. No-one expresses a wish to return to the residential home. However, they do not recount a life of strong and intense emotions, nor one of dark or gloomy experiences. During the conversations which took place it was instead the everyday events of daily life which dominated, the pluses and minuses that are experienced by all, not just by this group of persons.

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

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 expressions in these interviews which with delicacy and nuance say something not just about their own but more general impressions. The role of recreational activities is well perceived by the one who said "*leisure, we spend together*".

One also wants to know more about the significance of some expressions. What do they really mean when they speak about the relatively young staff as "*the old maids*"? Is it an expression for warmth and tenderness, that is closeness, equality and positive relationships, or is it an expression for fear and respect for superiors, based on earlier experiences?

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 post 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 consisted of a considerably higher material standard. Regarding his own person he had, however, not become visible and publically recognized in his local community. He, and all others who had been away for a long time, had a need to announce that once again one belonged to and participated in the life of that community.

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

### *Study 7: Interviews with families*

Being a member of the family to a person who leaves an institution which is to close down, places one in a situation where one can be subjected to considerable stress. In the development of new services for one's son or daughter, brother or sister in a new community means that during a period one lacks knowledge as to what the future is going to be. It is not until one has seen the options available that one can understand what the closure of the residential home will imply for the person concerned. The purpose of these interviews was therefore to gain insight into the views of family

members regarding this process of change. A total of 53 family members participated, parents, siblings and others, in interviews concerning 36 persons. A member of the project in Skaraborg County, Barbro Tuveesson, conducted the interviews (Tuveesson 1992; Tuveesson & Ericsson 1995, 1996).

Four areas were covered by an interview. "Kind of support" concerned issues relating to the type of institutional care received by the person. Information about the new community based services was also covered. "Time for breaking up" covered the reactions of the family to this new situation during a period starting when information was given about the decision to close the residential home and ending at the time of the interview. "The relation to the family member" is an area in which the family could describe how the relationship was developed during the period beginning with the information about the closure of the institution. "The future" was the area in which the family could express views concerning the future for both the person and the family.

The interviews were recorded. This provided the basis for characterizing the phases of the life of the family member and the reactions of the family, during the period which was covered by the study. One way of characterizing the family reaction was to identify whether it had been negative, neutral or positive towards the person leaving the residential home. As the family reaction was identified for two occasions, after having received the first information about the closure and at the time of the interview, the development of a family reaction to this transition could be described.

There is one question to which an immediate answer was attained. It concerns whether relatives who had been negative when the process of change began, maintained their negative attitude after their relative had left. The answer is that the majority of those interviewed had changed their opinion. While 28% were positive prior to the move, 78% belonged to this group when the process of change had been accomplished. One finds therefore a group who changed their views when they had seen the new services which had replaced the institution and when they had seen the new life which was offered.

There is also a group who are not entirely positive. Admittedly it is small but represents those who, in spite of the higher standard in material and formal respects are not completely satisfied with that which the persons have acquired. When they saw the alternatives to the institution, they sought other qualities which they regarded as more important if the option was to be considered suitable for their family member. A conclusion to be drawn is that it is not always enough, when creating new forms of support, that the formal and material requirements are met. It is also important to see that these are regarded as positive by others, in particular, by the family. If one is interested in their opinion they need to participate and be included in the process of change and to be able to influence the type of life which the son or daughter, sister or brother, is going to live.

Moving to a community near that of the family was regarded as an important factor. It was not so that all had come closer to the parental home, but many did come to live near each other after the move from the institution. This provided conditions which facilitated the development of an entirely new relationship between the person and his family. The previous more formal contacts which entailed travelling and visits to the unfamiliar environment of the institution, had been replaced by one where one was able to meet each other under spontaneous forms and in familiar circumstances.

A striking impression from these interviews was the very strong relationship of the family to the person in the institution. He was remembered as part of the family,

even if he did not receive many visits. When this process of change was viewed from a life-long perspective it was clear that one had the person in one's thoughts, in spite of his being far away and having been unable to affect his life during several decades. What had taken place long ago was well remembered, for example a critical comment by a doctor or a headmaster, this having contributed to perceptions still held today. At the same time one took a responsibility in that one planned for the future, for the son or daughter, brother or sister, in order to guarantee that someone else would take responsibility when one no longer was able to do so oneself.

The commitment which was shown illustrated that the family felt a responsibility for the relative with a disability, "the person belonged to the family", even if he had not always been a part of its everyday life. For the organization responsible for support this is an important assertion. The person with an intellectual disability does not "belong" to the organization and should therefore not be accessible for any measures which they wish to take. One has, of course, as a representative for a public service an important role to play in relation to these families. At the same time as one makes decisions concerning measures and contributions of support, one is also an intrusion, which can dramatically affect the life of the family. These factors are clearly illustrated in this study concerning this process of institutional closure and the person's move to new services.

#### *Study 4: Interviews with staff*

In order to gain an understanding of personal consequences this study was conducted at an early stage of the process of change at Carlslund residential home. The group concerned were the 24 persons who left during 1982. Two years later interviews were carried out with staff at the persons' new homes and their daily activities. A smaller number of interviews also took place with 3 persons and with 4 members of families. A total of 56 interviews were carried out. The study was conducted by a member of the Carlslund project, Maj Thorsell (Thorsell, Ericsson & Brusén 1986, 1988).

An interview began with the request "Describe what X:s life is like to-day. Focus preferably on the situations where you have seen change in a positive or negative direction. Remember that negative changes are as important as positive". X in this respect referred to the person the interview concerned. Each discussion contained several narratives, each in the form of some words or sentences, which expressed a change which had been observed. Each little narrative was taken as an indication of change. From each discussion a number of such indicators could be identified. The 56 interviews resulted in this way in a total of close to 600 indicators. When categorizing them, indicators expressing similar ideas were grouped into dimensions. This resulted in 13 dimensions which were in turn grouped so as to describe similar phenomena in a category. In this way four categories emerged which together gave a picture of the daily lives of these persons after they had moved. These four categories, in bold letters in the text, are summarized here. The wording of a category was chosen so as to describe the essence of the indicators they express. The dimensions which make up the category are presented in italics in the text.

**Becoming a person:** This was the category which emerged as most relevant. The picture which was found was that these persons now lived in smaller groups, with

more personal relations to their staff. They became visible as a person, with their own personal needs and wishes. This was illustrated in the expression *staff have time for me too*. In the interviews there was a group of indicators which described positive exchanges between persons and staff and that there was time enough for staff to meet needs and wishes. This came to be described as *they do listen to us*. But in these personal relations there were also examples of how a person's wish to control his own life led to a situation when he wanted to argue for his opinion. The dimension which expressed this is entitled *now one dares say no*.

**Finding a home:** As the unit where the person had lived at the institution was planned like a modified medical ward, moving to a new house meant a big step. The home provided new experiences and a new way of life. Persons responded to these opportunities and created a home for themselves with a personal touch. In this way they acquired a private life. *Having one's own home* was a way of summarizing the indicators which describe this. Of special significance was the kitchen and the free access to all that a home has to offer there. These were experiences which had not previously been accessible. The kitchen had therefore an important role to play, for these persons, as for everyone else. ... *with a kitchen* was the expression which summarized this new experience. That it is not entirely without problems to have access to a kitchen with its contents and the activities it offers, became apparent when one had to share a common kitchen. Food in the refrigerator had to be shared by many. There was also food purchased by the service organization. This raised the question of privacy and the freedom to use what was purchased for all: *whose is the food in the fridge?* Getting a house also implied that one was a resident, with an address and that one lived in a housing area like others. This also contributed to getting and keeping friends. This was summarized as *persons have personal relationships*.

**Something to do all day:** To offer daily activities which contribute to a good life for persons who had left a residential institution was not as easy and did not lead to the same positive consequences, as when the home was established. Few indicators say anything about the consequences of daily activities and those which are voiced are not all positive. *Passivity - my protest* was an expression which showed how persons who came to a day activity centre but who, when they did not experience activities which seemed purposeful, reacted with passivity and lack of interest. This became a protest which put demands on a continued development of activities in order to be able to offer a good life also for persons who had left an institution. The positive activities which were recalled were those which led to the person's participation in the activities which took place within the day activity centre. *I'm needed* was a way of describing this positive side of activities.

**Dad comes even if it rains:** In the person's home, in a house in a local housing area, it was more natural for a family member to make a visit. One visited one's son or daughter with a disability in the same way as when one visited another son or daughter. What went on in this home was the same as in any other home. In this way this type of contact with services became less dramatic. It was easier for a family member to make a visit and to contribute to what is going on when the competence one has in caring for one's own home can be seen as a contribution. *There's room for the family* is an expression which describes this.

Contact also became more normal between family and a son or daughter. One could be passing by and just drop in for a short visit and a son or daughter could

informally be invited home for a meal and a short visit. *Supposing I asked her to dinner?* was the expression which captured this feeling. With one's own home it had also become natural to have a telephone in order to keep in touch with one's family. It is easy to ring up and one does not have to speak in order to hear parents or siblings on the phone. *Phone-calls, a way of getting together* summed up this new form of contact. These social contacts were, of course, not as natural if one did not have a family that was interested in one's well-being. For these persons a desire to acquire new friends developed. *Fellow human being wanted* became the expression which communicated this aspiration.

The major tendency found among the personal consequences after these persons had left the residential home for new community based services, was expressed by the first category "becoming a person". Indicators of this were collected from interviews in the home as well as in daily activities. The individuality of the person was seen in the new setting offered by the new service. Seeing this personality also meant an awareness about social relationships, primarily to the family.

There are two aspects of the new life which could be expected, but comments on these were absent. One concerns the limited number of indicators relating to the daily activities of the person and when mentioned it was not only in positive terms. This is surprising considering the fact that this represents a separate service which offers activities to persons during five full days of the week. As the consequences of this service is hardly mentioned in the interviews, questions can be raised about its contribution to a good life for persons. One is also surprised about there being no mention in the interviews about participation in the life of local community, neither outside the home nor outside the day activity centre.

#### *Study 8: Questionnaire to staff*

In order to compare differences of working conditions between institutionally and community based services, a study was carried out addressed to staff who presently were working at a group-home and who previously had worked at a residential home. The questionnaire was sent to 207 staff, the addresses having been received by staff managers in the county. It was answered by 139 persons (67%). The questionnaire consisted of 42 questions covering a number of issues relevant to staff. Apart from information about personal background and the services where they had been employed, questions were asked about tasks and working conditions. Demands and expectations which one met as staff were covered, as well as experiences of satisfaction with one's work. The questionnaire also gave an opportunity, by some open questions, for staff to give personal comments about the issues. The study was conducted as part of the Skaraborg project, by Catarina Dahlgren (Dahlgren 1995; Ericsson & Dahlgren 1995).

The answers showed, in varying ways, that the ongoing change of services had created entirely different working conditions. There was an independence in the group-homes which had made it possible to work under freer conditions and with a greater degree of control over one's work. Because of this one also felt greater responsibility, something which was appreciated. The new working conditions had also led to a work situation with greater variation and different types of tasks.

One also considered that community based housing had created better conditions for the persons who lived there. They were able to experience a more quiet life and a

real home. The new conditions of life also provided opportunities for personal development, which had led to independence. These conditions had also enabled persons to have more influence and control over their lives.

For staff the group-home had created a new situation which influenced their way of working. They had more time for each person, which in turn increased their opportunities of contributing to a good life. They experienced new relationships towards those who lived there, including an element of friendship and affection. There were more occasions for better contact with relatives and it was now possible for persons to be together with their family in a more personal way, instead of in large groups as was experienced earlier. Supervision was no longer a feature of the working methods. Seeing that the person was enjoying life and making progress, was a source of gratification. It had become more of a pleasure to go to work and one was able to feel satisfaction over one's contribution.

However, there was no hesitation over expressing the feeling that the most negative aspect of the present job was having to work alone. When there was no-one to consult or to seek advice from, one felt isolated with one's tasks and thoughts.

Nevertheless, in retrospect one had no reproaches over having worked at the residential home. One saw the fellowship in the staff-group as a positive aspect of the work situation there. One belonged to a large group and this led to many positive contacts with others. It added to one's pleasure over the job and in the fellowship with other staff. It also contributed to a good atmosphere at the institution making it a secure place of employment. Another feature which was positive was that in the large staff group there were many with whom one could share one's thoughts or to seek advice when needed.

Agreement among those who participated was emphatic regarding what was considered the most negative characteristics of the residential home. It was a place for large-scale care and the services were provided in much too large groups. With this style of work no consideration was given to the person and everything was done in groups. As a member of staff one worked according to routine. Most striking was how the process of morning-hygiene was described, it being compared with work on an assembly line. There simply was no time or resources for a personal approach. It was also a workplace which was steered from the top, in a hierarchical organization. This led to a lack of flexibility and little interest for staff initiatives. As a consequence, it was difficult for staff to influence their working conditions.

Staff considered the care at the residential home as poor. It was institutional in character, with disturbingly high levels of noise because of so many persons living together. Personal facilities were lacking as one had to share one's room with others. In addition to these impersonal conditions it was difficult to create groups of persons who got on well together. Being shut in with locked doors was a means of control used, the task of the staff being primarily custodial.

When viewing these realities, the development within community based services is not surprising as it has been largely influenced by the thoughts, ideas and experiences of committed and knowledgeable staff. They are therefore not strangers to these new types of services. The dissolution of institutions has, of course, been a difficult process of change. But when it has been achieved, staff can freely look back and compare old and new tasks and working conditions. An explanation, of a more general character, regarding the change being seen as something positive, may be that it indicates a modernization of working conditions within the field of social services. The institution

and the working conditions it provided represented an older form of industrial work, whereas the community based services, with a higher degree of independent work in small groups, is more characteristic of ongoing developments in working life generally during the 1970:s and 1980:s.

### Answering the third question

In general discussions the issue of personal consequences during transition from institutionally to community based services often gives rise to a spontaneous response. The four studies based on interviews with persons themselves (Study 6), their families (Study 7) and staff (Study 4) and questionnaires to staff (Study 8) have been referred to here, as they express very well the common reaction to what has been called institutional closure. The main view is a positive one with regard to the new lives which have been established. The change has also meant a new life for families, which they also see as positive. For staff this has meant new working conditions. But the content of the stories which are told is not always positive. They also contain various critical views concerning the new services, consequently arguing for their further development. There are, however, no expressions of anyone wanting to return to institutionally based services.

The four studies have been summed up in this chapter. They are of course in their original form more rich in content. This is naturally also a limited version of the final follow-up study (Study 5) as it is presented (chapter 8). There is however one aspect in this study which ought to be given some attention, namely the availability of local services. Results show that the needs which have been identified have also been met. Persons seen as having a need for support, but who have not received adequate services, are few as regards chiropodist (1%), dentist (0%), physiotherapist (11%), social worker (0%) and psychologist (3%).

It is the expression "becoming a person" in the early follow-up study (Study 4) of persons who left Carlslund residential home, which can be seen as crucial when this process of transition is summed up.

This broader view of personal consequences provides the background to answering the third question, the one concerned with whether community based services contribute to the persons' participation in community life after institutional closure. Referring to the analysis in chapters 5-9, summed up in table 9:1, the answer is that there is an increase in community participation after institutional closure. There are nevertheless variations between different areas of participation. Most apparent in this analysis is that this is most extensive in those aspects which are organized by central bodies. The aspects of community participation which require local decisions and methods show a more limited degree of increase.

### Discussion

The predominant picture which emerges from these four studies is mainly positive. This is not surprising when one considers the nature of the transition which has taken place. One has left behind a life which had a low material and social standard and which was segregated from society, organized in a hierarchical manner providing limited freedom

for the person with a disability. That this was the situation depended on the fact that the residential homes in Sweden (chapters 1 and 2), were developed during the first half of the 1950:s. They were therefore influenced by the views and perspectives which applied both previous to and during this period. The new services were, on the other hand, developed during the 1970:s, in a society with an ambition to provide better housing and full employment for people in general. The right to housing and to daily activities outside the home for all persons with an intellectual disability, naturally became an objective for the disability services which were then being established. It therefore appears as natural that the new services can provide more modern living conditions and that the persons with a disability, their families and staff are well aware of this development.

A new life has been created for these persons through the new forms of services. These new living conditions have led to a new personal development, to new experiences and to new relationships with others. But the picture is not entirely positive. Within the general framework of change there is also an expression of discontent, for example the desire that the situation be even better. There is more to be done. The new life that has been created by the move from the residential home has, however, created a platform for further development.

## **Chapter 10**

### **A shift between two traditions of support**

The result of the analysis in chapters 5-9 showed that an increase in community participation had taken place during this transition from institutionally to community based services. The low level at the residential institution found in the studies, can be seen as an expression of the fact that this was never a concern in the provision of these services. Instead, the residential institution was seen as a miniature community in itself (chapter 1). Consequently, the idea of participation in the life of the local community did not influence the structure of the residential home. In an analysis of institutional life, based on this new objective, it is natural that one does not find community participation taking place. The problem of institutionally based services can therefore be described as their inability to contribute to participation in community life of persons.

In the analysis of community based services one finds a varying degree of participation. As the roots of these services were traced to a period when participation in community life was seen as desirable (chapter 3), these forms of support could be expected to have a structure which contributes to participation of persons in community life. When one describes these services, expecting to find full participation but finding it only to a limited extent, questions are raised. The lack of community participation found within community based services must, therefore, be regarded as an important problem.

Community participation can, accordingly, be seen as a problem for both institutionally and community based services. Consequently, it should be seen as a major problem in services to persons with an intellectual disability. This is the issue discussed in the present chapter.

A widening of the frame of reference

#### *Two traditions of support*

In the final part of chapter 1, I mentioned that the studies concerning the transition from institutionally to community based services had been carried out in a project called "Two worlds of services". This was primarily initiated in order to document and analyze the closure of Carlslund residential home. Persons moved from the specially constructed world which the institution offered, to places in the ordinary community. But this also became a special world as the housing and places for daily activities had been specially designed for these persons (chapter 4).

During the course of this project a historical analysis concerning the roots of the dissolution of institutions led to the document in which the 1946 principle of normalization was formulated (chapter 3). This gave a broader understanding of the ongoing transition. The meaning of this socio-political idea stood out more clearly when the studies on the transition of services in Skaraborg County were summarized (Ericsson 1995a). Based on a citizen perspective the conclusion could be drawn that development needs to continue after the closure of a residential institution if participation in community life is to be realized.

In other analyses (Ericsson 1995b, 1995c, 1997, 1999, 2000; Ericsson, K. & Ericsson, P. 1998, 1999) ideas were developed which led away from the concept of the “two worlds of services”. Instead the ongoing change was expressed as a shift between “two traditions of support”. A community tradition was developed while an institutional tradition was dissolved. The frame of reference for an understanding of the ongoing transition thereby became wider. Ongoing change was no longer seen as a normalization process, where daily life should become more normal for the person with an intellectual disability. It was instead characterized as a process of democratization, aimed at a realization of the democratic right for these members of society to participate in a welfare society, as the 1946 principle of normalization had pledged (chapter 3).

### *The residential home versus the normalization principle*

In the presentation of the residential home (chapter 1) one finds an illustration of the establishment of residential institutions and their development during the early period. A section also describes the ambitions of the 1950:s. Here one sees how the modern residential institution was envisaged, both regarding its physical design and the character of the work to take place there. The visions concerning the creation of a better world for these persons were advanced for the time. The development one wanted to achieve was to be brought about by making the institution into a miniature society, offering a normal life to persons without their having contact with the life of the local community. But the plan for the modern residential home also included destructive and pessimistic views concerning the potential of persons with an extensive need for support and the role of the institution. Chapter 1 provides a good insight into the institutional tradition as it was seen at that time.

In chapter 3 the idea of the community tradition is illustrated. A disability movement and representatives for society were united in the ambition of an increase in welfare for persons with a disability. By recognizing the democratic rights of persons with a disability this vision conveyed a spirit of optimism which could be realized by non-institutional services.

In the early 1950:s one can therefore find visions concerning the development of institutionally as well as community based services, each pointing to development in diverging directions.

The two traditions of support are schematically illustrated in figure 10:1. Development in Sweden is shown as being comprised of three 50-year periods. During the first period, the latter half of the 19<sup>th</sup> century, the institutional tradition emerged. This occurred when persons with an intellectual disability were identified in society and when the need to provide support from sources other than the family became increasingly demanding. Considering the conditions of this society, the residential institution was the natural way to organize support. The second 50-year period, the first half of the 20<sup>th</sup> century, was also dominated by the institutional tradition. This time the separation brought about by the residential institution was strongly influenced by the pessimistic views of persons with a disability which were dominant during these years (Söder 1978).

It is at the beginning of the third 50-year period that the community tradition emerged. In the same way as the institutional tradition was natural in the society in which it was established, so the community tradition was the natural way to organize

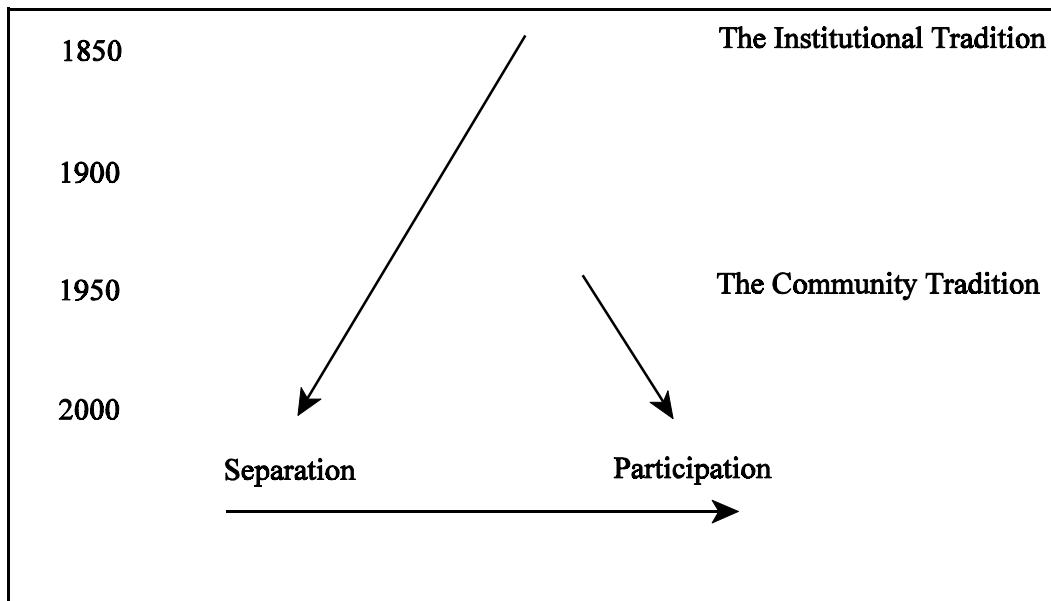


Figure 10:1. A schematic presentation of the two traditions of support.

support at the time when it evolved. It was a response to the conditions of the time, characterized mainly by the initial stages of the welfare society which was emerging at the end of the second world war.

At the beginning of this third 50-year period one finds, therefore, two traditions of support, representing two courses of development. To start with, the institutional tradition dominated, whereas the community tradition was still only a vision of welfare for persons with a disability. However, later on during this period the community tradition replaced the institutional one. The 1985 Act formalized its acceptance, as a life in community for all persons with an intellectual disability then became a legal right.

The traditions in figure 10:1 describe a development over time, with different courses of direction, indicating their different objectives. The institutional tradition is expressed in the referral to special units and thereby a separation from ordinary community life. The community tradition, on the other hand, aims at participation in the ordinary community, the welfare services intended for the general public being the means by which this is achieved. The community tradition therefore introduced a new objective regarding the delivery of support to persons with a disability. The shift between traditions implied that participation, instead of a separation, in community life, was to be achieved.

*A comparison between the two traditions of support*

The socio-political idea of community based support to persons with a disability is taken as the point of departure for a comparison between the two traditions. The normalization principle of 1946 (chapter 3) was characterized by three components. On an individual level this tradition aims at furthering the participation of persons in community life. On an organizational level this is expressed by the generic services taking responsibility for these persons and at a cultural level this tradition clarifies that persons with a disability are given the role of citizens. This adheres to a perspective which emphasizes the person's democratic right to gain access to life and welfare services offered by the

ordinary community, the life which is available to other citizens.

The wording of the title of the 1954 Act (SFS 1954:483) points to what one then saw as essential, namely education and care of persons considered mentally subnormal. On a cultural level they were seen as subnormal, the focus being placed on their disability and deficiencies, thus characterizing them as persons lacking in competence. Measures to increase their level of competence, special education and special care, were therefore both natural and self-evident. In this way one also ascribed the role to these persons. Those who receive education, the pupils, are those with a limited disability and seen as “educable”, whereas those with a more extensive disability, the patients, are those seen as “uneducable” and provided with care. The common factor in the roles of pupil and patient is the focus on the lack of competence. Therefore a competence perspective can be said to be part of the institutional tradition.

In characterizing this tradition a startingpoint is taken in the description of Carlslund (chapter 1) and in the Act of 1954 (chapter 2). These two sources together provide a view of the institutional tradition in the early 1950:s. The residential home is a good example both in physical structure and with regard to the type of activities pursued there (chapter 1). On an individual level the institutional tradition is characterized by the fact that ordinary services and environments used by the general public are not available for persons with a disability. Instead, they are taken care of and admitted, under coercion if necessary, to residential institutions specially designed for them. Separation and institutional life is therefore a characteristic of the institutional tradition. In the institution the person will gain access to the special measures which will increase his competence. When this has been achieved to the extent that he can meet the demands that society outside the institution puts on him, he can be discharged.

Table 10:1 summarizes the comparison between the two traditions. When one sees the change which is taking place as a shift between traditions, one finds that this occurs at three levels. At an individual level there is a move away from the separation of persons through the institutional life in special environments, in the direction of an increased participation and a more normal life, in the ordinary community. At an organizational level one finds a development away from specially designed institutions and a move towards the services used by the general public. On the cultural level one can see a shift in perspective in that a competence perspective is being replaced by a citizen perspective.

Finding an expression for the perspectives of these two traditions is of course a matter of choice. The terminology here has its basis in the work by Wolfensberger (1969) who related the role attributed to persons with a disability to the type of organization used to deliver support. The expression “citizen perspective” of the community tradition was chosen as the role of citizen was explicit in the normalization principle of 1946 (chapter 3). As there were two roles, the pupil and the patient, found to be associated with the institutional tradition the choice of an expression for a perspective was not that direct. Therefore a common characteristic was needed. As both roles focus the deficiencies and lack of competence of persons with an intellectual disability, “competence perspective” was chosen as an expression. This does of course not mean that the issue of competence is seen as uninteresting in a citizen perspective. While the lack of competence is seen as a group characteristic in the institutional tradition, the lack of competence is an individual matter in the community tradition. Development of the competence of a person with an intellectual disability must be based on an individual choice, the result of a process where the person and his

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Table 10:1. A comparison between the two traditions of support.

LEVEL	INSTITUTIONAL TRADITION	COMMUNITY TRADITION
Cultural	Competence perspective	Citizen perspective
Organizational	Special institutions	Generic services
Individual	Separation	Participation

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representative is a part.

### Analysis of transition

The transition of services presented in previous chapters is discussed here in terms of the two traditions of support. In figure 10:2 the issue of whether persons are separated from or participate in community life is related to the two perspectives. In this way one finds four alternative ways of providing support.

In alternative A the competence perspective and an aspiration towards separation of persons from community life results in the traditional institution. Alternative B, with a citizen perspective and the participation of persons in community life, represents the utilization of the welfare services used by the general public. This figure also shows a third alternative C, which contains the competence perspective and the participation of persons in community life. The organization which provides this type of support consists of the small units, specially designed for persons with an intellectual disability, which are located to places in the community where others lead their lives. Good examples of these community based services for housing and daily activities are presented in chapter 4. Alternative D is more difficult to exemplify with experiences from Sweden. This is an alternative which includes a citizen perspective and a life which implies a separation from the ordinary community. Characteristic for this separation is, however, that it has taken place as a consequence of the person's own request. A possible example could be the choice to live within a religious community which carries on its life alongside the ordinary community.

When the model presented in figure 10:2 is used to analyze the closure of Carlslund residential home, an issue which arises is whether its closure led to a shift between the two traditions of support. If that is the case the criteria for alternative B should be fulfilled. Regarding the organizational level one finds that the welfare services for the general public are not those availed of by the greater part of the group, as special housing and daily activities were created for them. They are, however, located to places where ordinary housing and other activities take place in community. When one considers the individual level an increased degree of participation in community life has been achieved but, as can be seen from the summing up presented in chapter 9, it has many limitations. Instead one sees that special services have created special lives.

Another issue remains, namely whether at the cultural level, work was carried out

	Competence Perspective	Citizen Perspective
Separation	<b>A</b>	<b>D</b>
Participation	<b>C</b>	<b>B</b>

Figure 10:2. The two traditions of support when the individual and the cultural levels are related to each other. Alternatives A-D show four possible ways of organizing support to persons with a disability.

according to the citizen perspective, thereby giving the person influence and control over his everyday life. As has been shown a certain degree of influence was possible when relatives participated in the planning of the new services. Some persons also had an influence over their everyday life. Judicially, however, there has not been any endorsement that the person and his representative had gained any control over the services which the person had acquired. The areas “quality of life” in the analysis of community participation (chapter 9), showed for example that persons had gained a limited degree of influence over their lives.

What has taken place during this transition of services is a development away from alternative A towards alternative C. On an individual level, increased community participation had taken place for this group, even if it was limited. This has been achieved because most of the support and services provided by an organization are comprised of specially designed units for housing and daily activities. The absence of a citizen perspective indicates however that work was carried out within the framework of a competence perspective.

When using this concept of two traditions of support to summarize the transition one can see the change as a modification of the institutional tradition. A considerable step has been taken away from the residential institution which dominated that tradition. One has not, however, captured the citizen perspective which has been seen as a key aspect of the community tradition. Figure 10:1 was used initially to present the idea of the two traditions of support. Figure 10:3 is based on this, but is supplemented by the conclusions from this analysis. This shows a modification of the institutional tradition in a direction towards an increase of participation in community life.

It is natural that this analysis also leads to conclusions regarding a further development. The closure of Carlslund residential home and the development of its alternatives does not mean that the process of change has ceased. Instead, a new platform has been created, the community based forms of housing and daily activities (alternative C in figure 10:2). From this further work can be carried out towards the development of the community tradition (alternative B in figure 10:2). As shown in

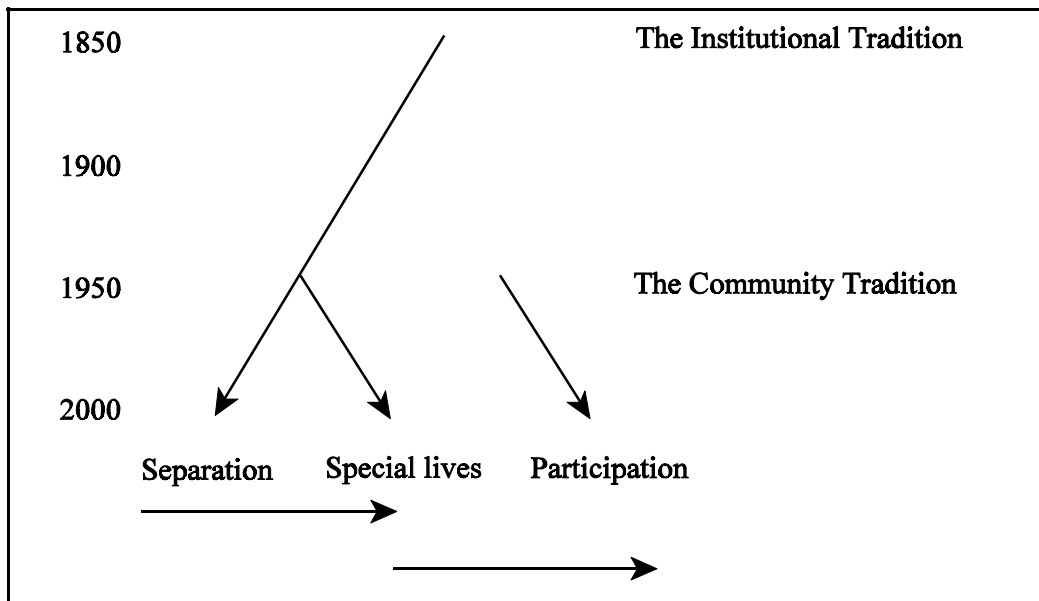


Figure 10:3. The two traditions of support, with a modified institutional tradition.

table 10:1, it was understood that this shift between traditions was comprised of a change on three levels. Further development should, therefore, consist of a greater participation in community life and a further development of ways of providing support and services through the ordinary welfare services. A change from a competence perspective to a citizen perspective is also part of this transition to a community based tradition.

At the same time as this is said, one can also raise the question of whether it is possible to achieve a shift between the two traditions while one is working within a residential institution. To what extent can persons be prepared for participation in community life with the institution as a platform? Can people running the institution really be involved in the development of local welfare services? Is it possible to conquer a citizen perspective from within a residential institution? In real life, with the conditions provided at the institution, perhaps it is not possible to take the full step towards a community tradition. What can be achieved under these circumstances is maybe what was achieved here, namely a modification of the institutional tradition.

In such an open process as the one illustrated here, dealing with such a critical change as that which has been presented, the use of a theoretical model has been of great help. In this case however the early concept of “two worlds of services” grew out of studies from the early 1970:s when institutional closure was not on the agenda (Ericsson 1981a). The concept was then seen as a reaction against a one-dimensional view of institutional and non-institutional services, seeing them as complementary and belonging to the same group of services. The formulation of the expression “two worlds of services” was motivated by an opinion which instead pointed to differences in structures and objectives of these types of services. During the course of the project, the concept “two traditions of support” expresses how the frame of reference was extended yet again.

With the original frame of reference, “two worlds of services”, it is natural to understand this transition as a process of change between two types of services, all taking place within one service organization. Objectives, methods of delivering support and factors influencing this process are mainly identified within the same service

organization. With this frame of reference normalization becomes a matter of making special services more normal and ongoing transition is seen as dependent on the various Acts of Parliament which provide the rules for the delivery of support.

With the “two traditions of support” this transition also includes factors found in society, outside the specific service organization. A clear example is that the origin for the key concept of normalization was found to be a general socio-political idea, part of the vision for a welfare society (chapter 3). When discussing factors influencing this transition towards community based forms of support for persons with an intellectual disability, the changing character of education and social services in society, as well as ideas regarding standards of housing and the policy for full employment were seen as decisive (chapter 2). The community tradition then not only becomes a phenomena in disability services but part of the restructuring of the welfare society, where concepts such as deinstitutionalization, decentralization and an increase in influence for the recipients of support, are common in several welfare sectors.

### Transition and its context

The change from institutionally to community based services which takes place when closing a residential institution is an extensive and complex process. It has therefore not been seen as realistic to cover all aspects of this issue in the work accounted for here. The analysis has instead focussed on the three research questions presented initially. At the same time it is important to provide insight into this process in order to shed some light over the results of the studies, primarily as expressed by participation in the community life of the persons. Sources for this analysis can be found in previous chapters, although everything concerning this change is not documented there. In this connection the information used is also based on personal experiences.

### *The task of closing a residential institution*

During the 1950:s and 1960:s Carlslund residential home was hailed as an important contribution to the reformation of services for persons with an intellectual disability, especially for those with an extensive need for support. An example of the innovation introduced was the system of pavilions which created wards with small groups. Another was the normalization of living conditions, a consequence of a residential home which strove to be a miniature community. But there were also problems. In spite of the modernization which began during the 1950:s parts of the old institution, with roots in the beginning of the 20<sup>th</sup> century, were not discarded. Ideas questioning the right to a good life for persons with extensive needs for support, were included in the plans for modernization, thereby retaining old ideas within the new residential home (chapter 1).

As a consequence critical views were expressed by both staff and families. The ongoing renovation and restructuring of the residential home did not however stop the critique. During a period of reform of services to persons with an intellectual disability in Stockholm County this critique was accepted by the politicians responsible and eventually led to the decision to close the residential home.

During the planning of the closure it was necessary to analyse and clarify the meaning of the expression “institutional closure”. This led to the understanding that the

key to the realization of the task was to be found in the fact that each person, then living at the residential home, would have to establish a new life outside the institution. The creation of community based services, providing non-institutional support, became an important issue and the further development of the Stockholm model for community based services the major task during this planning period.

From this perspective on institutional closure, the task of identifying the needs for support for each person became predominant. Together with families and staff it was possible to discuss what type of support should be provided and which requirements were seen as necessary in order to enable the person to leave and to set up a new life in a local community. The major limitation was, however, the fact that this information was based on knowledge of the person while he was still living at the residential institution. Consequently it was not possible to take into account how the person would react to the new services, which had not yet been developed.

The results from this assessment of needs for non-institutional support was used as a basis for a programme of establishing support through community based housing and day activity centres. For financial and construction purposes the period 1980-1988 was required to develop the new services and to close the residential home. Once this period was identified it was possible to arrange activities which helped prepare the persons for moving. Programmes for staff, to prepare them for working in community based services, or to assist them to change jobs, could also be carried out.

### *Setting up of new lives*

When looking at this transition as a matter of organizational change, one sees the period as one during which the residential institution gradually is closed. But when looking at it from the perspective of an individual, the change does not become a reality until the person has actually moved to a better life than that offered at the institution. For any person, the choice of a new home and of new daily activities, is a great challenge with extensive personal consequences. This is naturally also the case for the person with an intellectual disability. An additional task regarding these persons is to guarantee that the new environments are adjusted to the needs represented by their disability. An equally important task concerning persons moving to a group-home is the choice of other persons in the group with whom one is to live and these choices must of course be made with assistance from others.

The group-home and the day activity centre together make up the platform for developing the new life. When striving for community participation these have to be given a personal content leading up to a home and to a week of purposeful daily activities. Participation in community life, with conditions over which the person has his say, is also part of setting up the new life. In this lies some of the tasks for staff who work in community based services and in order for it to become a reality working methods need to be developed. It is necessary to work with personal relationships in small groups, in close contact with local community and under conditions characterized by respect for personal integrity.

The studies of personal consequences illustrate that it is possible to set up new lives outside the residential home. When the views expressed by persons, their families and staff were presented one found no resentment concerning the dissolution of the institutionally based services, essentially because adequate community based services

had been established as alternatives. However, one also pointed to the need for development of the community based services which had been provided. It was shown by some of the studies that the delivery of disability services is a complex process, participation in community seemingly being a major problem.

### *The context of transition*

In this process of transition factors could be found which not only supported development but also those which signified a resistance to change. As a consequence of these ambiguous attitudes the scope for development was not fully utilized. With a stronger support for the ongoing transition it would have been possible to widen the range and content of the conditions for participation in community life.

The type and extent of community based services which came to replace the residential institution were not decided on when the formal decision was taken regarding the closure of Carlslund residential home. The development of these was instead the main task for the planning group. This involved all parties concerned, those being mainly the persons themselves and their families, the staff at the institution as well as the administrators and politicians.

Apart from alternative services being developed on the basis of the existing Stockholm model for community based services, there was an open attitude towards finding new solutions. This created a process of development to which the different parties could contribute. A minor group used this openness to argue for better services, for example increasing economic resources for the process of transition. Others reacted with frustration towards this open process, allowing the lack of clarity about the expected result to contribute to a passive attitude towards the entire process of change.

The families of the persons at the residential home naturally argued for a good life for their family member. Some thought this could be brought about by endorsing the closure of the institution, thereby gaining access to better services. Others, who were apprehensive with regard to the idea of the community based services, chose instead to resist the closure of the institution.

Neither were all those employed by the county organization responsible for the closure of the residential home enthusiastic about this task. With three large and several smaller residential homes within the county, a strong institutional tradition had been developed. Many staff therefore expressed hesitancy regarding the prospect of closing a residential home, enabling all persons, irrespective of extent of need for support, to move.

As Carlslund residential home was the first institution for adults in Sweden to be dissolved there was also considerable national interest. There were those who welcomed the course that had been chosen. There were also groups and organizations who were critical towards the decision, considering it would have consequences for national development. Those expressing such criticism found support in the fact that the existing legislation, during the major part of the period of change, still sanctioned that the residential home for adults be provided as a form of service.

A long period of transition, in this case 1980-1988, may provide positive possibilities for preparation, but there are also risks associated. Over so many years changes will have taken place in the organization. Political elections change the composition of the County Parliament which has the final responsibility for the process

of change. The political process, when economic resources are allocated annually, requires considerable political insight in order that it be understood. Changes also take place in the administration of the service organization, those being brought about by reorganization, persons changing jobs and new staff being appointed. It was also during these years that the Act of 1985 was introduced, providing new rules for the delivery of disability services. During such a long period of transition one finds that ambitions and competence can change.

One factor which facilitated this transition was the fact that the service organization in Stockholm County was responsible for both the closure of the residential home, as well as the setting up of the new services. This meant that coordination between these two tasks was handled by the same organization, an advantage when realizing such a change. But there were also drawbacks, primarily because of the long institutional tradition in the county. In spite of social issues like housing, community life and social services being the tasks of the municipality, the social dimension in community based services and in the lives of persons concerned, was dealt with by the regional organization, without the participation of the local municipalities. The legislation during this period of transition did not however, require that the municipalities took responsibility for support to persons with an intellectual disability. The first time this was mentioned was in the 1985 Act and in the 1993 Act this became mandatory.

A possible development

#### *New conditions for disability support*

When discussing community based services in chapter 4, it was concluded that support to persons with an intellectual disability has a cultural dimension. What is seen as natural during one period in a society can disappear during another when conditions are different. During these last 50 years two generations of community based forms of support can be seen. The first step towards offering persons a life outside the residential institution came with the Acts of 1954 and 1967. Persons with a limited need for support were seen as being able to benefit from the normal life whereas those with a more extensive need for support were regarded as being in need of the institutional life. The expression “partially able-bodied” of the 1940:s communicates this attitude (chapter 3). This created the first generation of community based services. In apartments and day activity centres small staff-groups provided support to these persons with a limited need for support.

Over 40 years later, through the Acts of 1985 and 1993, all persons, irrespective of degree of disability, gained the right to a life outside the institution. In order to realize their participation in community life, extensive support must be available day and night, throughout the week. The work which has been presented here illustrates the development of this second generation of community based services.

As new conditions have been created and the residential institution no longer being recognized as a service, it can be expected that new forms of community based services, a third generation, will evolve after year 2000. The persons who during the coming years will be requiring support and services belong to a different group than those who left the residential institutions. Those who now will be in need of support are

persons who have grown up in their family. They are familiar with the character of a normal everyday life, know what a house and home is like and have experiences of working life as seen through their family members. These are the experiences which will form the basis for their future requests regarding support for the good life they wish to live.

Current legislation, the 1993 Act, also specifies a number of conditions for new disability services. A basis for these is the citizen perspective. This means, amongst other things, that persons with a disability have the right to avail of the ordinary facilities of society, for example child care, education, housing and employment, as well as services for health and social welfare.

As disability support no longer is compulsory it is required that a dialogue takes place between the person concerned, with support of his ombudsman and the representative for the organization which delivers the services. As this dialogue takes place between two parties, the person and the organization, it is necessary that it results in an agreement concerning the meaning of adequate support. The ultimate expression for this citizen perspective can be found in the right of both parties to have the support being offered tried in a judicial court.

A new condition is also found in that the previous regional organization of services providing for large groups, has been discarded. When support is organized in small groups, in the community where the person and his family have their roots, more personal relationships can be formed and individualized support can be provided. Through closer contact with the family of the person concerned and with the accessibility of local welfare services, the contributions of the family can also be seen as more natural.

To-day one can also find examples of new disability services which are a result of these new conditions (Ericsson, K. & Ericsson, P. 1999). Personal assistance, introduced in the 1993 Act is one such type of support (Ericsson, P. & Ericsson, K. 1995). In this way a person can receive the support he requires from a group of assistants. As these are personal, their task is to see that the person can experience a good life. He can choose them himself, together with his ombudsman and with such support be in charge of those who provide his assistance. As assistants are appointed for a person, not attached to any special house, he can choose whichever housing he finds most suitable from what is available in the community in which he wishes to live. In this way personal assistance illustrates that support is related to what is given by people, not what is provided in a building. This contrasts with the group-home, which is a specially designed house for persons with an intellectual disability, with special staff attached, whose task is to provide support to those who are placed there.

Support provided through daily activities was previously made available at specially designed and equipped day activity centres, to which the person was referred in order to participate in the activities being carried out there. The new conditions provide possibilities for a new model for the running of daily activities. The person's own requests for an adult life, a career into working life and participation in the local community, necessitates that the service organization is able to offer activities in places where the general public work or spend their time during the day. The transfer of responsibility for daily activities to the municipalities has increased the possibility of finding local resources, as these authorities have better opportunities to open up new places and environments, persons and activities, in their own local community (Ericsson 1991b, 1998).

The question of how a good life can be guaranteed within the community tradition also arises. In the institutional tradition this guarantee depended on whether the services offered fulfilled national requirements regarding buildings and their standard and whether recommended procedures for admittance and rules for placement were followed. In a disability service which emanates from local and democratic conditions, new ways to guarantee that the person experiences a good life need to be found. Methods for this can lie in clarifying whether the person himself personally perceives that he experiences a life with quality (Ericsson 2001a).

### *The normalization principle of 1946*

The work of the project “Two worlds of services” led to the document where the principle of normalization of 1946 was presented. Its logic, that it was a democratic right for persons with a disability to avail of the services of the welfare society and to experience more normal conditions of life, widened the frame of reference. This has led to the conclusion that there is still a need for further development if the ambition of a person’s participation in community life is to become a reality. This principle of normalization has not therefore lost its actuality. When introduced it acted as a vision of a new life for persons with a disability. Today, expressing a vision of participation in community life even for those who were considered by the 1946 committee as “unfit-for-work”, it still has the same function.

It is, however, doubtful whether the future would gain from reference to a 50-year old principle. This socio-political idea was compared to that used in the global strategy presented by UN under the concept of equalization of opportunities (chapter 2). For the persons who left Carlslund residential home a continued development of support, based on this more international expression, would not only contribute to local solutions but also to global advances.

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