INFLUENCING ONE´S EVERYDAY LIFE: DEVELOPMENT OF INTELLECTUAL DISABILITY SERVICES IN A SWEDISH MUNICIPALITY

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FOREWORD

EU-Project STEPS has consisted of representatives from disability services in five european towns, Barcelona, Hamburg, Lidingö, London and Rotterdam. It has been coordinated by a group from Hamburg. The work was carried out as national STEPS projects, dealing with local issues relevant for the major aim of STEPS. The project period has been two years, ending in 2004.

During these years STEPS/Lidingö has been the national Swedish project. The aim of this has been to develope disability services to increase the influence of persons over their everyday life. A group of persons with disability has therefore been the core of the project. Each has had a representative during the project, a family member or a formal representative. As the services in housing and daily activities of persons were involved, staff from these together with some administrating them, have also been part of the project group concerned with STEPS/Lidingö.

The project has been coordinated from Department of Education at Uppsala University by project director Kent Ericsson. Two representatives from the town of Lidingö, Kerstin Lundberg, responsible for disability services and Adriana Buzea, responsible for economy of these services, have made up the management group. Patricia Ericsson of Skinfaxe Institute has been the consultant to the project as regards the working method being used. STEPS/Lidingö is presented in more detail on the web-site www.skinfaxe.se

There has been a high degree of committment to the project by persons, their families and representatives, and by staff. This has contributed to a most interesting and promising result. In the final meeting when the results were presented to the project group, persons expressed regrets hoping that their influence over everyday life would not end. Promises were given though that the work of the project would continue! We would like to thank all members of the project group who have been part of making up this project. We would also like to thank for funds being made available for STEPS/Lidingö from the anti-discrimination program of EU, together with additional funds from Skinfaxe Institute, Uppsala and the Town of Lidingö.

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INTRODUCTION

In this report the work of Project STEPS/Lidingö is presented. As will be seen three types of tasks, all connected to each other, have been part of the project. These will be presented in the report though as three separate parts.

In part 1, the Swedish disability reform is presented. There an analysis is made of changes which have taken place, resulting in the dissolution of a regional special service, to the development of disability services in municipalities, using the general welfare services of the public. As the responsibility of municipalities is a fairly recent event, some discussion is given to the possibilities of these services to meet the needs of persons. A discussion is also given to the possibilities for community based services to realize the idea of a more normal life for persons. The Swedish disability reform is here seen as a shift between two traditions of support, indicating fundamental changes of disability services. The consequences for the issue of quality is being discussed. Together this part 1 sets the model for present day disability services.

In part 2, disability services in the Town of Lidingö are being presented. As part 1 presents a model for disability services, part 2 should be seen as an illustration of how this model has been implemented in a municipality. The main facets of the present disability act is described to start with. A presentation is then given of how disability services are being administered. To further illustrate these disability services some models of housing and daily activiteis are given together with comments on their use by persons.

Part 3 presents the empirical work carried out by STEPS/Lidingö. Recognizing the development of a community based tradition of disability services, the need for persons to have an influence over one´s everyday life is seen as a critical part of disability services. This idea is taken as the starting point for developing a way of running disability services. A new method is introduced, seasonal conversations, involving persons, their representatives and staff. Experiences from these conversations during a working year shows that the possibilities given to persons to influence one´s everyday life, is most important.

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THE SWEDISH DISABILITY REFORM

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

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

In the 40:s this principle characterized an idea, a vision, for new services and for a better life for persons with a disability, a view of life promoted by the disability movement of the time. Reality was, of course, another thing. During the second half of the 19th century residential institutions had been established and an institutionally based service was still dominant during the first decades of the 20th century. In the 40:s an institutional life, characterized by deficiencies and poor living conditions, was the only alternative offered to persons with intellectual disability. The realities of an institutional tradition, and reactions towards it, as expressed in a new socio-political idea represents therefore the commencement of the Swedish disability reform which has continued for more than 50 years.

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

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

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

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

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

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

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

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

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on a cultural level. A citizen perspective needs to be formulated and developed at the same time as a deficiency oriented perspective, focussing on the person´s lack of competence, needs to be discarded!

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COMMUNITY BASED SERVICES AND
THEIR CONTRIBUTION TO A NORMAL LIFE

Kent Ericsson

A new socio-political idea

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

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

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

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

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

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

Everyday life through housing, daily activities and community participation

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

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

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

In a study of persons with intellectual disability a structure was given to everyday life (Ericsson 1993). Four areas emerged as important when this life was to be described. The two main ones are the person´s housing and home (A) and his daily activities (B). In addition, the person´s contacts with community life is seen as important. As this can emanate from the home as well as from the place for daily activities, two aspects can be described, participation in the life of local community through the home (C) and through daily activities (D). These four areas can be said to describe a person´s daily life with regard to how he, in time and space, participates in and avails of settings, environments and activities during the day.

Eleven dimensions were chosen to characterize everyday life. "Activities in the home" (1) related to the activities of everyday life of the person in his home. This one was part of area (A), housing and a home. Participation in community life through the home (C) was covered by five dimensions. "The person and the neighbourhood" (2) illustrated his contacts with neighbours. "Recreation outside the home" (3) characterized the leisure activities in which the person participated. "Commercial services" (4) gave attention to the extent of the person´s participation in shopping, for example for food and clothes. "Social contacts" (5) pointed to relations with persons outside the home, e.g. relatives,

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representatives or others who play a vital role in the person´s life. "Services for personal well-being" (6) paid attention to whether the person benefited from services which contribute to his health and social well-being.

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

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

Services to realize a more normal life

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

This has led to the creation of two forms of community based services for adults, housing with support and daily activities with support. These are two services, contributing in different ways so as to realize the two basic functions of the everyday life. As these are two forms of services, there are two different staff-groups who deliver support needed. Housing with support has the task of contributing to a home of the person and to his participation in community life. If the person has got an employment in the open or the sheltered labour market, then this takes place outside disability services. But if the person hasn´t got a job because of his disability, he is in need of support during daytime. Daily activities with support has the task of contributing to a good life during the five days of the week by offering a set of purposeful daily activities.

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

Housing with support

Today when this service has been in use for several decades, and persons with all forms of disability live where others live, one will find a broad variation of housing with support. It is therefore not possible to describe this service in a simple way. One will find though that housing with support can be described in a number of dimensions (Ericsson 1996).

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

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The persons in the house will make up its character. Their needs for support is one aspect as some will have a mild, others a more severe disability. Another aspect is the number of persons living in the house as there might be a single person or a group living there. If a public service has set up the house, today the group mustn´t be larger than 5 persons.

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

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

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

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

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

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

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

Daily activities with support

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

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

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

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

For the local community it is more logic to organize this service as a number of activity groups (Ericsson 1991). This will enhance an ambition to participate in community life. An organization for daily activities will then consist of several groups, the number depending on how many persons have got the right to avail of this service. These activity groups will be localized to different places, dealing with different activities and with a variation of staff support, as the persons making up these groups have different needs. This will be illustrated later on as this is the way which Lidingö has organized this service.

The roles of housing and daily activities

This way of organizing community based services for adults has the consequence that there are two services which deliver support to a person (Ericsson 1997). The transparency between these two services is an alternative to the closed nature of the residential institution. As there are two staff-groups in this system of services, one delivering support through housing and the other through daily activities, the person´s needs and requests are debated on a daily basis. This should then lead to an ambition to further the life of the person.

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

Services for personal development

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

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

The process leading up to services

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

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

A factor which is brought forward in this tradition is the issue of influence and control over one´s life, from the person with a disability together with his representative, in the process leading up to his services. When one sees that it is a natural thing for any person to have some control over one´s life, he is invited to be part in the development of

his services. This is not only a correct thing to do but it also contributes positively to the services being established as their degree of personal character, and thereby their quality, is increased.

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

There is naturally an economic factor in this process of setting up community based services. At the same time this is said it must be pointed out that this is nothing special with these services. There is always an economic issue present when giving support to persons who do not themselves earn their living. It can even be argued that community based services are less demanding economically as the normal life which is being organized is using the normal structures of society. When institutionally based services have the ambition to contribute to the normal life of persons they have to create them artificially. The quality of services is however higher in community based services as the normal life and a higher degree of personal services is present and this has economic consequences. But this does not only concern community based services as a similar degree of quality in institutionally based services would also be economically demanding.

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

Conclusions

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

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

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

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

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

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

CONDITIONS FOR DISABILITY SERVICES
IN A MUNICIPALITY

Kent Ericsson

The Swedish disability reform has consisted of two major changes, the closure of residential institutions and the shift of responsibility from county to municipality. The first one has previously been covered extensively (Ericsson 2002). Because of the special county organization which was to meet all needs of the person with intellectual disability, local welfare services has been free from a responsibility for this group. Suddenly, at least this was how many saw this transition, they were to take a welfare responsibility for them. In many places there were, and still are, questions concerning the reasons for this transition as one does not see its logic. There is therefore a need to look into this part of the Swedish disability reform.

The shift of responsibility from county to municipality

From the middle of the 19th century until the second half of the 1990:s a special county organization had the responsibility of society to run services for persons with intellectual disability. As was seen the normalization principle of 1946 argued for the right of persons with a disability, at least those with a mild one, to use the welfare services which were to be set up for the public. At that time this was an idea, a vision for a possible development of society. The Social Act of 1980 can be seen as realizing this idea as it contains the legislation which points to the municipality as responsible for welfare for all citizens, also those with a disability residing there. This became the legislative basis for dissolving the county organization.

During the past five decades a new perspective was gradually brought into these services, seeing persons as citizens with a right to the normal life of others. Housing, daily activities and participation in community life for a person became the new goal to strive for. In the end there was also a realization in the special county organization that the right conditions for these new goals to be realized did not rest with them but with the municipality. This is the organization which has close contact with housing issues and with local business where there are places for work and day services. The municipality is also the body which has the task of facilitating recreation and leisure for the public.

The transition from county to municipality took place by handing over the community based services established by the county, to the municipality where a service was localized. This meant that local welfare services suddenly became in charge of a number of group-homes and day activity centres. There was also a change of taxation as the county tax was reduced and municipality tax was increased to finance these new services. The special county organization was dissolved at the same time as local welfare services got this new responsibility.

Legislation

General and special acts

The Social Act of 1980 (SFS 1980:620) gave the foundation to the two disability acts which followed in 1985 and in 1993. Today there is a debate about whether there is a need for a special disability act. Would it not be enough with the general act of 1980? One argument brought forward which support the special act is that the needs of those with a severe disability must be given special protection now when institutions no longer exist.

In these acts the relationship between the person with a disability and the organization offering services is clarified. He is to apply for support and this is to be offered to him. If there is agreement between these two parties the process to realize what has been offered will continue. If there is disagreement about the decision of support, they can go to an administrative court to test this decision. One significance of this is that the citizenship of persons with intellectual disability thereby is publicly recognized. A consequence of this is that the person will need a representative to request support need and to test the decision if he chooses to go to court.

This gives the logic to present legislation. The social services offered by the special act of 1993 should be seen as additional services to what is regulated in the acts, regulating welfare services for the public. The social act, the health act and the school act are just some examples of acts which had to be rewritten so as to clarify their responsibility for persons with intellectual disability, in the same way as for other members of society. What we can see here is the realization of the original idea of 1946, expressing a vision of how welfare services for the public are to be used for persons with a disability.

One must keep in mind that this comment concerns legislation, the formal rules for how society is to relate to persons with intellectual disability. For the person the important issue is of course how this has been interpreted and implemented in his municipality so as to offer him his support. The task facing municipalities today is to develop the new services and the new methods needed to make the ideas of current legislation a reality.

Some aspects of the Act of 1993

This act (SFS 1993:387) is applicable to three groups of persons with a disability. This is expressed in its first paragraph:

> This act contains provisions relating to measures for special support and services for those 1) who are mentally retarded, are autistic or have a condition resembling autism, 2) who have a considerable and permanent intellectual impairment after brain damage when an adult, the impairment being caused by external force or a physical illness, or 3) who have some other lasting physical or mental impairment which are manifestly not due to normal aging, if these impairments are major ones and cause considerable difficulties in daily life and, consequently, an extensive need for support and service.

As can be seen the support available through the Act of 1993 is open to persons with several types of disabilities, mental retardation being just one. If we talk about intellectual disability we see that persons with mental retardation, the type that has its roots during the developmental years, are eligible. But so are also those with an intellectual disability which has developed during adult life. Autism, too often misunderstood as mental retardation, has been pointed out in this act as a separate disability.

While identification of group 1 and 2 is based on diagnostic criteria in the classical sense, group 3 represents another way of identifying those who are eligible. Here the need for an extensive and permanent support, irrespective of type of disability, becomes the basis for deciding whether a person is eligible. The importance of this paragraph in the Act of 1993 is that it illustrates a shift away from criteria based on diagnosis of a disability in favor of basing the decision of eligibility on the person's need for support.

It has been mentioned that the process leading to support for the person, takes place between two parties, thereby recognizing his role as a citizen. This is expressed in paragraph 6 in this way:

> The activities pursuant to this Act shall be conducted in co-operation with other public bodies and authorities. The activities concerned shall be based on respect for an individual's right to self-determination and privacy. As far as possible, it shall be ensured that the private individual concerned shall be allowed to influence the measures provided and to participate himself in what is decided. For the activities pursuant to this Act, there shall be the personnel needed to enable good support and good service and care to be given.

There are 10 special services offered by the Act of 1993:

> The measures for special support and special service are

> 1. advice and other personal support that requires special knowledge about problems and conditions governing the life of a person with major and permanent functional impairments,

> 2. help from a personal assistant or financial support for reasonable costs for such help to the extent that the need for financial support is not covered by assistance benefit pursuant to the Assistance Benefit Act (1993:389),

> 3. escort service,

> 4. help from a personal contact,

> 5. relief service in the home,

> 6. short stay away from the home,

> 7. short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays,

> 8. arrangements for living in a family home or in residential arrangements with special service for children and young people who need to live away from their parental home,

> 9. residential arrangements with special service for adults or some other specially adapted residential arrangements for adults,

> 10. daily activities for people of a working age who have no gainful employment nor are doing a training.

When someone asking for support, he must apply for one or several of these services. This must be a formal request. The decision about a service must be a formal one, leading to a document about the decision.

Knowledge about intellectual disability

During the period of disability reform in Sweden, especially during the last three decades, development of community based services has contributed to an increase in knowledge about intellectual disability. The conditions given by these new services, the small groups

and the personal relationships among other things, has been the basis for an extensive increase in knowledge about this disability. This concerns especially persons with a severe disability, those which once were handed over to the residential institutions. The essence of this new knowledge is to see people belonging to this group as individuals with exclusive needs and who communicate with others in a personal way. To see them as full citizens, together with their disability, is also part of this increase in knowledge.

This development has taken place during the period when the county had the responsibility for disability services. When the municipality takes over this service they have not been part of the process of increase in knowledge. This can of course be achieved, but not everyone want to take the opportunity to learn. The risk is that they therefore do not work on the basis of the new knowledge which was the basis for the transition from county to municipality responsibility.

Organizing services for persons with a disability is something which they can handle very well as they already have got this competence, gained from meeting the needs of other disability groups. But when running services it is also necessary to be informed about the characteristics of each person which one meets. The need for adequate knowledge about intellectual disability becomes necessary to be able to respond to a person´s request.

A new group in need of support

Family support

A major change during past years made it possible for children to grow up in their own family. If this was not acceptable, a foster family could be a substitute. To make this a reality support to the family had to be developed. This was introduced with the Act of 1967. Gradually family support has been developed and today only a limited number of children grow up outside a family home, in a group-home for children.

When the child grows up in the family, this can be experienced as a burden on the parents and then practical and psychological support is needed. Assistance can be given by a person coming into the family to deal with practical matters while the family gives its attention to the child. When parents want to give attention to themselves or to other members of the family, it can be desirable to have relief from others, an extra family or a group-home for short-term visits. Psychological support to the family can be given by counsellors as "the first information", in response to having a child with a disability.

Early intervention indicates that not only the family but also the child is in need of support. As an infant it will have the same need of attention and care as other infants, but because of its disability there may be a need for extra support to cope with the various stages of child development. Pre-school activities, in the local day nursery, contribute to the child´s play and social interaction with other children. Schools and education for the child is organized during the school-years. During these the child can also receive services for habilitation offered by the social, psychological and medical staff set up for this.

It also means that this person has knowledge about what a home can look like. As he has seen the jobs which parents, siblings and others work with, they also have knowledge about the employment which is usual for adults in this community. They also know the recreation and leisure which is available as they have experienced this together with their family.

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A new group

The public enquiry from 1946 started a major project in which persons with intellectual disability were to receive the welfare of society which was enjoyed by others. For more than 50 years this work has gradually been going on through the creation of community based services which has made it possible to channel support to persons through ordinary housing and places of work that exist in a community. This has meant that the major task during these years has been to let the group, which has lived at residential institutions, move to a life in the ordinary community. The task of setting up a life in community for those residing at the institution has therefore dominated the work of Swedish intellectual disability services. This was finished by the closure of residential institutions in 1999.

Today we find a totally new situation for intellectual disability services as there is a new group asking for support. They do no reside at an institution but already live in the community to which they belong. This group has got needs and requests which are of another character than those brought forward by the group from the institutions. The child who becomes an adult has grown up under conditions leading to good health. He has also experienced activities leading to his habilitation. He has knowledge about what adult life is like which he has learned from his family. The person therefore starts his adult life with dreams of a good life, based on his experiences during his upbringing.

The community tradition with its stress on citizenship recognizes that a person belongs to a family, a community and to society. The basis for this is the fact that Intellectual disability is a normal phenomena which is part of human mankind. As long as there are children being born in a community there will be a certain number of children with a disability. The task for a municipality is to recognize this fact and to relate one´s services so as to meet the needs of these citizens.

With present legislation he has got the right to request those services he find desirable to fulfil his dreams of a good life and he can challenge what he is offered in a court. This is the situation which the welfare services of the municipality is faced with and which will be some of the new conditions leading to development of disability services. Welfare services of the municipality, which has got a rather short period during which to establish routines and methods for delivery of support, are faced with a challenging task.

The social network

When the child grows up at home, his family gets the opportunity to learn about the needs of this family member and about the conditions which exist for a good life for a person with a disability. They will not only learn about the disability but also about rules and regulations which sets the framework within which forms of support can be made available. When mentioning the family one thinks of parents. But there can also be brothers and sisters who get an opportunity to contribute to the well-being of the person. This means that the family will be a potent partner in the process of developing services.

When one looks into the social life of the person one will find more people, who are or who can be concerned. There is of course a broader family, with aunts, uncles, cousins and grandparents. There are also the friends of the family who will know about the person and his disability.

Outside the family the child will over the years have created social relations to several persons. These are for example teachers from pre-school and school, they can be the taxi-driver who has taken the child to school over a number of years. There can also be neighbours or other concerned people who want to contribute to a better life.

All these make up the social network around the person, some being more active others less so. With the right working methods this network becomes a resource to assist the person to participate in and to a be a member of his community.

Local resources for housing and daily activities

After having seen residential institutions being developed as well as being dissolved one comes to the conclusion that disability services are a relative matter. They are formed in relation to societal conditions. They were logical and natural in the 19th century. But with a society with other ideals, like the democracy and human rights of the 1940:s, community based services becomes the logical way of delivering disability services.

The same type of argument can be put forward as regards services organized by the special disability organization of the county. This had not got the housing responsibility in society and they had not got the natural relationship to business and other day activities of a community so when they were to organize these functions for persons with intellectual disability, they had to build special houses, the group-home and the day activity centre. These services were the logical ones in that organizational environment.

The municipality has got other conditions when the needs for housing and daily activities are to be met. In society this has got the responsibility for housing of their inhabitants as they deal with town-planning and the allocation of housing-areas. They know what sort of housing is to be built and they can plan ahead. So when they will have to organize housing for persons with disability they have other means, the local housing-market, to meet their needs.

The same goes for daily activities. As the municipality has got close contact with local business and various forms of daily activities for the public, often run by the municipality itself, this can easily find possibilities for small groups to be included into local daily life. There is no need to build special centres.

The municipality has got local resources to meet the needs of persons who want to live the normal life of this community. When they are to organize community based services they do not need to build special group-homes or day activity centres. They are not to copy what was done by the county.

The economy of special services

Economy of disability services is of course an issue as financial resources must be gained to run them. This was the case with the county and it is with the municipality for the very simple reason that these are persons who do not earn their own living. With the Swedish welfare society services are financed by public money, collected by taxation and distributed by parliament, either the county or the municipality parliament.

The financing of the 1993 Act has raised considerable anxiety among Swedish municipalities. The most concrete form this has taken is that there is an exchange of funds between municipalities, based on a national enquiry. Some are receiving economic support from others. This is not a place for a full analysis of this economic issue. What can be said however is that there is a debate about this shift of funds. One argument is that there should be state funding for this group, on similar lines as personal assistance, which is partly financed by state funding. The argument against this suggestion says that persons with intellectual disability belong to their community and the needs of all its citizens should be financed there.

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In my contribution to this debate I have argued that one reason for what seems like a group with high economic demands is that the closure of residential institutions was carried out in an unskilled way. The correct thing would have been to let the persons who left the institutions move to the community where they originally came from. But this did not take place as too many were kept in the municipality where the institution had been located. The reason to retain them was to generate as many jobs as possible in this community. What was not considered fully was the consequence in the long run that the responsibility for the welfare of all citizens, as based on the Social Act of 1980, laid with the community where a person is staying,

One can also argue that too few municipalities use its local resources. When they copy the services of the county, building special large group-homes for example, support becomes unnecessarily expensive. The demand for special funds for this group can also be seen as a sign of lack of knowledge about the fact that there is a small group of persons with a very severe intellectual disability. They were not seen locally when as they were sent away to the care of the county. But when they appeared in the local community after the closure of the institutions, they became visible.

A more extensive economic analysis would show that the Swedish welfare reform has had economic advantages for society. This was shown already in 1946 as the argument for the reform was partly human, partly economic. The economic motive was also present when institutions were closed and when municipalities got the full responsibility for its citizens. The costs of the present way of organizing welfare services for this group must be compared with an alternative leading to renovation and rebuilding of residential institutions during these last two decades. If this alternative had been carried out the low quality and living standard offered by institutions, understandable as they had been designed during the 1950:s, would not have been possible to retain. Instead a quality of services would have had to be related to what was offered in community based services at the time, that is a small apartment, full day services and participation in community life. If this had been build as special institutions, this service would not have been possible to fund for society.

A concluding comment

This analysis has focussed the recent handing over to the municipality of responsibility for services to persons with intellectual disability. It is found that this change is part of the Swedish disability reform. As this has been defined as a shift between two traditions of support, an institutional one is being dissolved while a community tradition is being developed, the framework is given for the intellectual disability services offered by the municipality.

A key factor in this framework is the idea that the general welfare services must be available to people with a disability for them to have the possibility to live the normal life lived by others. The simple reason is that they are members of and belong to society. The consequence of this is that the municipality should not organize and offer the special services of the county. Instead they should develop their welfare services to promote the realization of a community tradition. This demands a further development of municipality services.

A factor which underlines the need for development of services is the fact that there is a new group asking for support after the closure of residential institutions. These are the persons who have grown up in their own family, people who have seen and experienced the life lived in this community, by family and friends. They have also got the benefit of the new services in education and in habilitation which have been organized during the last decades, resulting in a high degree of well-being and health.

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This new group points to the need for more personal services in the municipality and this is supported by other factors. The social network of the person has had ample time to be established during the years when the person has grown up. The wider family, the friends of the family and significant others will know this person and argue for his well-being when there is need for this. As the municipality will give services to a small group, persons whom they have known since birth, they are not anonymous. Over the years their needs and requests have become well known to them. The act of 1993 which has introduced an increase in equality in the relationship between the person and the disability service will also contribute to a higher degree of personal services.

The basic idea expressed through the community tradition was that support to people with a disability should be channelled through the generic services of society, those which have been organized to meet the needs of the public. This means that what is being offered to the public is also to be offered to persons with a disability. The consequence of this is that disability services have got a local character. Services are formed with local resources, according to local customs. There is no longer any place for centralized service models.

There is also a need for a local character of disability services if requests for a good life of persons are to be met. The person and his representative will ask for what they see as the normal life in this community and to meet these requests services must be able to channel support through local housing, ongoing daily activities and community life.

This analysis points to the possibilities of the municipality to deliver disability services which has got a personal and a local character. To see these possibilities however one must work out of a perspective which recognizes the person with intellectual disability as a citizen and a member of a community. The development of this citizen perspective is a challenging task which needs considerable knowledge about this disability and the conditions for the welfare of these persons. This knowledge has been at the core of the ongoing shift between traditions of support and need to be encompassed to realize the disability reform.

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THE ISSUE OF QUALITY
IN DISABILITY SERVICES

Kent Ericsson and Patricia Ericsson

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The quality issue

The Swedish disability reform has been defined as an ongoing shift between two traditions of support. An institutional tradition is being dissolved hand in hand with the development of a community tradition. This has led to a new role for the municipality as a shift of responsibility has taken place from regional to local level. In the presentation of this new situation (chapter 2) two conditions were found characteristic for disability services run by the municipality. Possibilities have increased to run more personal and more local services.

With a minimized contribution from central bodies, centralized directives play a lesser role in the organizing of disability services. This opens up for a more process oriented way of setting up services. Consequently there is a greater opportunity for the person´s participation in deciding which services he will receive, as he himself, together with his representative and his network, can contribute in a more active way to finding the forms of services which are suitable for the person. His influence and control over his own life can thereby be increased.

But there are also risks involved in this process oriented delivery of services. There are no previously defined end services to reach for. Instead the end product will be the result of what has happened during the ongoing process. In a powerful service organization, which wants to economize and to avoid responding to the requests of the person, there is an increased risk that personal needs will not be met. It is therefore necessary to find a guarantee in order that abuse of the person cannot take place. The issue of quality of services is therefore seen here as a way to guarantee and further good services, which lead to a good life for the person.

Quality and the two traditions of support

Quality of disability services was of course an issue in the institutional tradition. As the organizations in this tradition are hierarchical and centralised, the work taking place was based on central directives. Plans for the building of services, e.g. residential institutions, day activity centres and group-homes were made by central bodies and these were expected to be adhered to. There were also Acts of Parliament and regulations which defined what should be arranged with regard to services. Recommendations were formulated by central bodies regarding how to meet the needs of persons with intellectual disability.

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Quality control, in this tradition, was carried out by the central body sending inspectors into services so as to control to what extent central directives were realized. The major task for them was to see whether centrally formulated directives were adhered to in the delivering of services. If the physical building, the square metres of the bed-room or the hygiene of the bath-room did not correspond to what was expected, a report was written by the inspector.

The community tradition has its roots in the citizen perspective. Based on this, the person with a disability is primarily seen as a person, a member of society, who has got the same needs and rights as other members of society. In this perspective the normal life is in focus and the person´s right to live this life, by way of adequate support, is the goal to be realized. His disability is not denied but is seen as a personal need and his rights extend to meeting the demands made by his disability. As the person is recognized as a citizen with rights, influence and control over his own life becomes paramount.

This has consequences for the process of setting up his services. The institutional tradition is based on specified and special services which are realized through the local process of organizing services. The community tradition however, does not specify that special services are to be the end product of the process. Instead it is the normal life of the person, as defined and requested by him, which is to be realized. To achieve this several forms of housing, which are to be found in the community, together with places of work and recreation, will be availed of. In the process of realizing these life goals there may be a variation of houses and places of work, which may contribute to the life the person wants to live. When looking to the issue of quality in the community tradition it is not a special service which is to be described, but the life of the person. Does he lead a life of quality?

Technical and functional quality

The concept of technical and functional quality may be of assistance to grasp the issue of quality in disability services. When applied in this field the technical quality concerns the service being offered, its structure and its content. Functional quality is more an issue of how this is being experienced by the person, the function it has got for the one concerned.

Some examples will help to clarify the differences. The group-home is a special form of housing with support to persons with a disability. Its form is specified by central bodies for example with regard to the size of the individual apartment. The technical quality of the group-home is therefore easy to control. The functional quality is concerned however with whether this group-home has contributed to the person having a home. Has the apartment the character of a home which the person enjoys? When applying this way of reasoning to the day activity centre, one may find a centre with a high degree of technical quality. The functional quality is however concerned with whether the centre has contributed to a purposeful week for the person. The bed of the person may have a high degree of technical quality, but does it lead to the person having a good nights sleep?

It is possible to find methods to describe the quality of disability services, but it is doubtful if one can find one method which will cover all issues which are seen as important. The two aspects which have been commented upon here may be of help and both can be used to illustrate the issue. It is necessary however to be conscious about the possibilities, and the limitations, of the various ways of describing quality.

Experiences of quality auditing

In a recent project we were asked to create a questionnaire in order to describe the quality of services for persons with intellectual disability. Based on the concept of functional disability the aim was to find the dimensions which are needed in order to describe the

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everyday life of a person. This was done through a series of interviews with persons with a disability, their families and staff, in all concerning 100 persons. Discussions with them led to a number of ideas as to how to characterize a life with quality. These interviews were analysed and 8 categories were identified which together give a comprehensive view of everyday life. These dimensions were (a) the dignity with which one is met, (b) influence and control over one´s life, (c) the degree to which support is personal, (d) social relations, (e) participation in everyday life, (f) participation in community life, (g) personal belongings and (h) physical aspects of the home/day activity centre.

The questionnaire with which to describe quality consisted of 32 questions. For each of the 8 dimensions, 4 questions had been formulated to grasp the meaning of a dimension. A question was then to be answered by indicating 1 of 4 alternatives. The questions of the form were naturally put together in a random fashion so as to avoid any possibilities of identifying which dimensions it was supposed to describe.

It was common that this method was used to describe quality in a group, for example in a group-home or in an activity-group in a day service. For each person to be described, the form was answered by a member of staff and by a representative, most often a member of the family. It took between 1,5 and 2 hours for a person to answer the form. The questions were not complicated to respond to, but were seen as interesting as it provided an opportunity to sit down and to reflect over various aspects of the qualities of the life, lived by the person with a disability, a situation which one had never experienced before. When all had given their answers one would end up with twice the number of forms as there were persons in the group.

These data were computed and presented. With this material it was possible to give three presentations for the group being described. For each presentation, data were given by both the member of staff and by a member of the family or some other representative. In the first presentation each person in the group was described as regards his 8 dimensions. This gave a view of his everyday life in these respects. The second presentation gave a view of the 8 dimensions in the group. Each dimension was now a mean, based on information from all persons. The third presentation described all persons in the group. Information for a person was now based on the mean of all dimensions for him.

This method gave a concrete expression of the dimensions, concepts such as "dignity" and "community participation", etc. Thereby the results gave possibilities to discuss the quality of the life lived by a person. A number of comparisons could be made between persons. It also gave possibilities for families and staff to discuss to what extent there was agreement on these dimensions. If there was disagreement on any point, this gave a chance for a discussion. The basic idea of this method was to get an instrument by which the life of a person could be described and the comments emanating from the discussion could then lead to development of services so as to give the person a better life.

At the same time as one must see that there are possibilities of describing quality of the life lived by a person with a disability, there are also a number of problems. One is concerned with technical skill and economic resources. When administering the forms one must be able to compute the results emanating from them and also to present them in an accessible way to the person, the family and to the staff. This demands some statistical knowledge. The issue of resources has got to do with the use of the method. It takes time to carry out this full process, from the answering of the forms to the final discussion of the results concerning a single person. This requires considerable effort for a group-home or activity group and there is not always time and money for this.

There is also a problem in this method which is especially related to persons with intellectual disability. As the method is verbal and the answering of the questions demands a cognitive effort, it is highly unlikely that the person with a disability will be able to participate.

There is also a more theoretical problem concerning the criteria for quality. In this method the criteria, the eight dimensions, came from a series of interviews with people who were knowledgeable about this field. In this way they could contribute in a constructive way to the method. But when discussing the idea of the community tradition and the concept of functional quality, it was claimed that the aim of services was to contribute to a good life for a person. Essentially this means that there is a need for personal criteria. We need to know what the person himself means by a good life!

A life with quality

What was seen as problematic in the previous project became the task to overcome in the present one. As functional quality was chosen as the theoretical concept for an analysis, quality was defined as the state which exists when the person has the possibility to live the life he wants to lead. The key question, when describing quality in this perspective, is the question as to how to describe what sort of life the person wants to live. This means that the person must be part of the process of describing quality. As some persons with intellectual disability have difficulties in expressing themselves, and therefore in answering this critical question, a representative must be part of this process. A part of this process of describing quality is therefore finding a representative for the person. For some this may be very easy, for others it is a more challenging task.

In order to acquire the necessary knowledge concerning the sort of life the person wants to live, seasonal meetings were introduced. The idea was to offer a situation when the person was given the opportunity to be part of making plans for his own daily life. To make this as concrete as possible, a situation was created when the person was given a chance to plan for the season ahead.

Persons participating in this meeting are the member of staff who has closest responsibility for support to the person concerned, the person himself and his representative. This is a meeting which belongs to the person himself and he decides whether it is to take place (the meeting being a voluntary, not compulsory occasion) and the conditions for the meeting. This includes for example the place where persons are to meet.

Practically, the seasonal meeting is organized and prepared by the member of staff. An invitation has to be made, a choice of meeting place has to be found and thoughts must be given to the wishes of the person concerning his daily life. Preparation for the meeting by the person and his representative means that they need to discuss a number of issues about the coming season and to decide which are to be brought up at the meeting.

The aim of this seasonal meeting is to come to an agreement about the various activities, or routines in daily life, which will take place during the coming season, that is the summer, the autumn, the winter or the spring to come. The topics to be discussed must be based on requests from the person and thereby be expressions of the life he wants to live during the coming season. Some requests may be rational expressions from the person concerning the sort of life he wants to live, but in the circumstances impossible to realize. This must lead to a discussion, between the person and the member of staff, which ends with an agreement as to what is a realistic way to meet the wishes of the person.

It is most important that the activities agreed upon are written down and signed by both staff concerned and by the person. This is a document which is important in the process of delivering services. As services are voluntary there is no way of forcing a person to carry out activities he does not wish for. A written agreement between the parties, the person (supported by his representative) and the disability service (represented by a member of staff), becomes the formal basis for the delivery of services. The intention is that during the coming season the agreed upon activities will be carried out.

After the season, and at a similar meeting, a follow-up of which requests were realized and if not, why they did not become a reality, is a topic for discussion. One will then find the proportion which were realized. If all became a reality, the life which the person asked for became a reality. If some did not, the life asked for by the person was not realized. The degree to which the life requested became a reality, is an expression of the quality of life lived by the person.

When all activities from the four seasons of the year are reviewed together, a system for describing individual quality has been achieved. If the person lives in a group-home with 5 persons, the results from all persons, for all of the year, can be reviewed. When combined the degree to which the group´s requests have been realized will be an expression of quality of the group-home.

Experiences so far have shown that persons do have views and requests and can express wishes concerning activities or changes in their daily life. It has also shown that they need not be many or dramatic, thereby making them realistic and desirable. Sometimes personal and most unexpected requests are expressed, to the surprise of staff who thought they had good knowledge of the person. The fact that requests for activities are expressed shows that this is a most relevant way of planning the services for coming season.

In the present project of STEPS/Lidingö the method of seasonal meetings is being developed further. Experiences are gained and collected as to how to carry out seasonal meetings for a person, both in his home as well as in his day service.

Discussion

The issue of quality in disability services is of course of great importance. If services have the ambition to contribute to a good life for persons, this must be reflected and illustrated in the quality of the services. If services on the other hand are unacceptable, leading to an undesirable life, quality must be a concept applied to find a way out of a dissatisfactory situation.

Quality is today a concept which is greatly discussed and one can wonder about the reason for this. One reason, which is found to be relevant in the framework of this paper, is that when services change, so do the concepts which make up the frame-work. One of these concepts is quality. Quality has therefore been discussed here in relation to the ongoing shift between two traditions of support as found in the Swedish disability reform.

As present development, seen in socio-political ideas, in Acts of Parliament and in the mood of society, is moving towards an increased democratization of disability services, the demand for influence and control over one´s own life becomes an increasingly important issue. This creates a challenge for disability services in general and specially for the task of identifying the quality of disability services. Based on this attempts have been, and are still being made, to handle the quality issue. Some progress has been made and the conclusion is that it is possible to find expressions of quality.

There is a specially demanding situation in the services for persons with intellectual disability, where there are many persons who do not communicate with spoken language and who have difficulties in performing cognitive tasks. The project presented here has met these demands by choosing functional quality as the theoretical basis and by the introduction of seasonal meetings which provide an opportunity for the persons, in their individual way, to express their wishes and feelings concerning the content of everyday life during the coming season. The necessity of a representative for the person is also seen as essential, as a moral support if the person himself communicates with spoken language and as a spokesperson if he does not master spoken language. This model, concerning quality in disability services, is currently being tested in the local project of STEPS, in the town of Lidingö.

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SOME FACTS ABOUT LIDINGÖ

Adriana Buzea

Lidingö is situated about 15 minutes travelling time from Stockholm and almost 1 km from the mainland. It is a town with around 41.000 inhabitants and has most of the services you can expect from a modern community.

Lidingö became a borough in 1910 and a town in 1926. In spite of being close to the capital, Lidingö has kept its character as an island in the Stockholm archipelago. Here you will find areas dominated by countryside and the sea which offer rich opportunities for relaxation and recreation.

In the centre of Lidingö, in industrial areas and in housing-areas, 10.700 persons work in 1.100 companies and in 140 workplaces organized by the public sector. Apart from these there are 2.500 companies with no employees, most of them initiated after 1993. These one-man companies work with commerce, computing, health, recreation and consultancy and services in other fields.

Just over 19.000 of the inhabitants of Lidingö are employed. Of these 13.100 travel to Stockholm and other towns, while 6.200 work within the municipality of Lidingö. More then every second person of the 10.700 who work in Lidingö, also live in the town.

POPULATION 2002-01-01			PROGNOSIS 2005-01-01	
Age	**Numbers**	**%**	**Numbers**	**%**
0-5 years	2.858	7	2.846	7
6-18 years	6.633	16	6.907	16,5
19-64 years	23.762	58	24.170	58
65-79 years	5.005	12,5	4.861	11,5
80- years	2.637	6,5	2.840	7
Sum	**40.895**	**100**	**41.624**	**100**

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THE MUNICIPALITY COUNCIL

Number of seats

	1995 - 1998	1999 - 2002	2003 - 2006
Conservative Party	20	22	20
Center Party	4	2	2
Liberal Party	5	6	10
Christian Democrats	-	4	2
Social Democrats	9	7	8
Left-wing Party	2	2	2
Green Party	2	2	2
Lidingö Party	9	6	5
Totalt	**51**	**51**	**51**

HOUSING

Housing 1985-2002 (1 january)

	1985	1990	1995	2000	2002	Andel
Apartments	10.910	11.141	11.495	12.066	12.307	64%
Self-contained	6.199	6.449	6.599	6.794	6.857	36%
Sum	**17.109**	**17.590**	**18.094**	**18.860**	**19.164**	

EMPLOYMENT 2000/01

People from Lidingö in employment

Men	9.450
Women	9.450
Total 20- år	18.900

Frequency of employment	
All 20-64 år	79%
Women 20-64 år	77%
Women with children 1-9 år	81%

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FAMILY INCOME IN LIDINGÖ YEAR 2000 (SEK 1.000)

Acquired income (mean) = Working- and business incomes
Disposable income = gross income - taxes + allowances

	Families	Acquired income	Disposable income
Families 20-64 years			
Cohabiting without children	1.378	690	547
Cohabiting with children	4.656	856	742
Singles 20-64 years			
Women without children	3.304	231	180
Women with children	1.268	272	276
Men without children	3.685	261	239
Men with children	306	497	399
Families 65+ years			
Cohabiting	2.239	456	418
Single women	2.780	174	185
Single men	901	240	224
All families	**20.517**	**430**	**380**

INCOME AND TAX OF LIDINGÖ YEAR 2001 (SEK 1.000.000)

Acquired and capital income	**11.438**
Local tax (municipality and county)	2.487
State tax	757
Capital tax	234
Property tax	184
State tax on capital	480
Self tax etc	215
Total tax	**4.357**

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TAX IMPOSITION YEAR 2003 (per SEK 100)

Lidingö	**18:97**
Stockholm county	**11:62**
Total	**30:59**
County mean year 2003	30:35
National mean year 2003	31:17

Adriana Buzea: Some facts about Lidingö

WELFARE FOR PERSONS WITH LEARNING DISABILITIES

Adriana Buzea

POLICY GOALS AND THEIR ACHIEVEMENT

Plan for disability policy

Since 2000 Sweden has had a national plan for disability policy (Govt. bill 1999/2000:79). The plan stresses that disability policy is about citizenship rather than merely care and nursing. Not everyone with a disability needs this help. Yet all citizens have certain rights. The policy may be illustrated briefly in the goals agreed by Parliament. These are:

- Accessibility of a social community based on diversity

- Full participation in community life for persons with disabilities and equality of opportunity concerning living conditions

- Conditions which facilitate independence and self-determination.

Sweden strives to enable persons with disabilities to participate fully in society. To ensure this the disability policy proposed in the legislation is based on, and should operate from, the perspective of citizenship. In comparison with earlier practice, based on a care per-spective, it is clear that Sweden is now tending to stress *equality of opportunity* for people with disabilities, thereby enabling them to play a full part in community life.

United Nations Standard Rules

In 1989 the Swedish Government was influential in taking the initiative, at the United Nations, to bring about international rules safeguarding the right to participation and equal opportunity for persons with disabilities. This led in 1993 to the adoption by the General Assembly of the document "Standard Rules for safeguarding participation and equal opportunity for people with disabilities". The document comprises 22 rules cover-ing, among other issues, the right to work and accessibility to society. The rules are not binding upon member-states but have significantly influenced the character of many nations' disability policies.

Sweden has approximately 9,0 million inhabitants. The choice of definition of disability affects the size of the group considered to have a disability, so there is no definite answer to the question as to how many people with disabilities there are. In their national surveys of living conditions, Statistics Sweden employs a definition based on functional ability. According to their criteria, around 1.3 million people aged from 16– 85 are disabled, of whom 700.000 are of working age (16– 64). Consequently, a large propor-tion of disabled people are aged 65 or older.

If instead we use one of the administrative definitions underlying the entitlement to special benefits from the community, the numbers are found to be lower. In December 2001 just over 100.000 people received disability support from the social insurance system. Another example, taken from the municipal services, estimates that over 47.000 people receive support under the provisions of the Act on Support and Services for Certain Disabled Persons (LSS 1993:387) (RFV, 2002a). In practice, these two categories overlap. People who receive social insurance support may receive support under the Support and Services Act at the same time.

AUTHORITIES RESPONSIBLE FOR THE PROVISION OF SPECIAL SUPPORT

Many people with disabilities require no special support. A well-functioning community, with good accessibility to the physical and social environment, may be all that is needed. For those persons who need support as a consequence of their disability, various kinds are available.

Responsibility for such support is divided between the municipality, the county and the state. Different laws and ordinances regulate each authority's responsibility. Thus the division of responsibility between different authorities can be seen as one way of realising the idea of integrating people with disabilities into the community (see figure 3:1).

This is referred to as the *principle of responsibility and financing*. The principle implies that all social sectors should plan and conduct their activities so that they are accessible to all citizens, irrespective of whether they have a disability or not. The underlying principle is that each area of society should take its responsibility for issues concerning people with disabilities.

The principle also means that the support given to people with disabilities should be integrated with general local-government services rather than being administered by a special "disability authority". This is an important concept. People with disabilities should not be separated from the rest of the population but should be able to avail of the same authorities as all others in order to have their needs for support and service met.

Figures 3:1 and 3:2 illustrates the relationship between the various bodies contributing to welfare. Figure 3:1 presents the three levels of Swedish society, the municipality, the county and the national level and their tasks. Figure 3:2 gives an example of what sort of contributions can be offered a single person with disability.

The municipality

Municipalities have the ultimate responsibility for ensuring that citizens living within their borders obtain the support and help they need. The municipality represents the basis of the support offered, by the community, to people with disabilities. For example, it is here that responsibility lies for seeing that people with disabilities obtain housing which is adapted to the requirements of their disability. The municipality is also responsible for ensuring that people with disabilities receive the personal support they need, round the clock. This may be anything from getting in and out of bed to following one's leisure interests. The following are some examples of support that can be obtained via the municipality:

- Home adaptation
- Transport services
- Organised daily activities
- Home help services

AUTHORITY	MAIN RESPONSIBILITY	IMPORTANT LAWS/ORDINANCES
MUNICIPALITY	Basic responsibility for all citizens and their living conditions	· Social Services Act (SoL, 2001:453) · Act on Support and Services for Certain Disabled Persons (LSS 1993:387) · Act on Municipal Transport Services for Elderly and Disabled Persons (1997:736)
COUNTY	Certain special (expert) measures	· Health Services Act (1982:763)
STATE / SOCIAL INSURANCE	Financial support and compensation for additional costs	· National Insurance Act (1962:381) · Act on Disability Allowance and Care Allowance (1998:703) · Assistance Benefit Act (1993:389) · Ordinance regarding Car Allowance for Persons with Disabilities (1998:890)
STATE / LABOUR MARKET	Assist people with disabilities to obtain or to keep a job	· Ordinance regarding Special Measures for People with Occupational Disabilities (2000:630)

Figure 3:1. The relationship between authority, main responsibility and some important laws which govern their task in the Swedish welfare society.

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- Service accommodation

- Personal assistance

Two important laws govern the tasks of the municipality in this field. The first is the Social Services Act (SoL), (2001:453) which regulates large parts of the municipal social services, including the care of the elderly and of people with disabilities. The Social Services Act obliges the municipality to ensure that people with disabilities can live as others do: the municipality should facilitate their participation on equal terms and provide the support they require.

The other important law in the municipal area is the Act on Support and Services for Certain Disabled Persons (1993:387) (LSS). This law was introduced in 1994 and may be seen as a supplement to the Social Services Act. While measures under the Social Services Act should in principle be available to all who need them, the LSS Act follows a narrower definition of who should be eligible for these measures. A further important difference between the Social Services Act and the LSS Act is that the latter has considerably stronger elements of rights legislation. A law of rights *guarantees* a citizen specific benefits, given that he or she meets certain criteria. Further, the LSS Act and the Social Services Act also differ with regard to what they seek to achieve. While the goal of LSS is for persons with disabilities to enjoy *good* conditions of life, support under the Social Services Act is intended to ensure a *reasonable* level of existence.

The following three groups are entitled to support under the LSS Act:

1. Persons with learning difficulties, autism or autism-like conditions

2. Persons acquiring, in adulthood, permanent and significant intellectual disabilities in consequence of external violence or somatic disease

3. Persons with other permanent physical or intellectual disabilities clearly not related to normal aging, if the disabilities are extensive and cause major difficulties in daily life and hence a comprehensive need for support or service.

The county

The role of the Swedish county in the support system regarding people with disabilities includes the provision of ordinary health care, habilitation, technical aids and interpreters. The county is also responsible, under the LSS Act, for a special service termed counselling and support. Basically, this service consists of providing expert support for especially for people with disabilities. This service includes support from, for example, social workers, physio- and occupational therapists or psychologists.

The organisation in the county is often divided into various administrative units, or clinics. For example clinics which are organised on the basis of the medical speciality for which they are responsible. Examples of such specialisation of county support are habilitation, technical aids, interpreter services as well as counselling and support.

Most county activities are, however, regulated by the Health Services Act .This Act stipulates that the county must provide good health services for all residents in its area. The goal of Swedish health care according to the Health Services Act is "good health and care on equal terms for the whole population". More specifically, this means that the county council, as well as offering medical care, must meet the need for habilitation and rehabilitation, technical aids for persons with disability and interpreter services for people who are congenitally deaf, deaf and blind, those who have acquired deafness or have

impaired hearing. The county has thereby an important role in the provision of support to persons disabilities, demanding the provision of support for relatively well-defined measures.

The state

Labour market authorities

The labour market authorities are responsible for ensuring that people with disability, and consequently limited working ability, gain access to the labour market and that, where necessary, the actual working environment is adapted so as to facilitate the person to continue in work.

Social insurance support to people with disabilities

Social insurance is a factor which concerns the lives of practically all citizens, and which is of great importance for their security and welfare. Every citizen is legally entitled to insurance benefits and allowances in various situations of life. The national social insurance system administers one aspect of the support which society provides for people with disabilities. For daily maintenance support, measures such as a temporary disability pension may be applicable. From 2003 these measures have been replaced by certain sickness benefits and activity compensation schemes.

Apart from a general maintenance support, four benefits are earmarked for persons with disabilities. Their main purpose is to cover various forms of additional expense which a specific disability may entail. These are disability benefit, care allowance, car allowance and assistance allowance.

Disability pension and temporary disability pension

Disability pension, and its time-limited form, termed temporary disability pension, have long been granted to people who, for medical reasons (mental or somatic), are incapable of work. Disability pension has therefore been an important source of maintenance for people with impaired working ability. Disability pension has been granted if the impaired working ability is expected to be permanent, whereas the temporary form has been granted if there is reason to believe that working ability can be gained or regained. The system of disability pension and temporary disability pension has been an important element in the Swedish welfare system, covering the whole population from youth to pensionable age (16-64 years).

These rules have remained essentially the same since they were introduced in the early 1960s. However, from 2003, a new system which is more in keeping with the times has been introduced which differentiates between "sickness benefits" and "activity benefits". Sickness benefits have come to replace the disability pension, but cannot be granted until the person has reached 30 years of age. The activity benefit is a newly introduced system for young people entering the social insurance system, the aim being to diminish the risk for a passive long-term dependence on benefits, and instead encourage the individual's own ability to provide for him- or herself.

Activity Benefits

The system of activity compensation or benefits was introduced on 1 January 2003 for people aged 19 to 29. It is intended to encourage the recipient to become and remain active without affecting their financial security. The aim is for people who enter the social insurance system at a young age to be given the incentive to increase their independence and create active lives for themselves. It can also lead to increased self-sufficiency. Examples are courses, hobby activities and sports. The intention is that the individual should

govern the choice of activities, while the Insurance Office should act by supporting the individual through planning and coordinating activities. An activity benefit is time-limited and can be granted for at most three years at a time.

Disability Allowance

A disability allowance can be granted to persons with impaired functional ability who need practical help to manage their daily lives or who, due to the disability, incur large extra expense. The allowance is age-limited, being granted at age 19 at the earliest (from 2003); and the disability must have arisen before the person reaches 65 years.

Care Allowance

A care allowance is granted to parents caring for a seriously ill or disabled child. The care allowance has two purposes: payment towards the care and supervision exercised by a parent and compensation for the additional costs entailed by the child´s illness or disability. The care allowance may also represent compensation for part of the loss of income the child´s need of care and supervision may entail if a parent must stay away from paid employment partly or entirely.

Car Allowance

The purpose of the car allowance is to help with the purchase of a car or other motor vehicle for persons with disabilities who cannot use public transport. The car allowance can thus be seen partly as compensation for shortcomings in the accessibility of today's transport services.

Assistance Allowance

Introduced in 1994, the assistance allowance is the youngest of the four special forms of support. Its purpose is to make it financially possible for people with severe disabilities to appoint, themselves or through a provider, a personal assistant. The idea of personal assistance is to create support as far as possible adapted to the individual and to optimise the person´s influence over how the support is arranged, and who provides it. This is often achieved by, for example, the person himself or herself being the assistant's 'supervisor'. The target group for the assistance allowance is the same as that for measures under the LSS Act .

The allowance is granted in the form of a number of assistance hours which the person may use within a certain period. In 2003 an hour was worth SEK 198. There is no ceiling, i.e. the number of hours can theoretically be unlimited where people with severe injuries or diseases may need several assistants at the same time. The municipality pays for the first twenty assistance hours per week, while the state, i.e. the social insurance system, pays for assistance hours exceeding twenty hours per week.

Figure 3:2 exemplifies the contributions from the various sources presented here to a person with a disability.

FINANCING OF SERVICES

The financial outlay for the municipality and the county is covered mainly through local taxation. It is usual in Sweden that expenditure can be supplemented by state subsidies and from individual fees. Lidingö, however, does not qualify for a state subsidy as the basis for revenue is so high that the municipality instead pays an equalisation contribution to other municipalities.

Social insurance is financed through social contributions, general pension contribution, state old-age pension contributions, taxes and returns from funds.

THE MUNICIPALITY			
Home Adaptation Unit Occupational therapist Engineer	**Social services/ Disability Care** LSS official SOL official Transport service manager	**Technical Aids** Occupational therapist	**Municipal Providers** Managers Staff

External Providers
(of municipal activities)
Managers
Colleagues

Job Centre
Job centre official
Consultant

The Person with a disability

T H E   S T A T E

Car Adaptation Firm
Mechanic

Social Insurance Office
Official
Reporter to Lay Board

Arranger of assistance
Personal assistant
Supervisor

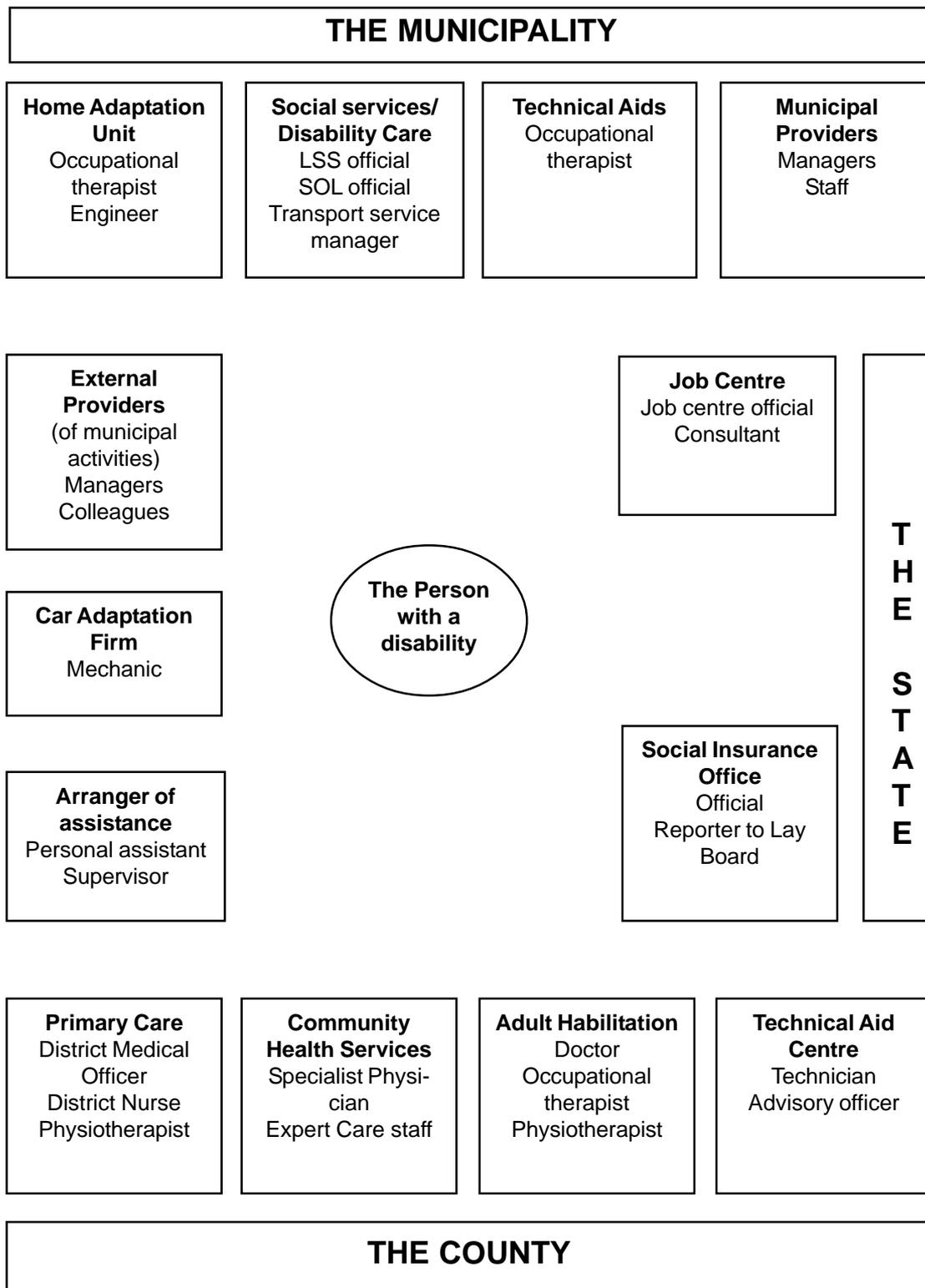| **Primary Care** District Medical Officer District Nurse Physiotherapist	**Community Health Services** Specialist Physi- cian Expert Care staff	**Adult Habilitation** Doctor Occupational therapist Physiotherapist	**Technical Aid Centre** Technician Advisory officer

THE COUNTY

Figure 3:2. An example of the contributions to a person with a disability, from the various services organizations.

The social contributions are based on employer contributions (32,86%) and individual contributions (31.01%). The employer contribution is paid by the employer, whereas the individual contribution is made by the person who is has general National Insurance based on a working income.

Health insurance fees are transferred to the state to finance the cost of the health services.

Another source of financing is VAT - Value-added tax. The legislation regarding value-added tax (1994:2000) refers to the general rule of sales taxation for the exchange of goods and services. Some areas are exempted from the main rule, that is to say are tax-free, for example education, health services, and social services. The tax level applied is usually 25%. Two additional percentage rates, 12% and 6%, can be applied in special cases.

HOW A GOOD LIFE AND QUALITY OF LIFE CAN BE GUARANTEED

The most important factors for guaranteeing a good life for persons with a disability are:

- Influence over one´s own life

- Personally adapted support

- The involvement of, and consideration for, the views of parents, guardians or advocates

- The facilitation of integration in society

- The opportunity to express complaints to the service provider, local authorities, politicians and the right to appeal.

As most of the provisions for persons with a disability are to-day expressed as rights, the person can appeal to a civil court to have his case tried. The initial appeal is made to the County Court, thereafter to the Court of Appeal and finally to the Supreme Administrative Court.

CONCLUSIONS

The principle of *responsibility and financing* is underlying the idea that different authorities administer different parts of the support provided to persons with disabilities. The intention is that persons with disabilities should apply to the same authorities as everyone else in the different contexts, instead of their needs being separated from other people's.

The emerging picture is one of a support system that appears relatively clear and logically arranged. The municipality, which is closest to the citizen, should be responsible for the citizen´s basic security in the form of support and service. The county should supplement this by providing expert competence through medical care and habilitation/rehabilitation. In addition, the labour market authorities should employ their competence to make it easier for disabled people to go out to work. Lastly, the social insurance system should provide compensation for the costs that a disability can entail

But how the system works in practice must be judged in terms of how it helps the people for whom it is intended. As we have seen, in this presentation, the system consists not only of three responsible authorities; each authority is also divided into various sectors. Moreover, certain additional measures have been added but are administered outside the respective authorities while linked to their support measures. Examples are the provision of personal assistance, or companies that carry out special modifications to vehicles.

Adriana Buzea: Welfare for persons with learning disabilities

Our experience is based on the "Study of Living Conditions" made by the National Social Insurance Board and shows that people´s experience of contact with the system, and its officials, reveal the following problems:

- It is hard to find relevant information

- You have to be able to take the initiative and formulate your needs

- You have to be able to appeal and fight for your rights

- The system is complicated and bureaucratic

- Coordination among different authorities is poor.

Much remains before equality of living conditions between persons with disabilities and the rest of the population becomes a fact. The educational level is lower for persons with a disability, as is emloyment insurance. In addition there is a lack of financial security among many of those persons who receive social insurance intended as support to persons with a disability.   This means that persons with a disability are excluded from several of the aspects of a persons life which generates independence.

It is clear that our society is still not fully complete and that simplicity is still not foremost. More work is required if all persons are to have the same conditions and the same opportunities to participate in society, irrespective of whether they have a disability or not. The process of change requires longterm approaches, committment and knowledge.

Adriana Buzea: Welfare for persons with learning disabilities

SERVICES TO THE
ELDERY AND THE DISABLED IN LIDINGÖ

Adriana Buzea

INTRODUCTION

Local self-government is a longstanding tradition in Sweden and of fundamental constitutional significance. The principle of local self-government has been enshrined in the Constitution as an integral part of democratic government in Sweden. Sweden has also ratified the European Charter of Local Self-Government. Local self-government is exercised at both local and regional level by the municipalities and counties, which are respectively responsible for vital public services in a variety of welfare sectors.

Municipal responsibilities, for example, include basic schooling, child care amenities and caring services for the elderly. Recreational and cultural activities are also important municipal concerns. On the technical side, municipalities are responsible, for example, for water supply and sewerage, rescue services and refuse disposal. County responsibilities centre mainly on public health and medical services, but counties also have other important duties, e.g. in connection with public transport and regional cultural institutions. The "democratic rules of the game" for municipalities and counties are laid down in the Local Government Act.
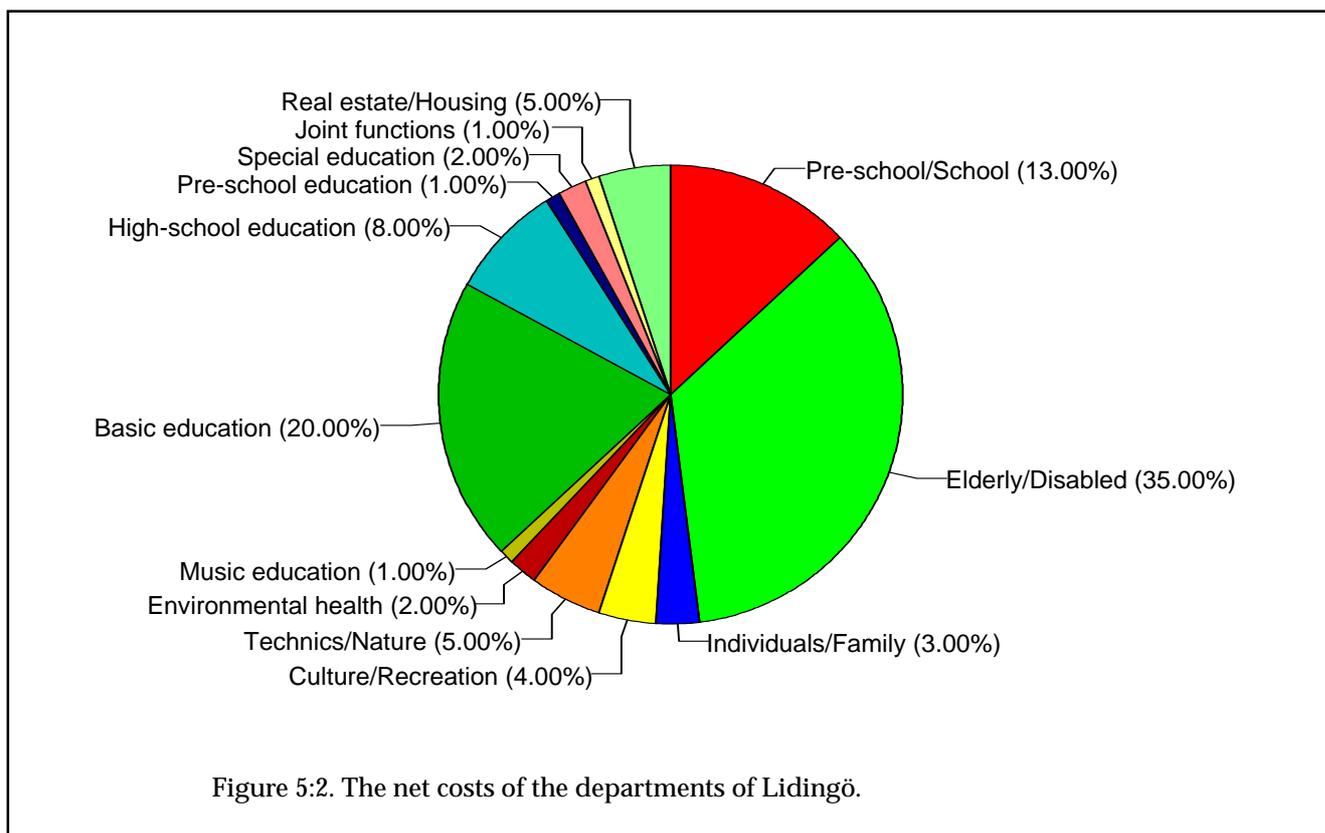
THE ORGANISATION OF LIDINGÖ MUNICIPALITY

The Municipal Council

The Municipal Council is the highest decision making level and has 51 members from 8 political parties. The Council is responsible for issues concerning budget, taxation and other important matters. It is also responsible for deciding which control mechanism for the authority are imposed. It is also the task of the Council to appoint representatives to the Municipal Executive committees and boards. The Municipal Council meets once a month in the Town Hall. The meetings are open to the public and debates are transmitted on the local radio.

Tthe organization of Lidingö Municipality is presented in figure 5:1, the net costs of the departments i figure 5:2.

The Municipal Executive Committee

The Municipal Committee is responsible for the development and financial status of the municipality. The Committee is responsible for leading, co-ordinating and the following-up of the affairs of the municipality. The Committee should also express its opinion in all matters prior to decisions being made by the Municipal Council. The committee is composed of eleven representatives under the leadership of a chairman.

Figure 5:2. The net costs of the departments of Lidingö.

Boards and committees

It is the responsibility of the municipalities Boards and Committees to carry out measures within their respective speciality.

Civil Servants

Responsibility for implementing political decisions carrying out the affairs of the municipality involves 2.500 employees. The majority work within the services for the elderly and persons with a disability as well as education and pre-school activities. Approximately 75% of the employees are women.

THE COMMITTEE FOR SERVICES TO THE ELDERLY AND THE DISABLED

The committees within the municipality, each within their different fields, shall ensure that the activities are conducted in accordance with the goals and guidelines decided on by the Lidingö Municipal Council and with regard for the provisions applicable to the various activities. They shall also ensure that internal control is sufficient and that the activities are otherwise carried out in a satisfactory manner.

The Committee for Services to the Elderly and the Disabled is responsible for fulfilling Lidingö´s obligations to meet the need for care, support, habilitation and rehabilitation of the elderly and those with disabilities according to the Social Services Act, (SOL) the Health Services Act (HSL) and the Act on Support and Services for Certain Disabled Persons (LSS). This responsibility applies to both the activities run by the mu-

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nicipality itself and those carried out by contract. In addition the Committee is responsible for the planning, follow-up and evaluation of the services based on the agreed principal goals and the budget limit allocated to the committee.

The department

The department consists of a head of administration, a staff administrative group (including a head of development, activity evaluator, staff officer and planning secretary), a senior nurse, a finance group, a needs accessment group and seven executive units. The department´s activities are organised in seven working areas: Rehabilitation, a Nursing home, the three service-houses Högsätra-Frimurarhemmet, Siggebogården and Tor, the Unit for Special Support, Home help service and Social psychiatry (figure 5:3).

Exercise of Public Authority

The Social Services Act regulates the services and how they are applied to meet the needs for care, support and rehabilitation of the elderly. According to Sol §2 the municipality has the ultimate responsibility for seeing all those resident in the municipality receive the support and help they require. To guarantee the residents the support and help they need the public authority, by way of an assessment officer, makes an individual decision based on the person´s need for care and support. Those who cannot provide for themselves, or can have their needs met in another way, have a right to assisstance (SoL ch. 4, 1§) . All assistance is personal and the individual has the right to appeal against a negative decision. The assistance for the individual should be arranged and implemented in close cooperation with the person concerned (SoL ch. 3, 5§).

Although the Act on Support and Services for Certain Disabled Persons (LSS) contains detailed regulations regarding special support and service for the persons who are included in the group qualified for assisstance according to this law, it does not imply any limitation in their rights to avail of other legislation. The intention of the law is that the individual person, through these measures, is guaranteed good conditions of life. The assistance should be permanent and coordinated. It should be adapted to the recipient´s individual needs and arranged so as to be easily accessible to the user, and facilitate the person´s ability to live an independent life.

The measures made available through the legislation are the following:

1. advice and other personal support that requires special knowledge about problems and conditions governing the life of a person with major and permanent functional impairments,

2. help from a personal assistant or financial support for reasonable costs for such help to the extent that the need for financial support is not covered by assistance benefit pursuant to the Assistance Benefit Act (1993:389),

3. escort service,

4. help from a personal contact,

5. relief service in the home,

6. short stay away from the home,

7. short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays,

8. arrangements for living in a family home or in residential arrangements with special service for children and young people who need to live away from their parental home,
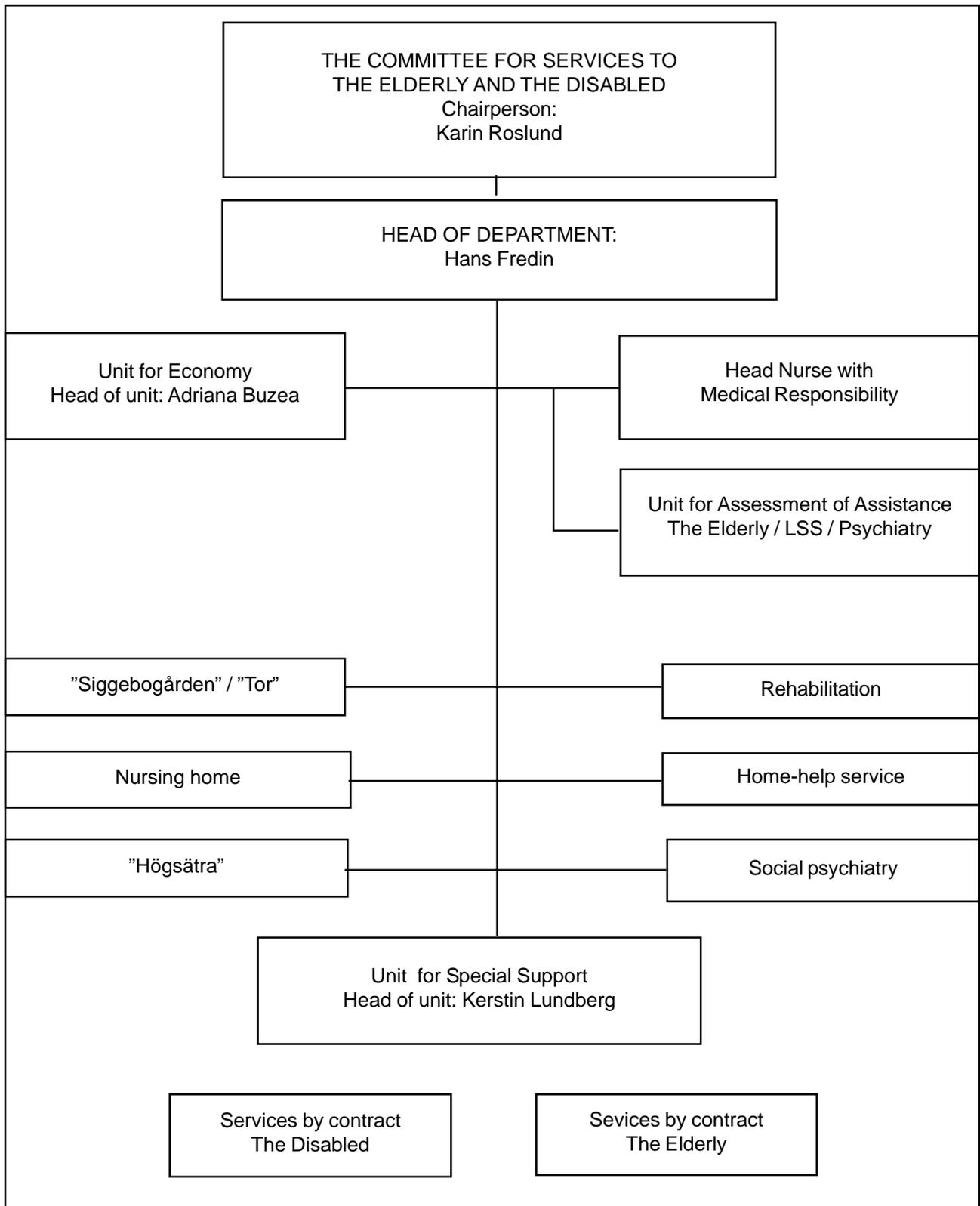
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┌─────────────────────────────────────────────────────────────────────┐
│              THE COMMITTEE FOR SERVICES TO                            │
│              THE ELDERLY AND THE DISABLED                             │
│                     Chairperson:                                      │
│                     Karin Roslund                                     │
│                                                                       │
│              HEAD OF DEPARTMENT:                                      │
│                     Hans Fredin                                       │
│                                                                       │
│  Unit for Economy                          Head Nurse with           │
│  Head of unit: Adriana Buzea               Medical Responsibility     │
│                                                                       │
│                                            Unit for Assessment of     │
│                                            Assistance                 │
│                                            The Elderly / LSS /        │
│                                            Psychiatry                 │
│                                                                       │
│  "Siggebogården" / "Tor"                   Rehabilitation             │
│                                                                       │
│  Nursing home                              Home-help service         │
│                                                                       │
│  "Högsätra"                                Social psychiatry          │
│                                                                       │
│              Unit for Special Support                                 │
│              Head of unit: Kerstin Lundberg                           │
│                                                                       │
│  Services by contract         Sevices by contract                    │
│  The Disabled                 The Elderly                            │
└─────────────────────────────────────────────────────────────────────┘
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Figure 5:3. The Department for Services to the Elderly and the Disabled. The upper part of the figure repesents the purschasing of services while the lower part ("Siggebogården / Rehabilitation) represents the delivery of services.

9. residential arrangements with special service for adults or some other specially adapted residential arrangements for adults,

10. daily activities for people of a working age who have no gainful employment nor are doing a training.

The number of persons currently receiving services according to LSS is 265, for whom 3 LSS-assessment officers are responsible. The task of this group is to decide which support and service the person is entitled to, and to ensure that their needs are conveyed to the department of special services, which in turn is responsible for implementation.

Budget

The goals and organisation of the economic administration in municipalities and counties are laid down in the Local Government Act chapter 8 "Economic administration". It is here stipulated that the municipalities and counties have good economic management of their activities and that these be carried out in accordance with relevant legal procedures.

The budget and its composition

Municipalities and counties are required to present an annual budget for the coming fiscal year. According to law (1997:615) the budget should be drawn up in such a way that income exceeds expenditure. The budget should contain a plan of activities and for the economic management for the current fiscal year. The plan should indicate the rate of taxation and the funding allocations. The plan shall also show how expenditure is to be financed and what the economic status is expected to be at the end of the fiscal year.

If expenditure for a particular financial year exceeds income, the deficit shall be adjusted and the net equity as entered in the balance sheet restored during the two succeeding years. A decision concerning such adjustment shall be made in the budget not later than the second year after the year in which the deficit occurred. The budget shall also contain an economic plan for a three-year period. The fiscal year shall always constitute the first year of this period.

The budgeting process

The Municipal Executive Committee decides the date by which other committees should submit their separate budget proposals to the executive committee. The budgeting process begins therefore when the Committee for Services to the Eldery and the Disabled receives the goals and guidelines from the executive committee, including the agreed amount of money reserved for these activities. During the spring period the department drafts their budget proposal for submittal to the executive committee. The task of the executive committee is then to decide whether it is necessary to adjust the guidelines, including the financial framework, or whether it is possible to carry out all the activities according to the guidelines, thereby deciding whether the budgeting process should/can continue as suggested. Following this the budget will be finally proposed by the executive committee..

Each department should, by 12 May, submit to the Municipal Executive Committee the proposed budget and investment plan, these being within the framework of the directives, and the proposed financial limits. Prior to this the department, including both those responsible for the exercise of public authority, and its implmentation, and the administration, should have surveyed the potential and expected needs for the coming year, and requested any additional funding thought necessary to cover expenditure going beyond the allocated framework. The process concerning the annual budget covers a period of around 3 months. Apart from the participation of the employees in the municipality, other interest groups such as the parents organisations are involved in order to better understand the needs of those concerned.

The Municipal Executive Committee will, on 10 June, and based on the suggested budget prepared by the department, make its decision with regard to any additonal directives to the different boards and committees.

The proposed budget submitted to the Municipal ExecutIve Committee should, in addition to the profit and loss account for the committee also include a proposal regarding any adjustments necessary in order to keep within the decided financial framework, and a presentation of the consequences of any proposed measures to be taken. The various boards are committed to submit a complete budget proposal to the Municipal Executuve Committee by 25 August. Throughout this period a political debate and negotiations can take place within the various committees, boards and the town council. The various political parties represented in these different authorities can, in addition to the proposal from the Executive Committee, also present their own budget proposal.

A budget should be drafted by the Executive Committee before the end of October. If there are special reasons for so doing, the budget may be drafted in November. If so, the Executive Committee must propose, before the end of October, the rate of taxation for the municipal or county tax to be included in the preliminary income tax for the following year.

The budget is adopted by the Town Council before the end of November. In years when elections have been held throughout the country the budget shall be adopted by the newly elected council.

The budget drafted by the executive committee shall be made available to the general public as from the announcement of the council meeting at which the budget is to be adopted. The location where the draft budget is made available should be stated in the announcement.

If the council decides on an item of expenditure in the course of the fiscal year, the decision shouldl also include an indication as to how the expenditure is to be financed.
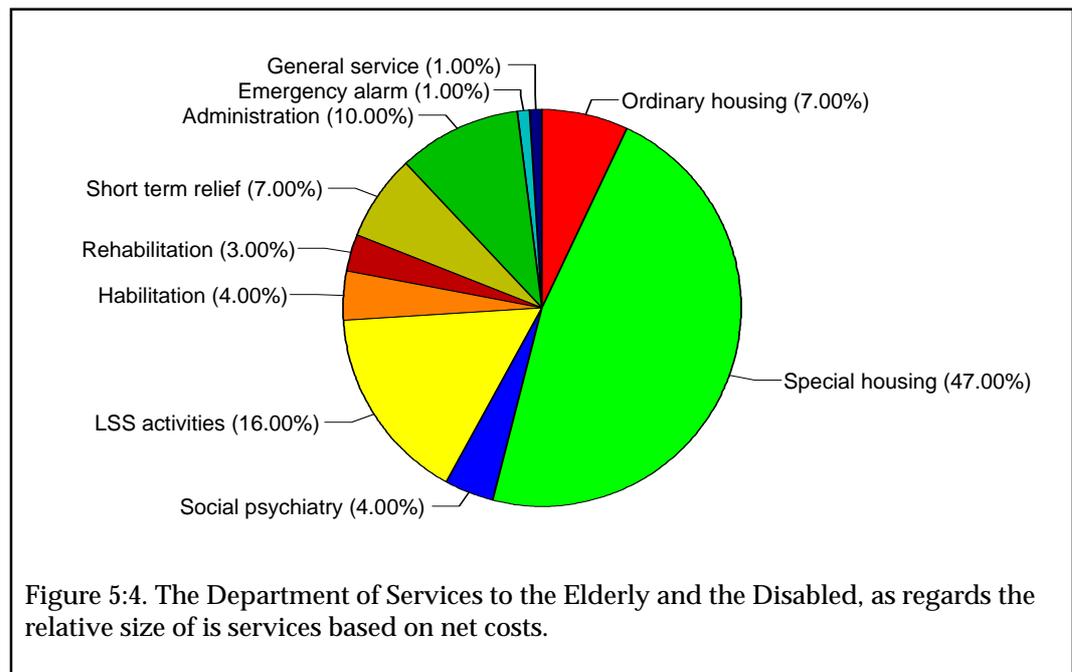
The goals of the Municipality

The Municipal Executive Committee stipulates, at the time when the budget is approved, what are the overall goals for the activities to be carried out. These are presented without any direct organisational connection. An overall goal can therefore be related to several different municipal bodies. When the Municipal Council approved the budget for 2003 it decided on the following overall goal:

The goal for the municipalitiy´s public activities is to meet the needs of the residents of Lidingö with regard to services which are required by the individual, and which are not available in another form. Such services should be characterised by their quality, and carried out with competence and financial discernment The residents should have the greatest possible freedom of choice regarding the required service. The town should therefore, within all areas of service, seek to allow for alternative forms of production and provision.

The exercise of public authority should be correct and effective, and charcterised by a good service attitude. The scope of municipal services should not be greater than that they can be financed by fees, state subsidies and municipal taxation based on low impositions.

The overall goals for services to the elderly and persons with disability, as decided by the Municipal Council, are as follows:

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Figure 5:4. The Department of Services to the Elderly and the Disabled, as regards the relative size of is services based on net costs.

- stimulate the elderly and persons with disability, to live in their own homes so long as they wish, and as long as it is possible.

- offer appropriate alternative forms of housing

- offer necessary care and service to those who need it

- assist in making life active and meaningsfull for the elderly, and for persons with disability.

Annual report

Book-keeping and accounting

The executive committee and other committees shall keep continuous accounts of the funds which they administer. More detailed provisions concerning the accounting records of municipalities and county councils are contained in the Local Government Accounting Records Act (1997:614).

The executive committee decides the latest date by which other committees are to report to the executive committee on their financial administration for the previous fiscal year. As described above the Council adopts the budget and the goals each year. The executive committee is responsible for following up the goals, and the economic result during the fiscal year, and for summarising them in the annual report at the end of the fiscal year. The Committee for Services to the Eldery and the Disabled has to prepare the annual report before February 14, the year after the fiscal year, in order to send it to the Executive Committee

After receiving the accounts of other committees, the Executive Committee should conclude the accounts in an annual report. The annual report should be presented to the Council and the auditors as soon as possible and not later than 15 April of the year following the year to which the report refers. The annual report shall be approved by the

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HOUSING			
YEAR	**2002**	**2001**	**2000**
USS, net cost per day and person			
Ungdomsboende (3)	2.040	2.202	2.024
Lejonet (5)	2.201	1.862	1.660
Odenvägen (4)	2.127	1.734	1.614
Lillåkersvägen (6)	1.340	1.141	1.190
Friggavägen (8)	1.102	1.021	809
Torsvik (5)	2.050	-	-
Eklövet (5)	1.826	-	-
Contract, net cost per day and person			
Kappsta (5)	2.097	2.028	1.934
Brevik, Hövdingevägen (4)	1.726	1.712	1.650
Brevik, Södra Kungsvägen (4)	1.708	1.683	1.645
Boarb (4)	1.921	1.828	1.740
DAILY ACTIVITIES			
USS/ "Ö-gruppen"			
Number of persons	72	68	63
Cost/person/year (SEK 1.000)	278	237	228
USS/"Mobilen"			
Number of persons	8	8	8
Cost/person/year (SEK 1.000)	382	320	337
Contract			
Persons (daily act. combined with housing)	7	8	5
Cost/person/year (SEK 1.000)	248	200	135
Persons (only daily activities)	13	12	15
Cost/person/year (SEK 1.000)	296	241	280

Figure 5:5. Costs for disability services organized by the Department for Services to the Elderly and the Disabled. Some are run by the department (USS) while some are run by others (contract). In brackets is the number of persons in housing.

Council. The annual report is to be kept available to the general public as from the announcement of the Council meeting at which the annual report is to be approved. The place where the annual report is kept available should be made public.

Finances in figures

The net costs for Services to the Elderly and the Disabled is 487.8 million SEK (53,0 million EUR (EUR 1 = SEK 9,15) and is financed by municipal taxation distributed in the final accounts for 2002 as illustrated in figure 5:4. Figure 5:5 present costs for some disability services over a 3 year period.

The activities of the department for Special Services were 98,6 million SEK (10,7 million EUR) or 20 %. In addition 11,6 million SEK (1,3 million EUR) was spent on administration and management.

Adriana Buzea: Services to the elderly and the disabled in Lidingö

The basis for calculating the ratios is to add all the costs for accomplishing the specifically decided tasks necessary to provide special services agreed on. A careful calculation of the costs per activity is necessary in order to follow one´s own productivity over time and to make comparisons between different municipalities.

In addition to the cost for the activities the cost of administration and management must be added. Administration can be divided into three levels: district level, running costs and central administrative costs. At district level the costs are for the local management, financial assistants and other administrative and operational staff such as consultants and service personnel. In the expenses for operational support the costs for the financial office, personnel office, ADB, telephone and caretakers are included. In the central office expenses are included for the management.

8

INTELLECTUAL DISABILITY SERVICES
IN LIDINGÖ

Kent Ericsson and Kerstin Lundberg

Previous chapters have been concerned with the national disability reform and organizational models related to the delivery of services in a municipality. This chapter is concerned with some key aspects on how services are actually organized. As this project is concerned with the lives of adults, less attention is given to describing services for children.

The basis for the provision of services is knowledge about who is eligible. In Lidingö the group which today receive support according to the 1993 Act consists of 8 pre-school children, 87 school-children, 145 adults (up to 65 years of age) and 13 who are 65 years and older.

Services for pre-school and school-children

The majority of pre-school children are to be found in ordinary pre-schools, run by the social authorities of Lidingö. In order for some children to attend the ordinary pre-school it is necessary to have extra staff. For school-age children there are 3 special schools localized to three ordinary schools. These provide education for the basic 9 years. For the additional 4 years there is a special high school.

Short-term relief for children

"Mobilen" is an after-school centre where the child can stay during the period of the day, when school is finished and parents are still at their place of work. This relief service is also available during school holidays. "Mobilen" also offers relief for the family to the extent of 1 night per week, 3 week-ends per month and 2 weeks of summer-camps. Today there are 8 children availing of the servcie, aged between 3,5-17 years of age. Short-term relief can also be arranged through the support of another family.

Housing with support

Adults using services vary considerably as regards to their disability and the conditions for their life. As a consequence there is variation regarding their housing. Some live in the parental home, while others live in a home of their own, e.g. by renting or owning an apartment. In that case they can have support in the form of staff coming to their home. Some live in special housing with support. If this is arranged according to SOL (the Social Act of 1980), they can live for example in a service-house or a nursing-home. When housing with support is arranged according to LSS (the Special Act of 1993) people live in small groups, in housing located to ordinary housing-areas,and with staff support. This special housing can be run by the disability service or by a private entrepreneur.
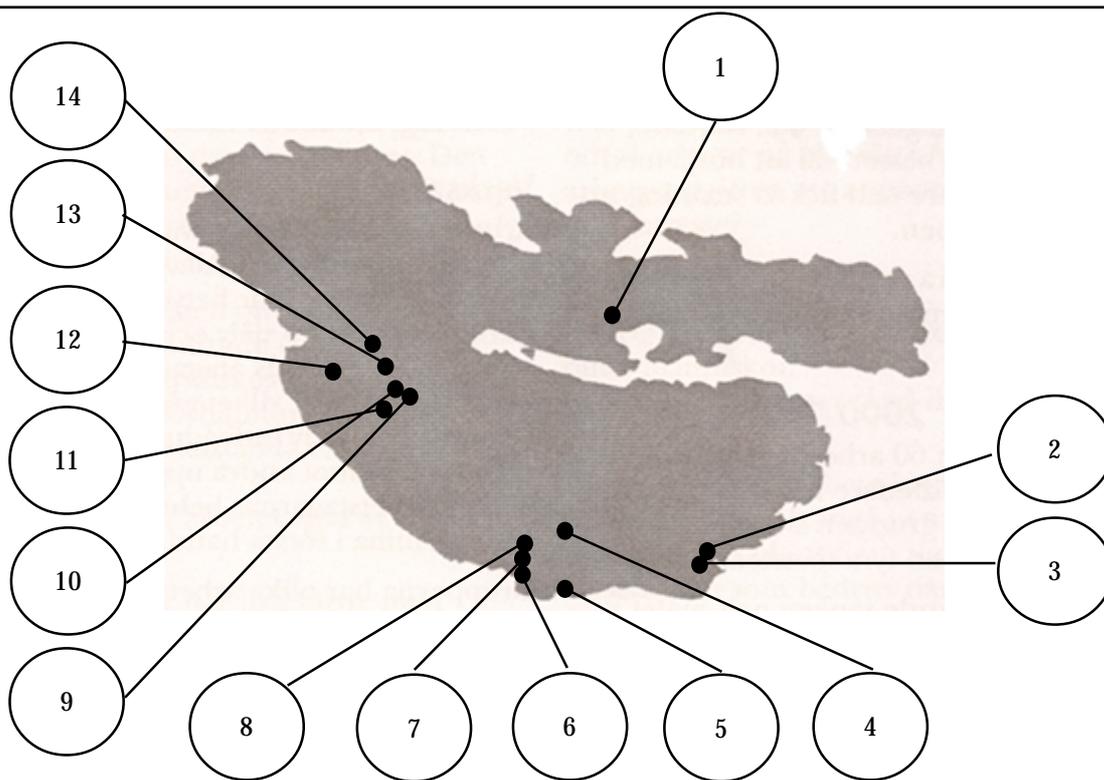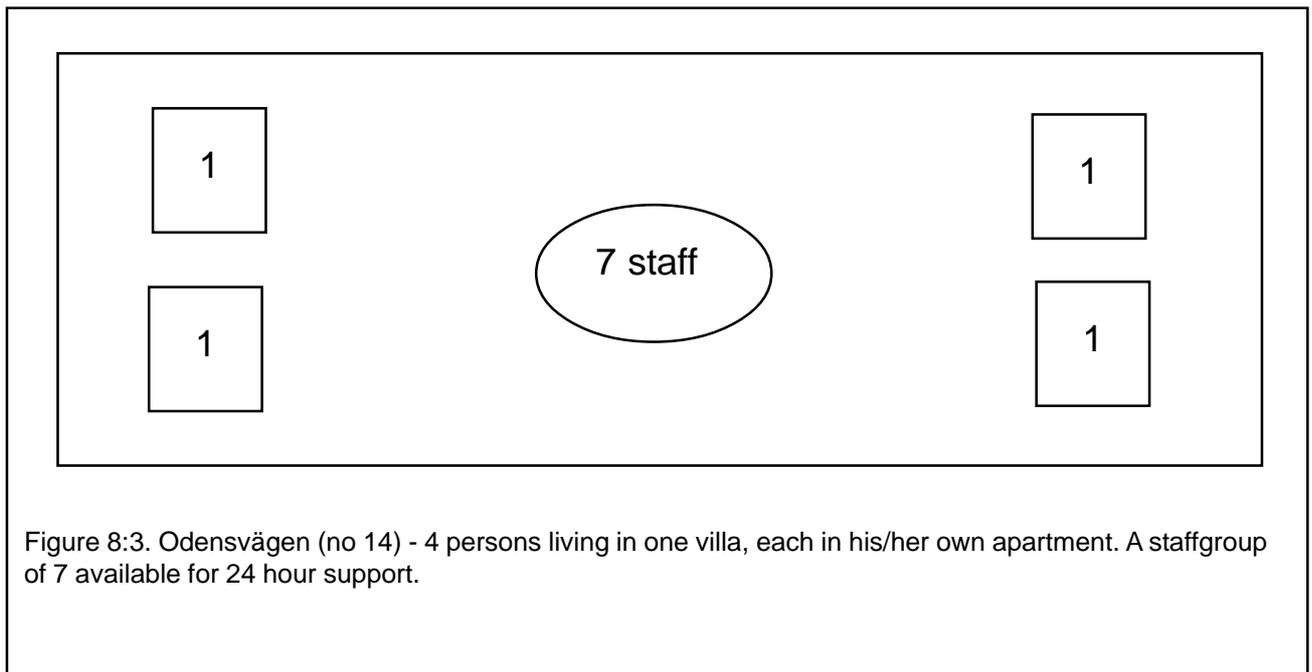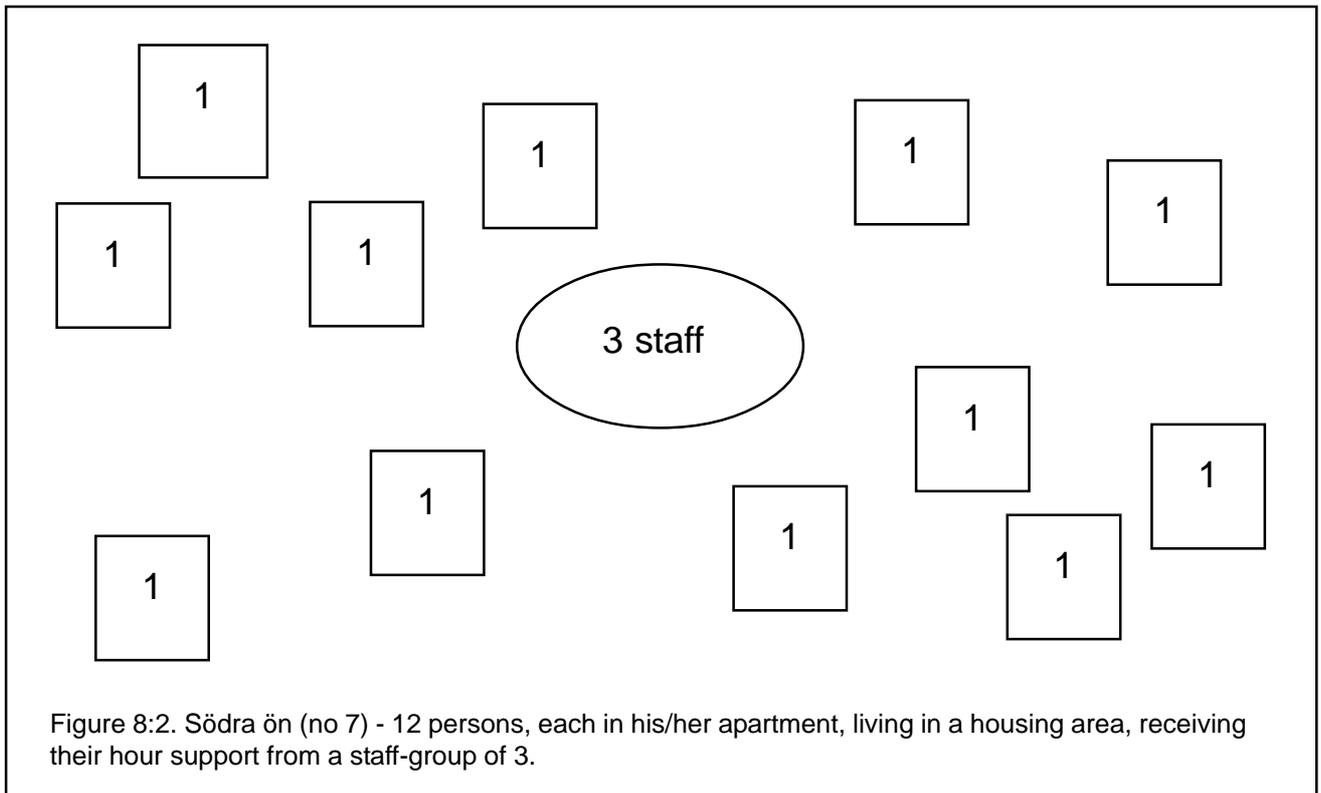
Figure 8:1. Housing with support in Lidingö, located to the housing areas of the community. The numbers in the figure are the different houses. Their names are given below.

1. Eklövet (5)
2. Brevik 1 (4)
3. Brevik 2 (4)
4. 29:an (4)
5. Kappsta (5)
6. Ankaret (5)
7. Södra ön (12)
8. Högsätra (10)
9. Karlavagnen (5)
10. Ungdomarna (2)
11. Lejonet (5)
12. Torsvik (5)
13. Friggavägen (8)
14. Odensvägen (4)

Personal assistance is a way of arranging support from assistants to the home of the person. This is primarily a service for persons with a severe disability. This service is organised so that the person with a disability is provided with a sum of money with which to purchase 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 within his own home. He can choose the assistants himself, together with his representative and with such support be in charge of those who provide his assistance. As the task of the assistant is to assist, support has become very personal. This has increased the possibility for the person to control his own life.

As assistants are appointed for a person, not attached to any special type of housing, he can choose whichever 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. Personal assistance can be given to people with extensive needs for support and the family can

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Figure 8:2. Södra ön (no 7) - 12 persons, each in his/her apartment, living in a housing area, receiving their hour support from a staff-group of 3.

Figure 8:3. Odensvägen (no 14) - 4 persons living in one villa, each in his/her own apartment. A staffgroup of 7 available for 24 hour support.

become involved in arranging housing. This system of personal assistance contrasts with the group-home, which is a specially designed house owned by society, with special staff attached, whose task it is to provide support to those who are placed there. Today 47

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Figure 8:4. Friggavägen (no 13) - In a house with apartments for families, one entrance to 8 apartments is used for the delivery of support. 8 persons, each in his/her apartment, receive 24 hour support from a staffgroup of 6, located to a separete apartment.

persons have got their support from personal assistants.

There are 14 housing units with support in Lidingö. Figure 8:1 shows how these are spread over the municipality. This shows their name and how many live there. These houses vary as regards degree of support. They also vary with regard to who is running them. The Department for Services to the Elderly and the Disabled run some of them while others are run by private entrepreneurs. These are companies specialized in running housing with support. One is an exception as this is a cooperative run by parents.

These 14 houses illustrate different ways of solving the task of providing support for persons. Some models are shown in figures 8:2, 8:3 and 8:4. In figure 8:2, "Södra ön" (No 13) illustrates how 12 persons live in a housing area, each in his/her own apartment. They receive their support from a staff-group of 3. This is based in a separate apartment in the same housing area. Figure 8:3 illustrates "Odenvägen" (No 5) where 4 persons live in a villa, each in his/her own apartment. A staff-group of 7 is available for 24 hour support. In figure 8:4, "Friggavägen" (No 3) is another illustration. This is a house with apartments for families, with several entrances. In one entrance there are 8 apartments which are used for the provision of support. These 8 persons, each in his/her own apartment, receive 24 hour support from a staff-group of 6, located to a separate apartment.

Daily activities with support

Day services were previously the task of the special county organization so when persons from Lidingö would avail of this service they were placed in day activity centres in various places in the county. No guarantee was given that they would be offered these

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services in Lidingö, their home community. In 1985 the town of Lidingö choose to run this day-service, based on a contract with the county. For several reasons it was not seen as a suitable solution to build a day activity centre. Instead a model was developed which emphasized the need to participate in the local activities of Lidingö. In 1985 eight persons werein need of daily activities with support. Today there are 75 persons in availing of this service, spread in small groups throughout Lidingö. As this is an island, the name for the group is "Ö-gruppen" ("The Island group").

The basic idea represented by this model is that focus is shifted away from the day activity centre to the activity-group. It is then no longer necessary to look for buildings suitable as centres, but instead of places in the community, where these activity-groups can settle. The model based on a number of activity-groups can be described as follows:

a. *The daily activities in which a person is involved are those which occur within his local community, these being carried out in places and environments where other citizens are involved in similar activities.* In a local community there are many activities in which a person with intellectual disability can participate. The task is to pursue or find these activities. Around these it is then necessary to create a setting, adapting it physically and socially in order to provide a stable and secure relationship to the local community.

b. *When several persons together have formed an activity group, it will be characterized by the needs of its members, its localization and the nature of the support provided.* The activity group will be characterized by the interests of its members. Different groups will vary in character if the participants´ activities during the day are individually chosen. If the specific needs of a group are to be met a high degree of independence for the group, in relation to the organization to which it belongs, will be necessary. Consequently, the organization should be highly decentralized.

c. *To enable an activity group to carry out its tasks with a high degree of respect for personal requests and the characteristics of the group, support from others, outside the group, will be needed.* A decentralized responsibility needs to be supplemented with support from outside if the group is to be fully equipped for its task. Professional support is needed to give advice regarding the specific needs of the persons. Knowledge about running such an activity group and methods for organizing activities, is also necessary. There is also an administrative responsibility within the group for which help from outside is required.

d. *If the daily activities provided are to have the function of personal support, a continuous dialogue concerning the dreams and the realities of the good life of a person, must take place.* As the task of finding adequate support for a person stems from the person´s initial request, and the legal right to appeal, a continuous discussion concerning the needs of the person must take place. This dialogue involves the person, and his representative and a representative for the services and is concerned with what is thought to be a good life for the person. It is this ongoing exchange which is the basis for the choice of activities.

e. *A series of activity groups in a community together make up the organization responsible for providing support through daily activities.* This model shifts the focus from the day activity centre to the activity group, with the objective of establishing a support system which contributes to participation in community life for the person. The group becomes the nucleus of the service, personal needs being met with suitable activities, these taking place in settings found suitable for the group. With the activity group as the core, a series of these together constitute an organization responsible for the daily activities which support persons with intellectual handicap in a community.

There is a risk that groups such as these be simply spread around a community without establishing a relationship to the part of the community where they are located. The ambition with "Ö-gruppen" has been to assure that an activity-group has a function
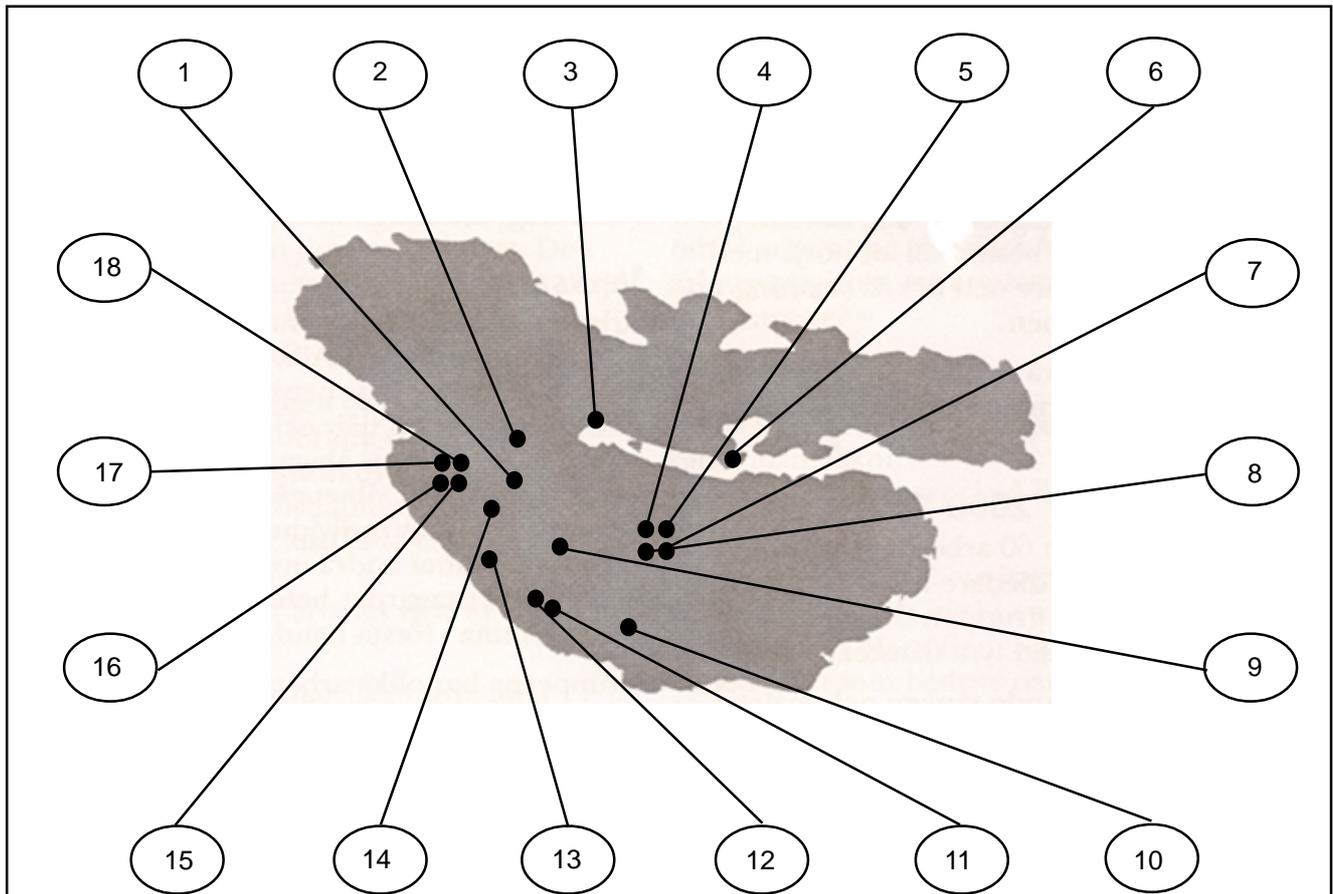
Figure 8:5. Ö-gruppen is the day service delivering daily activities with support to adults. It is organized as 18 activity groups. This figure shows how these groups are spread over Lidingö. The names of the activity groups are given below. They are presented in more detail in the text.

1. Kontorstjänsten	7. Matpatrullen	14. Arbetshuset
2. Resursteamet	8. Dataverkstan	15. Textilverkstan
3. Canada	9. Ö-gruppens kansli	16. Tvättbubblan
4. Stallgruppen	10. Dalénum	17. Ejdans
5. Naturgruppen	11. Hålligång	18. Ö-gruppsbutiken
6. Hugestaholm	12. Hantverkarna	
	13. Baggeby	

in relation to the local community. "Matpatrullen" (No 7, the Meal-patrol) could best be described as a social firm. They are organized like a business, with the task of delivering meals to old age pensioners in Lidingö. In this way they serve more than 100 people with their daily lunches. To do this they have organized themselves so as to be able to take orders from the pensioners, to collect food and drink from restaurants and to organize the daily

delivery of the meals. This is done within the framework of a social service so the task is at all times to see to the well-being of persons, not to productive goals expressed in economic terms.

In figure 8:5 you will find the 18 activity groups of "Ö-gruppen", spread around Lidingö. This illustrates the consequences of implementing the model built on a series of groups instead of a specialized centre. The following is a brief description of these groups. Numbers here a related to the numbers in figure 8:5.

1. "Kontorstjänsten": All the paper-work of an office provides the tasks for this group. The majority of the jobs come from the Town Hall, where the activity group is located.

2. "Resursteamet": The resource-team consists of 3 occupational therapists and 1 physi-otherapist, working with cognitive and technical disability aids, plans for personal development and training programs.

3. "Canada": Recycling is the theme for this group, material being collected from compa-nies and private people. Some of the recycled material is used by local pre-schools. Once a week the group cleans the cars for "Matpatrullen".

4. "Stallgruppen": This group assists with the activities concerning horses, taking place in a private stable.

5. "Naturgruppen": The group carries out tasks according to the requests of customers, which can mean tending to gardens or the clearing of trees. But they also work with computers.

6. "Hugestaholm": This is the place where a group is occupied with the chopping of wood into a size suitable for an open fire. This fire-wood is sold to local people.

7. "Matpatrullen": The group is responsible for the ordering of and the distribution of the daily lunches to old age pensioners in Lidingö.

8. "Dataverkstan": This work is centred around the computer as a tool, with the writing of texts and handling of pictures, for several types of material used in "Ö-gruppen" and generally in Lidingö. The home-page of "Ö-gruppen" (www.ogruppen.com) is produced here.

9. "Ö-gruppens kansli": The office of "Ö-gruppen" consists of a manager and two assist-ant managers. They deal with administrative tasks and the support to staff in the activity-groups of this day service.

10. "Dalénum": The main task of this group is the packaging and assembling of products, for several companies in Lidingö. Other activities also take place which gives variation to the activities of the week.

11. "Hålligång": In this group a lot of physical activities take place, often through walks in various places of Lidingö. Activities enhancing communicative skills are also offered, as well as a lot of creative tasks.

12. "Hantverkarna": The group makes a number of products from wood. On Mondays it is the task of the group to tidy the public notice-boards in various public places of Lidingö. They also have responsibility for various tasks for other organiza-tions in Lidingö.

13. "Baggeby": This is a place where programmes for personal development are being arranged. Examples of these activities are sensory stimulation and physical activity.

14. "Arbetshuset": This group work with jobs received from companies based in Lidingö and in Stockholm.

15. "Textilverkstan": This group makes their own designs which they then print on cloth. From this various products are made which are on sale in the shop (No 18) of "Ö-gruppen".

16. "Tvättbubblan": This is a laundry which receives jobs from the public.

17. "Ejdans": This is a lunch restaurant for persons and staff of "Ö-gruppen".

18. "Ö-gruppsbutiken": This is the shop where the products of "Ö-gruppen" are on sale: it is open 4 days of the week.

Leisure activities for persons with a disability

This programme of activities is organized by the Department of Culture and Leisure of the municipality, a department whose task is the organization of these types of activities for the people of Lidingö. In this way it is an illustration of the idea that the services for the public are open for persons with a disability.

"Supervision" for children attending special school, who are 10 years of age and older. This takes place at the leisure centres of Lidingö during afternoons, when school is finished. Some activities are aimed at all young people, while there are some specially organized for those who attend the special school. During school holidays this supervision can be open all day.

"Everyone´s house" is a place with a wide variety of activities open for adults with a disability. These take place in the afternoon and evening. The activities can be organized as courses or as informal groups which work for example with handcraft or cooking.

"Short-tem relief during week-ends" in the form of week-end camps. These take place between 6 pm Friday and Sunday evening. The intention is that the family get some relief while the child is away at camp.

"Camps during holidays" is naturally most common during the summer. This is the period when a number of special arrangements are organized according to taste and interest.

"Hobby and culture" offer activities like cooking, theatre and library and books.

"Sport and physical activity" offer a number of activities like swimming, riding, gymnastics, bowling, hockey and skiing.

"Entertainment and pleasure" arranges a café, disco-evenings, social clubs and parties during the various seasons of the year.

Services for health, well-being and personal development

"Förenade Care" is a private company which has a contract with the "North-Eastern Health Board" of Stockholm county. One of their tasks is to be responsible for health and medical support to persons who receive services according to LSS. Basically these are persons in group-homes and those using the services of "Mobilen". Persons who prefer however, can attend their general practitioner and the local district-nurse while declining support from "Förende Care".

Discussion

Intellectual disability services vary between municipalities depending on the fact that conditions for organizing services are different. In previous chapters it has been stressed that the services which are actually offered are the result of a process incorporating the conditions which exist. One factor in this process is the needs of the persons requesting public support, another is the support provided by the person´s family. This is not the place for a full analysis of the process leading up to an understanding of the disability services being offered today. Some can, however, be referred to.

An important factor is the character of local resources, not merely economic but even the general circumstances seen in a wider sense. Type of housing, business life and possibilities for recreation and leisure in a community are important factors when a person´s everyday life is formed.

Time is a factor in this process. When services have been created over a number of years, they have been built on experiences which have gradually been gained. At one time some models may have been seen as desirable, while at a later stage, other models have been preferred.

An important factor is however the fact that this community has the desire to take responsibility for persons with a disability who belong to the municipality. It is necessary to stress the fact that this is a small and local community, not a town which is part of Stockholm, the capital. This, for example, was one factor which contributed to the fact that the day service, today called "Ö-gruppen", once became a matter for the municipality.

To respond to the needs of the people of this municipality, the department responsible for disability services have chosen a type of competence which responds to local needs and conditions. Lidingö thereby have avoided using the centralized and large-scale models which were common in the county during the period when they were responsible for organizing the special disability services.

An attribute of importance, which has not been fully presented here, is the fact that an active parents´ organization has existed and over the years promoted the needs of persons with intellectual disability. In this way they have given a voice to the needs of these persons.

Kent Ericsson and Kerstin Lundberg: Intellectual disability services in Lidingö

A SOCIAL POLITICAL IDEA
AND ITS REALIZATION

Kerstin Lundberg

INTRODUCTION

Every person needs support, stimulation, security and solidarity in order to thrive and develop as an individual. Some of us have greater requirements than others, or we may need to have them met in a different way, perhaps because of an intellectual disability. Our task within the Services for Special Support is to offer a service in a manner which enables the person to live the sort of life he himself wishes.

Our goal is to provide an individually adapted, purposeful and fulfilling activity for the individual and to further his full participation in community. The person should be given the opportunity to live an independent life, with respect shown for his individual wishes and personal integrity. In the housing situation a person with intellectual disability should be able to experience a feeling of home, freedom and security with personal support and have the opportunity to enjoy a meaningful leisure.

All the services for persons with intellectual disability are provided within the same organisation which is included in the Department of Services for the Elderly and the Disabled. To ensure cooperation both housing and daily activities are the responsibility of the same organisation .This also enables the staff to maintain a common comprehensive perspective regarding the needs of these persons. The organisation for the provision of daily activities goes under the name "Ö-gruppen" ("The Island Group").

SERVICES FOR EVERYDAY LIFE

Daily Activities

Initially the group was comprised of 8 participants and 3 staff members. From the beginning the goal was to create an awareness of, and respect for, persons with intellectual disability within the community. No special building or house was built for the provision of daily activities and there was no decided number of persons for whom the service was provided.

Today the groups vary in size from two to eight persons. The fact that the groups are small facilitates their integration into the local community. The activities of Ö-gruppen are available to all who have a right to the services according to current legislation, who request and are found to be in need of this service. The person´s degree of disability can vary from those with a severe intellectual disability with additional handicap to persons with a mild disability who have not acquired regular employment on the open labour market.

Each group works independently with responsibility for the daily activity being carried out and for their own budget. The staff, whose title is "group leader", are personally responsible depending on the specific task for the daily administration of the work, bookkeeping and staff replacements. Each of the participants has a personal working plan as a basis for their daily activities. The daily activity should be purposeful for each individual and all should be able to feel that their contribution is meaningful not just for themselves but also for others. In several of the working groups the tasks carried out have consequences for others which implies that each person´s need for a personally adapted activity has to be seen in relation to the requirements of the assignment or needs of the employer.

In this situation the needs of the participant must be given priority. Depending on the particular needs, or personal problems of the participants, each group varies in their working patterns and methods. The development of the work must be based on the needs of the participants. Each question or problem must be approached from this perspective. The question to be kept alive is "in whose interest are we employed?"

New participants

Most usual is that the person already lives in Lidingö and very probably is already well known. Contact with Ö-gruppen is usually taken about 2 years prior to the time when the person would wish to join the organisation. The first contact may be initiated by the persons themselves or together with a representative and/or for example a teacher if the person is still of school age. One representative from Ö-gruppen has special responsibility for discussing the issue of daily activities with new candidates. This can often lead to shorter periods of auscultation in one or more different groups and in total covering a period of 6 weeks. It is seen as important that the person is given an opportunity to experience new situations as such can often be seen as rather frightening!

It sometimes happens that a person expresses the wish to participate in an activity which is not currently provided. An example of this, from some months ago, is a girl who wanted to work with dogs. The group leader contacted a local kennel-club which was able to arrange a period of auscultation at a day-centre for dogs! This girl, with an intellectual disability, is to-day employed as a daily minder at the club. The manager of the centre has thereby taken responsibility for an employee and in return has the support of a staff member from Ö-gruppen who visits the centre certain times of the week. At present two persons are employed at this centre and plans are ongoing to increase the group. Hopefully this can be achieved and the present quality of the service be maintained without having to increase the support provided by Ö-gruppen.

The weakness of the system is however, that the group leader is alone as representative for Ö-gruppen making the situation vulnerable in the event of absent leave or sickness. To counteract this staff members who work alone are always organisationally attached to another group where there are more staff. This means that there are several work-groups who together can provide collegial support and opportunity for discussion of work problems etc. In the event of unexpected absence an arrangement exists with the kennel manager to act as substitute in return for temporary remuneration.

Which work tasks are suitable for the participants in Ö-gruppen?

The basic point of view is that tasks should not be artificially concocted just to suit the person with a disability. Many real life tasks in the community can with adequate support, adjustment or intellectual aids provide excellent work opportunities for the individual concerned.

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Suitable and appreciated tasks also include the provision of services to others. An example of this is the so called "Meal Patrol" which on a daily basis distributes over 100 meals to pensioners in Lidingö. Another example is a group for the delivery of internal post, a group for the care and posting of advertisements on the local notice boards and a group for laundry service for the public authority in the community.

Housing

A person wishing to leave his home, for example after having lived with parents, contacts the official in the municipality responsible for investigating the needs and wishes of the person concerned, together with his/her relatives and/or an appointed representative. To provide individually adapted housing for a person with intellectual disability requires several things:

1. advanced planning and good co-operation and communication with the responsible housing authority,

2. good knowledge concerning the person´s need for support and an open relationship and communication with the relatives/ the representative,

3. established good contacts with the Housing Department, Housing Agencies and local officials responsible for planning, distribution and adjustment of housing.

Naturally the choice of a home is related to one´s own wishes as to how, where and with whom one wishes to live. Some persons with a extensive need for support live together and have comprehensive staff support, sometimes including on-duty night staff. Others live in individual apartments close to each other, with access to support in the morning, evening and at week-ends. A third category live in private apartments with a personal contract and with support needs which can vary considerably.

Young people or elderly persons live together in the category to which they belong, in one large apartment with certain common facilities. Persons with for example Asperger Syndrome do not live together with persons with an intellectual disability, instead having access to specially qualified staff and therefore living in close proximity to each other. They also receive more support for a structured leisure than others.

In the establishment of new housing considerable attention is given to establishing of contacts with neighbours. Initially they are invited to information meetings. Even if many have been reticent or even critical to begin with, today there are no problems concerning contacts with neighbours. On the contrary there are many examples of very good neighbourly relations.

Leisure

Cultural and leisure activities are organised in Lidingö in a separate department which is responsible for such services to all inhabitants, inclusive of those with intellectual disability. This includes activities such as swimming, riding etc. If the public swimming baths requires special disability adjustments, or extra staff are thought necessary for a specific event, responsibility lies with the Department for Culture and Leisure Activities. This department also runs a special facility called "Everyone´s House" especially for persons with intellectual disability, irrespective of age. The programme provided includes activities such as a café, dances, handicraft, special lectures and social gatherings.

As this department is specialised in matters of recreational and leisure activities they are commissioned to organise these services on behalf of the Department of Services for the Elderly and the Disabled, that is inclusive of the persons stipulated in the legisla-

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tion for persons with intellectual disability. This includes afternoon services and week-end activities for children whose parents need relief and camp activities during winter and summer vacations.

The leisure activities organised by Lidingö are extensive and well made use of. Persons with intellectual disability meet each other in varying groupings dependent on their recreational interests. A good example of this is a Bowling Club with 35 members. They practice once a week and take part in competitions throughout Sweden. Even organisations like Lions and Rotary in Lidingö challenge this Bowling Club.

Additional Services

The Department of Services for the Elderly and the Disabled also runs transport services for persons who, because of their disability are unable to use the ordinary public transport system. This also enables the service to offer a personal choice. During the winter when there is ice on the streets it is possible to have the security of a special service whereas in the summer it is adequate for the same person to use the ordinary public transport.

With the help of special intellectual aids many are able to use the normal bus service and to be able to travel alone on a bus which gives increased self assurance and pride for many of the participants. Many social contacts have been established on such journeys. It has also led to a greater familiarity with the local community and thus enabled persons to find their way to shops, post-office etc. There are five local Health Centres in Lidingö where persons can visit the doctor, dentist, physio-therapist, dentist and others. Which facility one avails of is a personal choice as for all other citizens!

IMPORTANT FACTORS FOR THE DEVELOPMENT OF THE SERVICES

Attitudes and values

A question I often meet is whether there are more persons with intellectual disability in Lidingö than in other parts of Sweden? The answer is that this municipality does not deviate statistically, but perhaps this group of persons are more visible here on the buses, in shops and at the lunch restaurants. The local inhabitants in Lidingö have for many years been accustomed to meeting persons with intellectual disability. Most people who have not met this group may initially feel uncertain and unsure as to how to approach such a person. But if they are around in the community, knowledge and awareness spreads like rings on the water!

Staff have of course an important role in this process. Each newly appointed staff, permanent or temporary, receives a personal introduction from a member of staff in Ö-gruppen when issues concerning values and attitudes are given central importance.

As already mentioned there are no segregated environments in Lidingö! No special houses have been built, no special dining rooms or other facilities for persons with intellectual disability. These persons are included in the ordinary community in a natural way.

Time

An important aspect if the integration of persons with intellectual disability is to succeed is that it must take time. We had the advantage of starting our activities on a small scale, in a limited area, but with a clearly defined task. To change attitudes and create an awareness of values also takes time. Persons with intellectual disability and their relatives also

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need time to think through these issues and to make important decisions. Staff involved must also have time for advanced planning with regard to new activities or new premises and even more so with regard to new housing.

Relatives

Our most important partners in this task are the relatives. In Lidingö there is a very active, knowledgeable and interested parents association, FUB. Two of the board members are persons with intellectual disability. The municipal office has close co-operation with this organisation and regular discussions concerning current matters, for example housing issues. The parents of those who are still young are closely involved in the well-being of their child, whereas those who are older can be represented by a support-person, especially if the parents are themselves elderly. However, it is emphasized that the person himself is given the opportunity to influence his own life, especially in everyday matters. This is the subject of special interest in the local project of STEPS, viz. the development of a system of seasonal meetings.

EXAMPLES FROM THE SERVICES

Example 1

Lisa is 40 years of age and has a mild intellectual disability. Previously she worked in a sheltered workshop in a packaging department but had been unemployed for some years. Her dream was to work in catering. When it was decided that she could join Ö-gruppen she began at a unit specialised in developing contacts with the ordinary labour market and in preparing and supporting persons seeking employment in ordinary places of work.

Lisa spent her first year in preparation, with emphasis on important issues for the task in which she wished to participate, in this case good time-keeping and personal hygiene! Such preparation takes time. The goal need not necessarily be full-time employment, part-time may be more suitable. To begin with the contact with the group leader can be quite intensive and later be gradually reduced.

Lisa now lives in her own apartment in an ordinary housing block. To begin with staff gave her morning and evening support on a daily basis, today a couple of times a week is adequate. Her leisure is spent mostly with a friend with whom she chooses activities in which she herself is most interested.

Example 2

Lars is 30 years of age and has participated in Ö-gruppen for 8 years. His fine motor ability is poorly developed, he can neither read nor write and has difficulty understanding verbal instructions. When he joined Ö-gruppen he showed extreme anxiety and could be obstreperous, often requiring 2 staff to support him. It was difficult to find an activity in which he was interested. Indoors he was most anxious, whereas outdoors he seemed to be over-stimulated.

Eventually it was discovered that working with firewood was something that gave satisfaction. With the help of pictorial communication staff could show him and give him the support he needed in order to understand and become interested. To start with he had only one task to be carried out. Today he has several tasks concerned with the different aspects of preparing the firewood and with the help of his pictorial material his relation to his work-mates is harmonious and free from conflict and it has been possible to reduce the amount of staff support.

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For some years Lars has lived in his own apartment. To begin with it was not easy but he now seems contented and now participates actively in some recreational activities. His relationship with his family and siblings, which previously was described as being "stormy", is now seen to be good.

Example 3

Karl, who is 21 years of age, has both an intellectual and a severe physical disability. He uses no verbal communication but is both alert and aware in relation to his surroundings. He has access to a personally adapted work environment with individually adjusted technical aids for his computer, a purposeful task with which he expresses his personal satisfaction. He carries out a meaningful task and knows that his printing job is valuable for others. An important factor is that his personal name appears together with the logotype.

Karl moved recently from his parental home to his own apartment, which is in close proximity to other apartments for four other young persons with disability. As he is in need of extensive personal support he has access to around-the-clock staff. The task that now remains is to discover which recreational activities he would enjoy participating in.

CONCLUSION

In the municipality of Lidingö the conditions for full participation in community life have been developed for persons with intellectual disability. The intention from start has been that these persons should be both visible and respected in the community. During the process of developing the services there has been no reason to question or modify this goal. The services have expanded and to-day can offer all those with intellectual disability in Lidingö, personally planned housing and daily activities. By being constantly receptive to new ideas and wishes, from both the persons themselves, their families and the employed staff, the services can continuously change and develop. It takes time, but it brings rewards!

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INFLUENCING ONE´S EVERYDAY LIFE:
ON SEASONAL CONVERSATIONS
IN DISABILITY SERVICES

Kent Ericsson and Patricia Ericsson

TWO TRADITIONS OF SUPPORT

A shift between traditions of support

The introductory chapter presents the Swedish disability reform as it has evolved during a 50 year period. The changes which have taken place have not, however, been random. Instead, they have, to a high degree, been inspired by the socio-political idea of 1946 which can be seen as the vision which provided the direction for reforms. In order to realize change a solid frame of reference is necessary. One can therefore see this disability reform as a shift between two traditions of support. While an institutional tradition previously dominated support of society to persons with a disability, it has gradually been replaced by a community tradition.

The institutional tradition became established during the latter half of 1800, during the period of industrialisation which was currently taking place. As a consequence of the demands being made on the population, persons with a disability, those who were unable to meet the new demands of society, became visible. One outcome of this development was an awareness of the need to provide support for these persons. This was achieved through the establishment of institutions of various kinds. Each disability group was provided with the type of institution which was believed most suitable to meet their needs. In this way the foundation was laid for the establishment of institutions, specialized for different groups. While one type was intended for persons with intellectual disability, another was established to provide for persons with psychiatric problems. Persons with epilepsy were specially provided for, as were those who were deaf or blind. By way of such institutions it was possible to provide for those whom society regarded as deviant.

The tradition of support which evolved during the 1940:s had a community orientation. This envisioned a social welfare system which was extended to include all, the view being that persons with a disability would also be given the opportunity to live a life as lead by others. Acceptance existed regarding the fundamental value of these persons´ right to participation in the everyday life of their community. A democratic optimism prevailed, while internationally the establishment of the UN and the Declaration of Human Rights, provided the basis for a natural endorsement of this community tradition.

What is illustrated by these traditions is that the type of service chosen for persons with a disability reflects existing conditions in a society. The institutions which were established during the 19th century were natural to that society. In the welfare society which one aimed at establishing 100 years later, entirely different conditions existed. It could then be conceded as natural to recognize the rights of these persons to participate in the life led by others. From this perspective the idea behind the Swedish disability reform can be seen as quite natural in the society in which it has evolved.

Disability services in the community tradition

The Swedish disability reform is an expression of how one can succeed in realizing forms of services which reflect and belong to the community tradition. A number of services have been created which did not exist at the commencement of this process, that is to say, during the 1940:s. Education is no longer provided in special school institutions but instead is found within the framework of the ordinary school system.

Various kinds of housing has been created, making it possible to provide support to persons within the framework of their own home. Daily activities are also provided, outside the home, in varying settings and environments in the local community. Experiences and knowledge has also been gained regarding the dissolution of the large institutions. These are just some illustrative examples of the many social innovations which have taken place in the realization of the community tradition.

As already mentioned, the shift in administrative responsibility for persons with intellectual disability to another authority, the local municipality, has led to a further development of new forms of support which are natural to the new circumstances. It is this task which is the big challenge of to-day. To tackle these issues requires an active process to bring about an awareness regarding the implications of providing services within the new tradition.

The basic idea: The origins are to be found in the socio-political idea from the 1940:s when the democratic rights of persons with a disability, to avail of the services of the welfare society, were recognized. Here one finds an expression for the idea of regarding these persons as full citizens. During the following years one also finds, within the UN framework, a further development of the basis for the community tradition. The Human Rights as they were formulated by UN in 1948 offered implications which have been gradually developed since then. To-day there are several declarations on which these human rights are based and which together provide the platform from which the UN can take action. The essence of the perspective which this tradition represents is that persons with a disability are not a deviant group but instead belong to the human community with the rights and obligations which are attached.

The task of disability services: Within the community tradition the person with a disability is not characterised by his disability but by the fact that each one is first and foremost a person and a citizen. As such one is in need of, and has a desire to live a good life like everyone else. Based on this the task for the disability service is to contribute towards the realization of the good life. In consequence persons with the same disability cannot be regarded as a group, in need of the same service and support. Instead they are seen as a number of persons with differing needs and wishes.

What then comprises a good life? It consists of both the desire to live an ordinary everyday life as well as accessing the support required for personal development. Everyday life consists of, amongst other things, access to good housing and a home, employment or other daily activities, leisure and recreation as well as social relations with family and friends. Already this implies variations between persons regarding needs and wishes about one´s everyday life. Concerning personal development an individual´s

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requirements are related to, for example, the persons disability, health and other aspects of life one may wish to develop. These issues are also personal, as it is not necessarily so that everyone with an intellectual disability has the same wishes or requirements regarding their personal development.

What sort of life does the person wish to live? Responding to the task of contributing to a good life for the person with a disability, requires that a general answer to the issue of the goal for disability services is formulated. But does one know the implications for a person? There is no general answer to this question, the answer can only be found with the person himself. It is only the he knows what sort of life he wishes to live! To get an answer to this question it is necessary to ask the person himself. This is therefore the initial question in the task of formulating which services are to be offered to the person.

A conversation between the person and his staff: Within the community tradition there is no given solution regarding the character of services provided. Instead they become personal and thereby more related to what contributes to providing a good life for the person. Such assistance, based on the outcomes of the process of interaction arising between the person, together with his representative, and those responsible for providing his service, determine the extent and manner in which a good life can be achieved.

The process is therefore depending on whether conversations take place between the two parties. This relationship should be compared with that which takes place in the application of the Act of LSS, which provides the legislative framework for the provision of disability services. The person applies for a service which is then offered, and which can be appealed against if not considered suitable. Such conversations require, and are presumed to reflect, a relationship based on equality and which leads to an agreement which is respected when being realized.

A personal everyday life with local resources: The life the person wishes to live becomes a reality through his/her daily experiences. When the person has expressed his/her wishes, and the responsible authority has provided the support and service sought, then the person has acquired the everyday life which was requested. Within the community tradition two demands are made regarding everyday life. One is that it is personal, in order to meet the individual´s requests regarding what is a good life. The second requirement , as expressed in the fundamental idea of the community tradition, is that the ordinary welfare services are made responsible, and local resources available, to provide the content of the everyday life of the person.

Has it become an everyday life with quality? In a process orientated service, as is the case with the community tradition, there is a risk that the needs and wishes of the person get lost, or are mismanaged. It is therefore necessary to find a form of control regarding whether the everyday life provided has a content, and quality, relevant to the task of providing a good life for the person. The answer as to whether it is a life with quality is to be found in the relation between the original question regarding what life the person wishes to live, and a description of whether the everyday life provided does actually contribute to its realization.

SEASONAL CONVERSATIONS

In a project concerned with the development of services for persons with a disability, working methods were sought which would provide ways for a person to be given the opportunity to influence his own life according to the spirit intended in the community tradition. This resulted in a method which came to be termed seasonal conversations. The purport of this term was to provide, within his housing and daily activities, regular accessibility to a series of conversations which would give him the opportunity to influence his everyday life. In order to provide a structure for these conversations it was found

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purposeful that they be carried out in such a way that the person could participate in planning each of the seasons of the year. As there are four seasons it is possible for a person to participate on four occasions during a year.

As the seasonal conversation is in the interest of the person it is he who decides whether they should occur or not and under what terms they take place. According to the wishes or needs of the person a representative is invited to participate and to assist. The other participant in these conversations is a representative for the service, in housing or daily activities, being availed of by the person. The intention is that within this small group to provide the opportunity to have an open discussion on the issues of importance to the person and for the person to participate in the planning of everyday life in the immediate future. Any questions considered important to the person concerned can be brought up to discussion in such a conversation.

These conversations are however not only an opportunity to discuss issues of importance for the person. The intention is also that they can lead to an agreement as to what should happen or take place during the coming season. Such an agreement is expressed in some form of documentation signed by the person concerned, the representative and the staff, the purpose being to provide documentation of the agreement which is accessible to all parties. Such a conversation can result in a number of agreements regarding activities during the coming season. In this way the person has been guaranteed influence over the events of coming daily life.

The conversations which have taken place have generally been greatly appreciated occasions which have provided an opportunity to discuss matters important to the person concerned. There have also been occasions when one has not necessarily been in agreement. In such a situation the conversation can have the character of a negotiation. A conversation can also be postponed to a later occasion. The important matter is that a conversation takes place at the will of, and on the terms of, the person concerned. These conversations are not a new type of case conference which is initiated or administrated by the service provider. It is their prerogative to initiate such a conference if found desirable.

Regarding the practical realization of a conversation it is essentially on the initiative of the person concerned that it takes place and it is their prerogative to have views as to where and when it should take place. It then becomes the responsibility of the staff concerned to see that the event occurs. Documentation of agreements made are also seen as a task for which staff is responsible.

The current seasonal conversation includes a follow-up of the events of the previous season with regard to the agreements made on the earlier occasion, and their implementation. This also provides further opportunities for a discussion of the person´s everyday life and how he wishes to live it. It is also the occasion on which possible non-fulfilled agreements, and the cause of this, can be discussed.

Within an organisation which utilizes seasonal conversations as a working method it is possible to see it as a basis for a quality review, or audit, of the total service. The term functional quality is used to examine whether events or activities have contributed to the realisation of a person´s wishes regarding his life. Agreements which have been realized, are to be seen as the fulfilment of the person´s wishes. When one later, for example at the end of a year, analyses the extent to which agreements have been fulfilled one can find either a high or low degree of realisation. This can be taken as an expression for the quality of the support received by the person. If this type of quality is examined for all persons within a group, one then finds an expression for the quality of the entire service.

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Introduction to a project

The present project had the purpose of applying a working method entailing the holding of regular seasonal conversations with persons in order to increase their influence over everyday lives. The choice of localizing the project to Lidingö municipality was based on previous co-operation concerning the development of disability services. It is also a municipality which has created a service culture open to the ideas and views on which this method is based (Ericsson and Ericsson 2004).

Within the framework provided for the project it was possible to offer participation to six persons. The proposal included that persons with varying degrees of disability should participate. Each should also have a representative, a family member or a legally appointed representative, to assist them during the period of the project. A member of staff from housing as well as their daily activities, was also appointed. The management group consisted of a researcher from the Department of Education in Uppsala, a person with responsibility for the provision of services in Lidingö and a person with responsibility for financial affairs in the municipality. In addition a consultant, with qualifications and previous experience of working with seasonal conversations was included.

Persons, their representatives and staff, together with service administrators and the management group were those who constituted the project group.

After the establishment of this group a period of preparation began to introduce the seasonal conversation as a working method. The program consisted also of a presentation of the implications of the community tradition and the person´s right to influence and control his everyday life.

Following this introduction a series of seasonal conversations took place during a working year. The objective was that each of the six persons would participate in four conversations within each of the his two services, housing and daily activities. The staff appointed for participation in the project had responsibility for seeing that the program was carried out. The consultant in the project group was assigned to follow-up and support this aspect of the project.

After the end of the year experiences gained from conversations were documented, the basis being personal interviews with all who had participated in these conversations. The purpose was to collect the experiences by those who had participated in the conversations. A questionnaire was also administered in order to describe the views of the project group regarding this method.

Completion of seasonal conversations

During 2003 seasonal conversations were held according to the plan for the project. Prior to the interviews which took place in February 2004 a review was made over the number of conversations which had actually taken place. According to the model for the project the expectation was that for each person four conversations could have taken place concerning housing, and four with regard to their daily activities. It was also intended that each person should have an appointed representative.

The outcome for the year was as follows. Person 1 is to be regarded as an "absentee" because of ill-health at the start of the project, therefore being unable to participate as planned. For the remaining five persons the program was carried out as follows.

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Person 2: 2 conversations of 4 concerning housing, 3 conversations of 4 in daily activities.

Person 3: 4 conversations of 4 concerning housing, 4 conversations of 4 in daily activities.

Person 4: 4 conversations of 4 concerning housing, 4 conversations of 4 in daily activities.

Person 5: 5 conversations of 4 concerning housing, 4 conversations of 4 in daily activities.

Person 6: 4 conversations of 4 concerning housing, 3 conversations of 4 in daily activities.

Of the 20 expected conversations concerning housing 19 (95%) were carried out, and of the 20 expected conversations in daily activities 18 (90%) took place. These figures relate to the conversations which took place during 2003. In reality these conversations have taken on the character of an ongoing process, with individual variations. Person 5, for example, requested a greater number of conversations regarding housing during 2003. For person 3 a 5th conversation was planned regarding daily activities, and for person 6 the 4th conversation concerning daily activities was already planned to take place. It should also be mentioned that person 1, who is recorded as non-participating, was not excluded from the project: her staff supporters continued to participate and in relation to the person acted according to the intentions and principles of the project, even if formal seasonal conversations could not take place. Regarding the participation of an outside representative four of the five participants had such support. One person had chosen not to be assisted by a representative. Of the four participating representatives three were a parent, the fourth an appointed guardian.

INTERVIEWS WITH PERSONS, THEIR REPRESENTATIVES AND STAFF

A series of interviews were carried out with all of those who had participated in the seasonal conversations during 2003. The consultant to the project did conduct and documented them. An interview began by addressing the main issue, namely how the participant felt about the use of seasonal conversations as a working method. The situation was however characterized by it being an open interview where the opportunity was given to freely express views held regarding the methods which had comprised the project. This allowed for the persons themselves, their representatives and the staff from housing as well as daily activities to talk of their experiences and impressions from having taken part in these conversations.

When the term "contact person" is being used, it refers to the member of staff with explicit responsibility for support to a person to whom the staff member has been allocated.

As the persons were allowed to choose where and when the interview should take place, all four chose to be in their own home during their leisure, after their daily activities had ended. The interviews with a family member and a representative took place on one occasion in the home, the other at a parent´s place of work. The interviews with the other two representatives took place in premises belonging to the service organisation, as did all the interviews with staff members.

Each interview was documented by the interviewer, concurrently making notes. Later an analysis was carried out based on these notes. For each of the four groups, that is persons, representatives, staff in housing and staff in daily activities, themes were sought which could describe the views of the group. A theme was a way of summarising a collection of common views and opinions expressed in the interviews. When presenting the various themes for a group, they are depicted and their content commented on. In the following presentation the themes from the four groups are presented separately.

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The views of persons themselves

Of the original six persons chosen to participate in the project, five took part in a final interview. According to their own wishes, four choose to participate without their representative, saying they wished to "speak for themselves". They were prepared in advance and informed about the purpose of the interview, time and place having been chosen and arranged in advance by telephone. For one person the interview took place together with the mother as the person was unable to express views unaided. The impression given was that the person understood the content of the interview and could show agreement or disagreement with the mother´s views.

"Good to be alone"

All persons expressed satisfaction over having had the opportunity for a regular time together, their *"own"* time, without being interrupted or pressed for time, watching the clock. That the conversation took place in an undisturbed setting, either in their own home or a secluded place in the premises for a daily activity, was highly valued. Some expressed this appreciation strongly, for example comparing it with how it feels when one is always in, or treated as, one of a group. Being alone, by oneself, just *"you and me"* with the staff member was something highly valued.

"This is the way it should be"

All persons regarded the working method which had been introduced as something natural, to be taken for granted: *"It should be like this …"*. Having an appointed contact person among the staff was not new, but the opportunity to develop a more personal relationship was an appreciated experience. All were aware of the fact that they had a contact person but the role the person was assigned in the project was a new development which was viewed positively: *"Now we know what they are for …"*.

"The choice of contact person"

Two persons also expressed views regarding the choice of contact person, maintaining that they themselves should be able to choose who they wanted. Both age and sex were mentioned as important factors to consider. No-one expressed direct dissatisfaction with the present situation but thought that with the nature of the project it would be better to be allowed to choose. One person declared: *"Next time I want to decide myself"*.

"A time to think about things"

These conversations were not only about practical or routine issues like food, shopping, daily tasks or leisure. The subjects which were touched on also could include more general issues and reflections on life, for example a person´s childhood experiences, wishes to visit places or relatives with whom one had lost contact. Also more general questions about ongoing events which were felt to have an impact on the person´s life. Common for all was the feeling that they themselves had been able to steer the conversation, this being a positive and seemingly a new experience: *"I could think about what I wanted to talk about"*.

But to tell others about these conversations was not taken for granted. The time together was seen as an opportunity to have a confidential talk about issues and views which one did not necessarily want to be spread around in a wider circle and this issue could in itself be part of the agreement made after the conversation. This showed that persons often feel they are exposed, everyone having the right to know everything about them, and that their wish for privacy is not respected. This request was also made to the consultant in the follow-up interviews.

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"Persons do have requests!"

During the project all four persons had discussed issues concerning their housing. One person had expressed a wish for alternative housing and during the period of the project had acquired a larger apartment. Another had plans for a change of apartment which would take place during the coming spring.   Yet another person´s wish to have a garden allotment had been realized during the year. Not only the character of housing but also the content and daily routines were also subjects discussed.

It became clear that persons had views and requests which others had been unaware of, for example, concerning the times and ways in which their support was provided. These experiences illustrate not only the fact that persons do have views which are highly personal, but which others are not aware of, this showing the need for greater sensitivity and flexibility in an organisation, if the person´s wishes are to be heard and respected.

Concerning the person´s daily activities it was said that it was neither new nor different to discuss which daily activities one wished to participate in - it has always been like that. Being allowed to make one´s own choice was therefore not seen as being a consequence of the project or of seasonal conversations. However, it was seen as a change that one could ask or wish for something different and not just to choose from existing alternatives. It was also seen as positive that these conversations took place regularly, and with the same contact person. There was also a chance to talk about daily routines and to be asked to take part in the planning of activities. Having a personal time to talk was not so different, but that this led to a written agreement and a regular follow-up, was seen as both new and positive.

"Even others listen to me now"

It was spontaneously expressed that as a consequence of the project other people cared more about thoughts and feelings of the person. One of the persons expressed it as a fact that being someone who had participated in a project gave a new "status", which meant one was shown more respect for one´s views. Persons also expressed the feeling that having taken part in the project lead to one´s own expectation that others accepted that one had views about things. So now one was expected to be shown more respect!

"Its good to have things in order"

Two persons expressed expectations that the project would lead to getting more *"law and order"* in everyday life. To plan, to make personal agreements and to follow them up regularly was seen as a way of working which appealed to all. Feelings of confusion and not knowing what was going to happen were expressed in different ways: *"One wants to know what´s going on ..."* or *"One never knows anything ..."*. In consequence there were expectations that there would be a change and that they would feel less confused and better able to understand what was going on.

"Influence in everyday life"

Even if the term influence was not used by the persons, the idea they expressed in their thoughts and feelings was the wish to have more influence over their everyday lives. Two persons expressed for example the wish to be able to decide which of the staff carried out certain tasks and also to influence how some tasks were carried out. The perception of the situation is that they are not asked for their opinions. The ideas of having these regular conversations concerning everyday life was seen as a possible way to bring about change.

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"Promises should be kept"

As a natural consequence of the desire for maintaining order, the wish was also expressed that promises should be kept. Those with such views had a good understanding of the idea of having an "agreement" and now expected that these should be respected. The documentation of such agreements varied, depending on the person concerned as well as on the routines and traditions in the organisation. The person´s expectations that promises be kept included a demand that explanations be given when they were not fulfilled. The persons, as well as others participating in the conversations, also had views with regard to documentation and which practices should be applied. This included the use of computer records, formal signed minutes as from a business meeting and handwritten notes in the person´s own "record" book.

The views of the representatives

As mentioned, representatives for four persons did participate in the project. Three of them were parents and therefore had long experience of the services and their organisation. They are also formally appointed guardians. A fourth was a guardian appointed for one of the persons at the start of the project. A fifth person wished to act on his own behalf and refrained from having a representative to assist him.

"Continuity is crucial"

There was a high degree of agreement that the project had been a rewarding and positive experience for all persons and one found it constructive that these conversations were held regularly. Another essential aspect of the project was that the method in itself provided the opportunity for increased insight into the organisation for the appointed representatives. The ambition that this would become an ongoing process was thought commendable. They saw the project as a process they had themselves wished for, but found difficult to realize. This applied especially in relation to housing where the frequent change of staff gave particular rise to the need for such a forum. They now saw that the project had in this way achieved the continuity they had sought.

"There is a challenge in the person´s participation in the conversation"

The fact that staff, and the person´s representative, earlier have met for meetings and discussions has been seen as natural. The idea introduced in the project, that the persons themselves should participate, and meet with a certain regularity, was viewed as a new and positive approach. To talk together with the person has been seen as a real challenge for all.

"Persons have gained experience and taken their own responsibility"

Representatives expressed the view that the persons have defiantly appreciated the project and the opportunity it has given them to influence their own everyday life. They also consider that in addition to being given the chance to participate they have also developed their own confidence and are better able to speak for themselves: *"They will see that this relationship continues - there is no turning back now!"*

"More knowledgeable about services"

As a representative it was usual that the contact with services occurred when there was a crisis, or some important decision was to be taken. The experience which this project has given is that the representatives have been given the opportunity to learn more about the service, and gained greater insight into the everyday life of the person, in housing and in their daily activities: *"One feels less of an outsider in their everyday life when one has a role to fill in the conversations"*.

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"A limited experience which should be extended"

The representatives found it regrettable that the project was so limited, in the number of persons involved and in time. All expressed the hope that it would continue for those already involved and even be extended to include others. Such a continuation was considered necessary if the project was to have a permanent effect, representing a "new culture". Concerning this issue a greater interest and involvement was sought from others within the organisation.

The views of the staff from housing

Included in the project group were staff from housing, the intention being one member of staff for each of the participating persons. Of the original six staff members four participated throughout the project, one was absent without a replacement for a greater part of the project, and one of the persons had two staff members as the one initially appointed left services before the end of the project. The replacement could therefore only participate in the follow-up and counselling meetings, not having taken part in the initial introduction and preparatory programme.

Within this staff group were those who were relatively newly employed without previous experiences from services for persons with a disability, as well as those with many years of experiences. There was also a variation with regard to their educational background. While some had a traditional training in institutional care, others lacked training for disability services, but had other professional qualifications and experiences.

"Confusion in the beginning"

Initially, staff had not been given a choice as to whether they wished to participate in the project, the reason being that participation was related to persons chosen, their contact staff being automatically a participant in the project. In the concluding interview the situation at the start of the project was described as confusing as the staff, to begin with, had limited knowledge about the project. At the same time the persons who had been chosen to take part had great expectations on their staff to support them.

"Appreciated participation"

The prevailing impression expressed in the interviews was an appreciation of having had the opportunity, as a member of staff, to participate regularly in conversations with the person and his representative. The purpose of the conversations, to listen, to interpret and generally to respect the person´s own wishes regarding the services and the life they wished to live, was seen not just as something positive for the persons themselves but also provided a new chance to learn more about the person they were employed to support. All of staff being interviewed regarded this as a long awaited development. Some felt that the project had given legitimacy to a working method which they had themselves sought. It was felt that it was now it was seen as acceptable to take time to listen. To be given the opportunity and responsibility, to meet and talk with the person and his representative, also involved the taking of more responsibility for interpreting the person´s views as to what constituted and contributed to a good life.

"Who should be the contact person?"

In retrospect it was felt that in the choice of contact person, more attention should have been given to the question of the character of the personal relationship between the person and his staff, and that areas of interest of the person was to be given more attention. The significance of sex and age were seen as important aspects to be considered if one is to take responsibility and develop the type of relationship implied in being a contact person. Based on these reflections it was natural that the wider issue of the staff

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role came under discussion. For example, the difference in relationship between being employed by an organisation or authority, or by the persons themselves, as is the case of the personal assistant?.

"A new professional role"

It emerged that most of participating staff saw these conversations as a different way of relating to and to view the person, than the customary way one had been taught. Of tradition one had been expected to refrain from and to avoid establishing a personal relationship to the person and his representative. Instead, one had now seen the need to develop a more personal way of relating to each other. It was agreed that this was a desirable development but that one needed support and advise in finding suitable ways of relating to each other.

The difference between being a professional member of staff and being just a friend was an issue which gave rise to much discussion. For some the approach presented in the project, that it was seen as desirable to develop a more personal relationship, was seen as a personal redress for their views, a view however which was not necessarily shared within their own staff group where they worked. Those who agreed with this approach could find conviction in the experience of reduced areas of conflict between the person and staff. A problem referred to by some was the occurrence of conflicts regarding this issue within the same staff group. In consequence the view was held that an entire staff group should be given the opportunity to participate in a project together.

"New qualities seen in each person"

An experience which was reflected upon was that during the project one had got to know and to see new qualities and characteristics in the person for whom one was responsible. Not only did one see new aspects of the person but also got to understand them better. For some this gave a new dimension and meaning to their task as staff. This was expressed by one staff in her questioning of the term "the residents", an expression which they suggested neutralized the person and prevented one from seeing the unique qualities in each and all.

"A person with a representative"

The development of a new relationship for staff applied not only to the persons but also to their representatives. Apart from it being regarded as formally desirable that the person had access to support from outside the organisation, it was also found enriching that in these conversations staff also had access to the experience and knowledge which a representative contributed. Several staff members pointed to the value of the knowledge and understanding one had gained from the representative who knew the person well, often since childhood. This experience was described as an illustration of the new relationship, where the person could be perceived as a family member and a citizen, with his own background, social identity and history.

"Being an interpreter, but without authority"

There was an element of reluctance regarding the role of a contact person in a staff group, where one feels limited to the role of interpreter. One can support a person in expressing his requests but lacks the authority which can be required to implement them. To accomplish the wishes of the person one is often dependent on other "bodies" who have not participated in the project and have no understanding of the perspective which it represents. The consequences can be that the realization of the person´s requests be limited to what the contact person, as a staff on the ground, can achieve.

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The views of staff from daily activities

All of the six staff from daily activities who had taken part in the seasonal conversations had participated throughout the entire project. Four of those taking part had long experience of working in these disability services, whereas two were recently appointed without earlier experiences from this field of work.

All six of the persons took part in different activities which illustrates the fact that there is an extensive variety of activities made available within the municipality of Lidingö. Activities were provided for one person at a centre for persons with a profound physical disability. Another participated in the "food-patrol", a group which delivers packed lunches to pensioners in the municipality. While others participated in a group doing office work at the town hall, others worked in a carpentry workshop.

"Choice of contact persons was easily decided".

Within daily activities there was a natural relationship between persons who participated in the project and the staff in the activity group in which they participated. It was also normal that one held regular and recurrent meetings concerning the daily activities in which persons participated. The new aspect which was introduced was the regularity of the conversation, the fact that they should occur ahead of every season, and the systematic documentation of agreements arrived at.

"Participation of a representative"

The participation of an outside representative was a new feature introduced by the project. In the area of daily activities there is a tradition that says *"Mum doesn´t come to your workplace!"* But it was agreed that the representative for four persons did take part in these conversations. From the point of view of the staff it was felt to be enriching to develop a regular relationship with the person´s representative. It also gave new insight into the ongoings of the person´s daily activities, something which contributes towards preventing daily activities from being a "closed world".

"To converse with someone who cannot speak"

Two of the persons in the project did not communicate with spoken language, this being the real challenge for a project working with seasonal conversations. The decision to be made was whether to refrain from including these persons in the project. The conclusion was however that even these persons should have the opportunity to have their own *"personal moments"*. A consequence of this experience was an increased awareness of how often one talks about a person, and not with the person. During these so called "personal moments", one began to discover and observe reactions which previously had been unnoticed. One even questioned whether these persons´ ability to understand what was going on in their presence had been gravely underestimated.

"A chance to negotiate"

At times the conversation could take on the character of a regular negotiation. It could include a discussion on conditions and regulations of work such as working hours, lunch breaks or the organisation of an ongoing activity. Examples were given from conversations when a person had views which no-one had previously been aware of but which were highly relevant for the persons carrying out a particular daily activity. In one case this led to the person being given greater scope to influence the organization of the activities taking place.

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Table 1. The four topics of the questionnaire, with 3 questions within each topic. N indicates the number of answers and MV the mean value of the answer to a question.

A. Preparation for the project	N	MV
01. In general I was well prepared when the seasonal conversation took place	(17)	4,9
02. The preparation which took place at the beginning of the project was adequate	(17)	4,8
03. The seminars held during the project have widened my view regarding handicap services	(17)	4,5
B. Consequences for me personally		
04. My view of P has changed in a positive direction after the project	(15)	4,0
05. My participation in the project has contributed to developing my role as representative/staff	(16)	3,5
06. It has been enriching for me to participate in these seasonal conversations	(16)	3,1
C. Consequences for the persons		
07. Participation in the seasonal conversations has lead to P having greater influence over his everyday life.	(16)	4,1
08. The persons who have taken part in the project have, to a greater extent, been able to experience a good life	(16)	3,8
09. The seasonal conversations have been important for P	(17)	3,6
D. The seasonal conversation as a working method		
10. It is important that others can also be informed about this working method	(17)	4,1
11. Seasonal conversations should be a natural part of handicap services to-day	(14)	3,7
12. To find ways of increasing the persons´ influence over their daily life is an important task for handicap services.	(14)	3,6

"An increase in influence over my own day"

In several of the conversations one had discovered that a person had views about a number of issues but the opportunity had not arisen, or been given, for these to be expressed. These persons had amongst other things expressed several wishes, like the need for a new handicap aid, the adjustment of a seating arrangement, a wish to take more responsibility or to have a greater say in decision making regarding working routines. Previously one had not been aware that these persons had views regarding these matters.

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"Appreciation of having time for oneself"

In these conversations the same views were expressed as in housing, viz. the person´s appreciation of having reserved time to talk alone, and confidentially, and to know that what one has talked about is not repeated to everybody.

"It goes without saying that the project should continue"

Staff took it for granted that working methods introduced should continue for those who had already taken part in the project. It was also seen as desirable that others should be given the same opportunity. The proposal was that other persons who belong to the same activity groups as the persons in the project should automatically be included. The view was held that an introduction and counselling was a prerequisite for a continuation. The working method is based on a perspective which has not been prevalent in disability services.

The views of the project group as expressed in a questionnaire

Those who were interviewed were given the opportunity, prior to the interview, to complete a questionnaire. This was issued to both groups of staff and to the representatives for the persons of the project. The questionnaire consisted of 16 questions, divided into four topics of relevance for the evaluation of the project, (table 1).

The topics covered in category A are concerned with the preparations which took place prior to the holding of the seasonal conversations. B was about the consequences of the seasonal conversations for the persons who answered the questionnaire. C covered the issue of how one viewed the consequences and effect of the seasonal conversations for the persons who had participated. The topic covered by D dealt with the general significance of the seasonal conversation as a working method in handicap services.

The answers to 12 of the questions have been presented here. The four omitted questions were parallels to those presented. Each question was answered on a 5-grade scale, with 3 as a neutral response. Above 3 indicates a positive understanding while lower than 3 expresses a negative response. The questionnaire was answered by 17 persons, viz the persons´ family or other representatives, their contact persons from the two staff groups and the administrators who were included in the project group. The answers are presented in Table 1

The highest scores are found within category A, which expresses a feeling of being well prepared for participation in the seasonal conversations according to the project programme. In category D the scores are also high, though not as high, expressing the view that this is a working method which should be applied within the handicap services. One considers that the project has had positive consequences for the persons themselves, category C. The project has also been of value for themselves, category B. Here the scores are very similar except that one does not think the seasonal conversations have been valuable for the representatives of staff (question 06). Regarding the answers to the questionnaire one can say that all have an average over 3. 6 answers (50%) lying in the interval 4-5, while 6 answers (50%) are below. The questionnaire therefore reflects a positive perception of the project and its consequences for persons.

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