

A SOCIAL POLITICAL IDEA AND ITS REALIZATION

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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.

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 legislation 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 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.

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!