

RESPIRE CARE PROVISION - AN EXAMPLE OF A LONG STANDING COOPERATION WITH LOCAL MUNICIPALITIES

Ågrenska is a private centre in Gothenburg, that provides many kinds of services and programs for children, teenagers and adults with disabilities, their families and professionals.

We cooperate with the authorities on all levels.

I will tell about the cooperation with municipalities concerning the respite care provision, but first a few words about the most recent legislation and who is responsible for what.

In the Swedish system the central government is in charge of legislation and general planning as well as social insurance. Regional governments i.e. county councils are responsible for health care and city councils/municipalities are responsible for social services for everyone, including e.g. measures for the elderly, schools, children's day care and services for people with disabilities

The cornerstone of Swedish disability policy is that everyone is of equal value and has equal rights and therefore the objectives are full participation in society, equality, equal opportunities.

This is expressed in the most recent legislation of 1994.

This law, The Act on Support and Service (for People with Certain Functional Impairments) applies to people with all kinds of severe disabilities, motor as well as intellectual ones, autism and severe chronic illnesses; either from birth/childhood or damage obtained in adulthood. The persons shall have significant difficulties in daily life and have an extensive need of support and assistance to get access to the services.

The law is about ten services/ measures of which respite care is one.

In 2002 about 53 000 people got services, i.e. 0,6 % of the population.

Many people get more than one measure and altogether these people got 97 000 measures.

(85% of the measures were directed to people with intellectual disabilities and/or autism and about 30% were directed to children)

About 10 000 people got the measure respite care away from home.

To obtain any of the services, you must be covered by the law by having a severe disability and you must apply for the services. In every separate case an individual assessment and decision is made by a special employee from the municipality. If you apply for a service and don't get satisfied with the decision,

you can go to court. All municipalities are also obliged to spread information about the law and the services that can be obtained.

Often the first info about the law can be provided by the social worker at the rehab unit quite early in the child's life. The social worker can also help in connecting parents with this employee.

The employee usually has the overall picture of the measures of each family concerning decisions and services in connection with the Act on Support and Service.

We must remember that families also have lots of other contacts to handle, e.g. with school, day care, medical care, social insurance etc.

Recent Swedish studies show (SIT o Soc styr -05) that cooperation between different authorities, as well as information spreading about the child's disability and needs, eg to teachers, still depend on the parents' initiative and organising.

What does Ågrenska do then?

We provide different programs/services for people with disabilities, of which repite care is one. All our services have been planned in cooperation with representatives from authorities and parental organisations.

When we started Ågrenska in May 1989, before the Act of Support and Service had entered into force, respite care was already a right according to existing legislation, but to a lesser extent and to fewer people.

At this time most of the social services for people with disabilities had gradually been transferred from regional to local authorities, or were in the process of being transferred.

Most of the existing respite care was provided in families and was not enough. Very few municipalities had respite care homes, e g Gothenburg, the second biggest Swedish city with half a million inhabitants, did not have any. So the supply was less than the demand and probably the demand was less than the need, because when a service is not available people usually can not imagine what it would be like and therefore do not ask for it.

The start of the Ågrenska respite care, in 1989, was really welcomed both by the authorities and families. We were the first and only private provider in the Gothenburg area.

For the first four years the politicians of the county council and city council together decided to buy respite care from us for a certain amount of money per

year, covering the costs for up to about 40 children, fewer in the beginning and then increasing, attending on a regular basis.

Every child got respite care during 8 weekends per year and 2 weeks in the summer.

The service was available to children with all kinds of disabilities, including those with motor disabilities without intellectual impairment, who in spite of big needs, were not comprised by existing legislation.

The children were referred to us mostly by social workers at rehab units. We also spread information through the parental organisations and many parents also contacted us themselves.

When the new law was launched, in 1994, this kind of arrangement ended and for every separate child an individual decision and financial agreement was needed.

In 1994 quite a tricky time started for the municipalities. The Act on Support and Service contained new services and also applied to more people than former legislation.

Every single municipality became responsible for these services.

They did not know how many people the law applied to and did not have systems to find them all. Neither did they have systems for providing all the measures.

Gradually they increased their knowledge about the target groups and built up services e.g. respite care homes and respite care camps.

But they also needed and still need supplementary suppliers and continue to buy services from private providers. Young modern families also want to choose themselves among the services and among service providers.

We have encountered that the demand increases when the supply, and especially the supply of alternatives, increases.

How does the formal cooperation of today work between Ågrenska and the municipalities?

With certain intervals there is a public procurement.

(at first every year, then every second year with possibilities of prolongation for two further years)

It is stated in the conditions of the procurement that agreements can be made with more than one provider and so has been the case every time.

And Ågrenska has always been the biggest provider. Today a little more than 150 children attend our respite care regularly.

All providers have to meet certain demands, except of course following present legislation, concerning:

- Educational level of staff
- Premises, location and equipment
- Cooperation with parents
- Documentation

We are supervised by the County Administrative Board and the Municipal Board of Social Welfare.

They visit us for inspection once a year and we have a very fruitful, unbureaucratic cooperation. They are advisors and discussion partners and I never hesitate to call when I encounter a problem or need information about a formal matter.

And then there is the cooperation concerning every individual child

This is handled by the special municipal employee, who refers a child to us. Parents and child visit us and is put on our waiting list, if they find us a good option.

When there is a suitable place available a formal written agreement is set up concerning the individual child and is revised once a year. Usually the participants attend for many years.

Invoices are sent to the municipality concerning every single child after each occasion. Parents do not pay any fee.

Sometimes parents have not yet established any contact with their special employee. Then they call us themselves. I provide them with information about the respite care, but always advice them to turn to the employee for a decision. Sometimes I help to connect them.

(If time left)

Respite care at Ågrenska - How does it look in practice?

Today we receive 15 groups, 150 participants

Attend regularly about 12 times a year, about one weekend a month, all school holidays during the terms and 1-2 weeks in the summer.

Some children with more extensive needs also come during ordinary schooldays/weekdays.

Once they have started they usually stay on in the same group for many years.

We created and introduced a new concept for respite care which today has spread to other providers.

All participants come regularly in fixed groups. On each occasion they encounter the same group members and the same staff. We try and create groups as homogeneous as possible.

We plan the contents of the stays according to the needs of the group.

Competent staff is necessary both for the parents' trust and for quality of the contents. Of course good care is needed, but also promoting independence and participation according to modern values and objectives.

Evaluation is really important, because expectations and needs vary and develop according to the development of society. We must adapt to these needs.

Evaluation - what do parents, participants and authorities say?

Parents:

competent staff is a condition for the trust,

also that it is the same staff all the time and every time - the staff and child know each other

dare to feel free and relax

appreciate to have time for the siblings

do not feel restricted because of the preplanned dates, preplan themselves instead

Participants:

want to come, appreciate the friends and activities

some of those with only motor and no mental disabilities express that they can relax, do not have to compete with teenagers without disabilities as they have at school

Authorities:

excellent reputation

considered to be very good especially with children with complicated disabilities including those with severe behavioural problems

big queue

