



EJA WP6

Specialised Social Services Workshop

Guiding Principles for Specialised Social Services

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EJA WP6 Workshop on Guiding Principles for Specialised Social Services

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“Placing one foot in front of the other, I've climbed to higher lengths. Reaching beyond my own limitations, to show my inner strength. No obstacle too hard, for this warrior to overcome. I'm just a man on a mission, to prove my disability hasn't won.”

**Robert Michael Hensel, Born with Spina Bifida
Guinness World Records holder for the longest non-stop wheelie in a wheelchair (6.178 miles)**

EUCERD JOINT ACTION – SOCIAL CHALLENGES

General Information on the service

Name of Service: Ågrenska

Type of Service: Respite care

Dates/Times of the Year:

All year round on weekends, school holidays, summer

Target Population: Children, teenagers, young adults
– all kinds of disabilities, many of them rare

Age-Groups: ~7 up to ~25 years

Countries of Origin: Sweden

Languages Spoken: Swedish

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EUCERD JOINT ACTION – SOCIAL CHALLENGES

Main Figures

Total Budget/Year: ~SEK 25 000 000

Total Nr. of Beneficiaries/Year: ~170

Total Nr. of Permanent Staff: 70

Total Nr. of Intermittent Staff: 100



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History



Date of Start: May 1989

**Created by:
The Ågrenska Foundation in cooperation with Patient Groups and
Authorities**



Short History:
**Old convalescent home for children 1914, built and donated to the
children s hospital by a private donor.**
**Today children with disabilities grow up in their families - needs for
new services. When the programs of today s Ågrenska were planned,
in the 1980 ies, respite care was one natural part.**



Were patients involved in the creation process?
**All our services have started out of needs, either experienced by
ourselves or described by patients and authorities.**
**Representatives from parental and patient organisations were
involved in all steps.**

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Governance and Management

Run by:

Ågrenska is a private, non-profit service provider, owned by the original foundation from 1914, and run as a private limited company, Ågrenska Ltd

Funded by:

All services are ordered by and sold to authorities that are by law responsible for the services

Governance structure:

Board of Ågrenska Ltd:

Chairman and eight board members

Executive body:

President and six executive managers, one of them responsible for the respite care



Are patients involved in the governance process?

Yes

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Quality Assessment



Are patients evaluating the service after attending?
Continuous evaluation in discussions with participants and parents.
Written questionnaires every/ every second year

Is the service accredited by any authority performing quality control?
National Board of Health and Welfare

Requirements:

- **formal education and experience of staff**
- **premises and accessibility**
- **working methods following international conventions, Swedish legislation, other formal documents**
- comprehensive!

Is the service connected to a Centre of Expertise/Hospital?
Yes

Ågrenska- a centre for people with disabilities, their families and professionals

- Family program – focus on rare diseases
- Adult program – focus on rare diseases
- **Respite care including summer camps
- all kinds of disabilities**
- Staff with disabilities – day centre
- Personal assistance
- ADHD consultant
- Courses and conferences for professionals
- Projects/development

Ågrenska – private non profit service provider

Formal cooperation with authorities:

Public procurements

Agreements with the

- board of health and welfare – state level
- health care system – regional level
- **social services – municipality level – respite services**

Legislation – disabilities

General legislation:
Social Services Act and Health Care Act

Act on Support and Service
For Certain Persons with Functional Impairments
(1994, 2002, ongoing revision)

Act on Support and Service

Applies to:

- People with developmental disorders
 - intellectual impairment
 - autism and autism spectrum disorders
- Significant and permanent mental disabilities obtained in adulthood
- Other major and permanent disabilities
significant difficulties in daily life
extensive need of support

Act on Support and Service

- About ten rights, of which respite care is one

In 2011

- 63 300 people ~ 0,7 % of the population
- at least one measure

Act on Support and Service

To get access:

- Apply yourself
- Entitled to the services by this law according to the criteria?
- Individual assessment and decision, based on needs, not diagnosis

Ågrenska respite care

- Respite care away from home
- Public procurements every 4 years
- Ågrenska biggest private provider in the Gothenburg area

Ågrenska respite care

~170 children/teenagers/young adults
attend regularly - 19 groups

To allow

- recreation and own experience
- rest for the family

Ågrenska respite care

- 12 times a year:
one weekend/month (Fri – Sun)
school holidays during terms
1-2 weeks in summer
- Big needs – also ordinary week days

Ågrenska respite care

Groups for most kinds of disabilities

- autism, Asperger syndrome, ADHD
- multiple disorders
- motor disabilities without intellectual impairment
- many participants with rare disorders
eg Duchenne, SpielmeyerVogt, Prader Willi,
Soto syndrome

Aims

- rest for parents and siblings, good care
- social development-refining social skills
- meet others in same situation
learn from each other – identification
- make friends
- try different recreational activities

Aims

- Promotion of independence and participation
– modern objectives and values:
- help to prepare for adult life
- exercise everyday practical tasks
- start cutting bonds to parents

Methods

- continuity and fixed groups – same friends and same staff on each occasion
- homogenous groups – similar needs
- carefully planned contents
- competent staff
- long term planning
- evaluation
- documentation

Methods

- Longterm contents planned by staff – discussions and wishes from participants
- Detailed plans before and on each occasion together with participants according to their possibilities

"Children s" staff – for all our programs

- preschool teachers
- teachers
- special educators
- recreational specialists
- nurses
- social workers

Staff – intermittently employed for the respite care

- often students in relevant fields
- stay on for many years

"Children s" staff – for all our programs

Competent and modernly educated
staff important!

Other important staff

- cooks and dietary experts
- service personell for caretaking, repairing, gardening etc

Evaluation - parents

- Competent staff condition for trust
- Appreciate same staff every time
- Dare to feel free and relax
- Appreciate time for siblings
- Appreciate long term planning
can preplan themselves

Evaluation - participants

- Want to come
- Appreciate friends and activities
- Relax themselves - do not have to compete with children without disabilities

Evaluation - authorities

- Good reputation
- Complicated disabilities,
including behavioral disorders

Cooperation with municipality individual level

- The municipality refers a person to the Å respite care
- Formal written agreement/individual contract, revised every year, price, number of days/yr
- Invoices after each occasion
- All cost paid by referee, no parental fee to provider
- Parents charged for food from referring municipalities
- Some municipalities pay travel costs, some parents pay themselves

Quality - individual level

- Plan for carrying out is set up together with participant and parents
- Goals and methods, some common for the group, some individual
- Individual follow up and evaluation
 - what goals are still relevant?
 - are the methods purposeful?
 - new goals to add?

Quality - individual and organisational level

Documentation:

- plan, goals, methods, follow up
- continuous documentation after every occasion

Procedures and clear routines for:

- Handling of complaints
- Handlings of incidents/events

Keep clear, precise and short!

Self – evaluation/assessment

- Risk/consequence assessment in everyday work
- Written questionnaires every or every 2nd year to families and participants
- Annually written follow up: quality system, staff, activities, budget
Clear, precise and short!

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Thank you!
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