



EJA WP6 Specialised Social Services

Workshop Guiding Principles for Specialised Social Services *Lisen Julie Mohr Frambu , Norway*



“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: Frambu

Type of Service: Resource Centre

Dates/Times of the Year: All year

Target Population: Patients, families, professionals

Age-Groups: All age groups

Countries of Origin:

Languages Spoken: Norwegian, english

Country: Norway

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EUCERD JOINT ACTION – SOCIAL CHALLENGES

Main Figures

Total Budget/Year: euro 7 600 000

Total Nr. of Beneficiaries/Year: 28.250

Total Nr. of Permanent Staff: 90

Total Nr. of Intermittent Staff: 150



EUCERD JOINT ACTION – SOCIAL CHALLENGES

History



Date of Start: 1975

Created by: Political authorities in Norway.

Short History:

Frambu was in the beginning a centre for diagnosis like asthma, allergy and other larger groups of chronic diseases. The first course for a rare disease, haemophilia, was arranged in 1975, and the focus is now on the family as a whole. Parents of children with the diagnosis is from that year being sick paid for a stay. These concerns the charge of social security , not the employer. During the 1980s, Frambu played an important role in the national efforts for rare diagnosis. In 1996 the centre was turned into a nationwide resource centre for rare disorders.

Were patients involved in the creation process? Frambu has always worked close with the patients organisations.

EUCERD JOINT ACTION – SOCIAL CHALLENGES

Governance and Management

Run by: Frambu is a private trust.

Funded by: The money for the centre is established by the state budget.

Governance structure: Frambu is run by a board.

Are patients involved in the governance process? They have two representatives in the board.



EUCERD JOINT ACTION – SOCIAL CHALLENGES

Quality Assessment



**Are patients evaluating the service after attending?
The patients are always evaluating the services by an evaluating program named Quest back.**

**Is the service accredited by any authority performing quality control?
Frambu reports to the South-Eastern Norway Regional Health Authority.**

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

The staff has a connection to a hospital when needed.

Rare Diagnoses in Norway

A rare diagnose as pr. Norwegian definition are having a prevalence of 1 pr. 10 000 or less pr. diagnosis

Some 30 000 people in Norway suffer from rare hereditary or congenital disorders



National Plan for Rare Disorders

An area of priority in governments plans of actions for disabled

1990-1993 and 1994-1997

Followed up and developed to meet current needs



Department of Rare Disorders and Disabilities

2013 A project

2014 In operation

**Oslo University Hospital
will be the head of this new
department.**



The Resource Centres

A national service

10 Resource centres

**Services have been established
for 320 diagnosis**



Specific resources for rare diseases are outlined

Caregivers (parents) of patients with rare diseases are permitted training allowance

These are designated for parents to attend courses at a resource centre for rare diseases



Frambu offer assistance to about 100 different diagnosis. Frambu is the only one with a hotel accommodation



What do we do at Frambu?

Residential courses

**Communication and
Documentation**

**Outreach activities in users
local community**

Research projects

Summer camps



Important

To meet other people with rare diseases who are able to understand their situation

A very positive experience

Contacts made at Frambu / or other resource centres have proved to be very important



Important issues

User orientation and a life-cycle approach have a central place at the centres

Importance is attached to collecting and disseminating specialized knowledge

Users and next-of-kin can contact the resource centres directly



What do we offer to our patients / users ?

**No medical
treatment**

**No individual
follow up
or therapy**

**The centres are a
complementary to medical
and the municipality
services in Norway**



But...

Some medical examination

Some advices

Some ideas

A lot of counselling

Advices about modification of activities and environment

Sharing of experiences between clients and professionals



What can Frambu learn from our clients?

Share experiences about living with a rare disease and how to achieve the best possible quality of life



Guidance to families, clients, relatives and other people from the health service



Visit

About the diagnose

**A team of medical doctor,
physiotherapist,
nutritionist, special educator**

**When a child is diagnosed
someone from the team visit
the parents**

**They visit the kindergarden,
school, work**



To find yourself in a different world – and have to stay there



Thank you!
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