EURORDIS
Rare Diseases Europe

Specialised Social Services: need, policy, case studies

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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)

GENERAL INFORMATION ON THE SERVICE

Name of Service: Frambu

Country: Norway

Type of Service: Resource Centre

Type of institution: Private foundation/ public organisation

Origins of funding: Public funds

Cost for beneficiaries: None / (travel – only the professionals)

Dates/Times of the Year: All year

Target Population: patients, families, professionals

Age-Groups: All age groups

Countries of Origin: Norway

Webpage: www.frambu.no

MAIN FIGURES

Total Budget/Year: Euro 8000000

Total Nr. of Beneficiaries/Year: 2389

Total Nr. of Permanent Staff: 86

Total Nr. of Intermittent Staff: 170

Nr. of Volunteers/year: 0

BRIEF HISTORY

Date of Start: 1996

Created by: Political authorities in Norway

Short History:

Frambu started up as 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.

GOVERNANCE AND MANAGEMENT

- Overskudd på 551.320,-
- Fond 6 MNOK
  - Pensjon (2,6)
  - Forskning
  - Vedlikehold
  - IKT

Currently managed by:
The Department of Rare Disorders and Disabilities, Norway.

(The South-Eastern Norway Regional Authority)

Funded by: Public funds

Governance structure: The Frambu Board has 7 members. 2 official authorities, 2 patients organisations, 2 Frambu staff, chairman.

Are patients/patient representatives involved in the governance process? Yes.

How many? 2

What is their role and their scope of action?
Board members.

QUALITY ASSESSEMENT

Are patients evaluating the service after attending?

Yes, a questionnaire is sent after all courses and consultants and returned by e-mail.

Is the service accredited by any authority performing quality control?

Yes, by our health authorities.

IS THE SERVICE CONNECTED TO A CENTRE OF EXPERTISE/HOSPITAL?

- **The service is performed mostly at and by Frambu**
- **Frambu has a close connection to the university hospitals for advice and participation during courses:**
    - **Paediatrics**
    - **Medical genetics**
    - **Specialists in treatment for different rare diseases**
- **The responsibilities of national competence services is regulated in the Specialist Health Service Act**

RARE DISEASES AND HEALTH CARE NEEDS

- **Health care needs and treatment for patients with a rare disease are implemented in the ordinary Norwegian health system**

- **The patient with a rare disease is entitled to a Individual Plan**
  - **This plan will contain an outline of objectives, resources and the services the patient requires**

- **Daily follow up routines should be provided by the municipalities in the patients homes as long as possible**

FRAMBU OFFERS ASSISTANCE TO ABOUT 100 DIFFERENT DIAGNOSIS

SPECIFIC RESOURCES FOR RARE DISEASES ARE OUTLINED

Next of kin (parents) of patients with rare diseases are granted training allowance

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

Residential training courses for patients, families, professionals

Staff visits patients - home environment

Meeting people with a rare diagnose

Professional staff

Staff – Hotel

70 beds

20 families

Kindergarten

School

Who is working at Frambu ?

Director

Administrative staff

Hotel staff

Medical doctors

Nurses

Psychologists

Physiotherapists

Occupational therapists

Special teachers

Trained assistants

Consultants

Training of the staff

New staff - mentor

Learning by advice and practice by colleagues

One – two years of working experience at Frambu before you are considered as an rare disease expert

What does Frambu offer ?

Residential courses

Communication and Documentation

Outreach activities in users local community

Research projects

Summer camps

Important

Some medical examination

Some advices

A lot of counselling

Meeting patients and professionals

Advice about modification of activities and environment

Sharing of experiences between patients and professionals

What can we learn from our patients?

Experiences about living with a rare disease

How to achieve the best possible quality of life

Communication

Courses

Seminars

Conferences

Video meetings

E – learning

Web site

Facebook

Twitter

Issuu

You tube

Domiciliary visits

Outreach activities in users local community

Creating local networks

Meeting each person and/or
family at home

Consultations

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Local community

Guidance to families,

clients, relatives

people from the health service

Pass on information

Guidance meetings

Contribute to

courses
conferences
seminars

Frambu's main aims

To collate, develop and impart knowledge about rare disorders and disabilities

To provide leading-edge expertise

SUMMERCAMP = EMPOWERMENT

The best quality of life

Knowledge and services in the field of rare disorders

A life in harmony with ones condition, aspirations and needs

Take part in the society

Visits and contacts

The NoRo center, Romania

Rare diseases, Bulgaria

Rare diseases, Portugal

French national alliance and authorities

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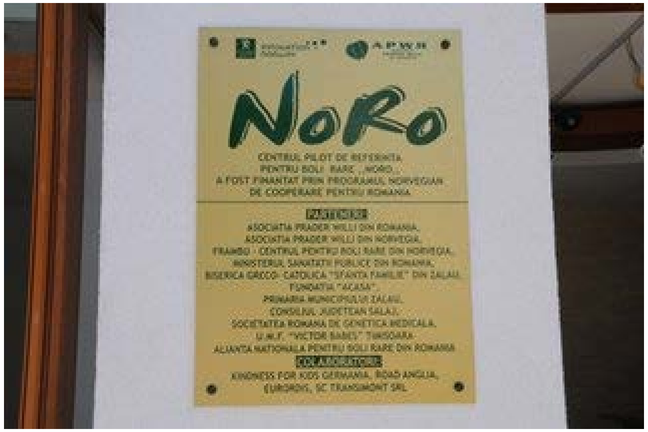
Hungary

Japan

Mongolia



Thank you!

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