

# Social care issues in rare diseases



«Nasjonal kompetansetjeneste for sjeldne diagnoser» (NKSD) er en nasjonal tjeneste som samordner alle kompetansesentrene for sjeldne diagnoser i Norge. Kjernevirksomheten i tjenestene skjer ved sentrene.

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# The Norwegian welfare system

- Historical and political events has given Norway a very strong well-built welfare system with **universal rights** to Norwegian citizens.
- The Norwegian welfare system is a security net that is ment to catch all citizens who for different reasons can not provide for themselves (Rare or not rare).
- The system is **wide ranged** from
  - money transfers to people unable to work
  - free hospital care
  - free rehabilitation in specialized centers
  - technical aids such as wheelchairs, hearing aids, learning aids etc.
  - etc
- Funded through taxes and given to all citizen regardless of socio-economic status, geography, diagnosis, background = a system based on **equality (equal rights)**.

# Do we need special social care for people with rare disorders?

## The challenges:

- People with rare disorders say being rare means: lack of knowledge and understanding, isolation, complex and compound needs
- The nature of rarity creates extra challenges in meeting needs of people with rare disorders. How do we provide enough knowledge and know-how on a local level?
- Not just medical needs but: educational, economical, social, psychological etc.

# Our conclusion:

**Multidisciplinary, long term, individual and coordinated services, as for many other citizens with not-rare disorders.**

**A national advisory service to build and spread knowledge about rare disorders!!**

# NKSD

*"Making rare disorders more known through  
knowledge and collaboration"*

NMK National Neuromuscular Centre  
University hospital of North Norway,  
Tromsø

## Ten (nine) CoE

Services for >350 RD,  
(probably *many* more...)

- 1/10.000 (<500 in Norway)
- ~30.000 PLWRD in Norway
- 16.000 reg. users (in 2013)
- Under development...

NAPOS Norwegian Porphyria Centre  
Haukeland University Hospital,  
Bergen

NKSD Norwegian National Advisory  
Unit on Rare Disorders  
Central Unit  
Oslo University Hospital HF

Frambu Resource Centre for Rare Disorders  
Private foundation, federal funded. Siggerud

SSD Centre for Rare Disorders  
Oslo University Hospital HF

TRS National Resource Centre for Rare Disorders  
Sunnaas Rehabilitation Hospital HF

NK-SE Centre for Rare Epilepsy-related Disorders  
Oslo University Hospital HF

TAKO National Resource Centre for Oral health in  
Rare Medical Conditions  
Lovisenberg Diakonale Hospital, Oslo

Norwegian Resource Centre for AD/HD, Tourette  
Syndrome and Narcolepsy  
The National Autism Unit (co-organized and  
collocated from 2015)  
Oslo University Hospital HF

NSCF Norwegian Resource Centre for Cystic  
Fibrosis  
Oslo University Hospital HF

# What do we do?

## Building and spreading knowledge and know-how of rare disorders

Multidisciplinary services to patients and families:

- Easy access with no need of a doctor referral
- Free of charge
- Diagnosis = Admission
- Consultations, classes, advice and information
- Supporting local services (by travelling, video conferences etc)
- Multi-professional, life-long, individually based services
- Focus on coping strategies in transitional phases

# What are centres of expertise and what do they do?

## Services to professionals:

- Classes, courses, lectures, advice and discussion partners
- Local support (social services, education, health issues, ...)
- Research partners in development of knowledge
- Stay updated and distribute knowledge on rare disorders

**Diagnostics, treatment and follow up is primarily *not* our responsibility.**

**Cooperation with other parts of the public services is crucial for success!!**

# Rights within the welfare system of special importance for PLWRD

## Individual plan and coordinator

Anyone who needs long-term, coordinated services is entitled an 'individual plan'. The purpose of an individual plan is to provide a complete, coordinated and individually tailored set of services and to ensure that one professional has the main responsibility for follow-up and coordination at all times. Without a coordinator, the plan has very limited value.

Other subplans, such as individual training plans, habilitation plans, care plans, etc. have to be coordinated and adapted to the main individual plan.



# Special rights for PLWRD and their families?

A training allowance and refund of travel expenses are granted when parents attend courses at one of our CoE.

Support may be available to cover the cost of taking part in courses/seminars abroad. Support is conditional on there being no resource centre or expert group for the rare disorder or disability in Norway.

Financial support for dental health services (RD-list)

<http://helsedirektoratet.no/publikasjoner/barn-og-unge-med-nedsatt-funksjonsevne-hvilke-rettigheter-har-familien-revidert-utgave/Publikasjoner/IS-1298E.pdf>

# What can/ should be done?

Continue to address social services in meetings, workshops, conferences etc

Include specific social challenges in national plans and strategies

Voice the needs of people with rare disorders in development of legislation and regulations

Continue to make expertise accessible and spread knowledge about rare disorders, in close cooperation with other services

**Our vision is to make rare disorders more known through knowledge and collaboration!**

[www.sjeldne-diagnoser.no](http://www.sjeldne-diagnoser.no)

**National Help Line:**

+47 800 41 710

