

Social Care Pathways

Experience of Sweden



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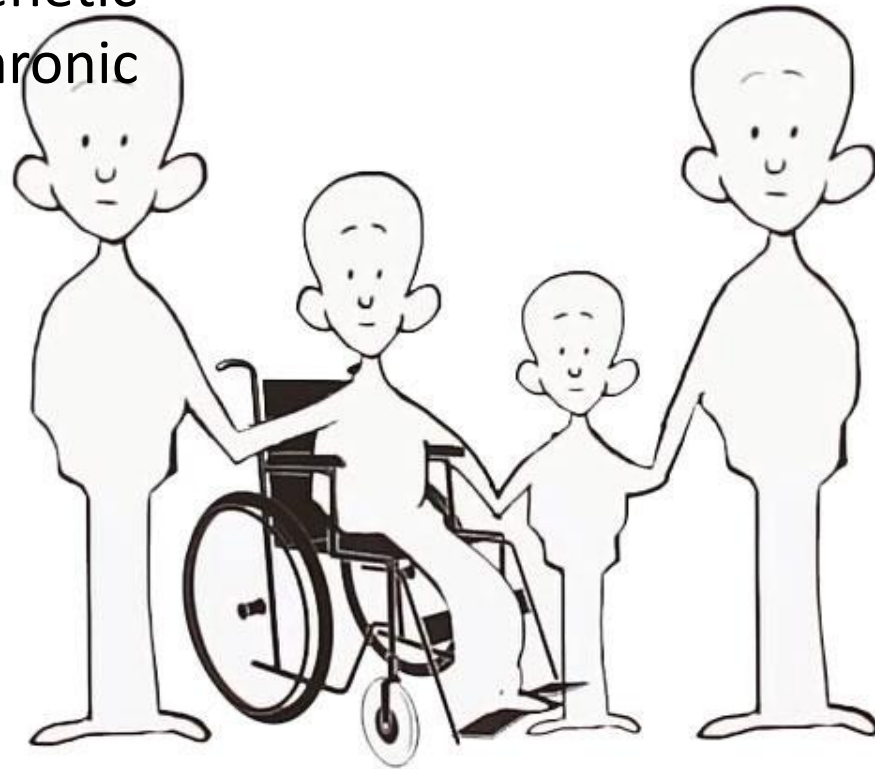
EURORDIS Membership meeting 2015, Madrid

Context

- Rare disease definition in Sweden
- The Swedish welfare system and structure
- The legislation and available social services
- Does it work?
- Challenges
- On going work

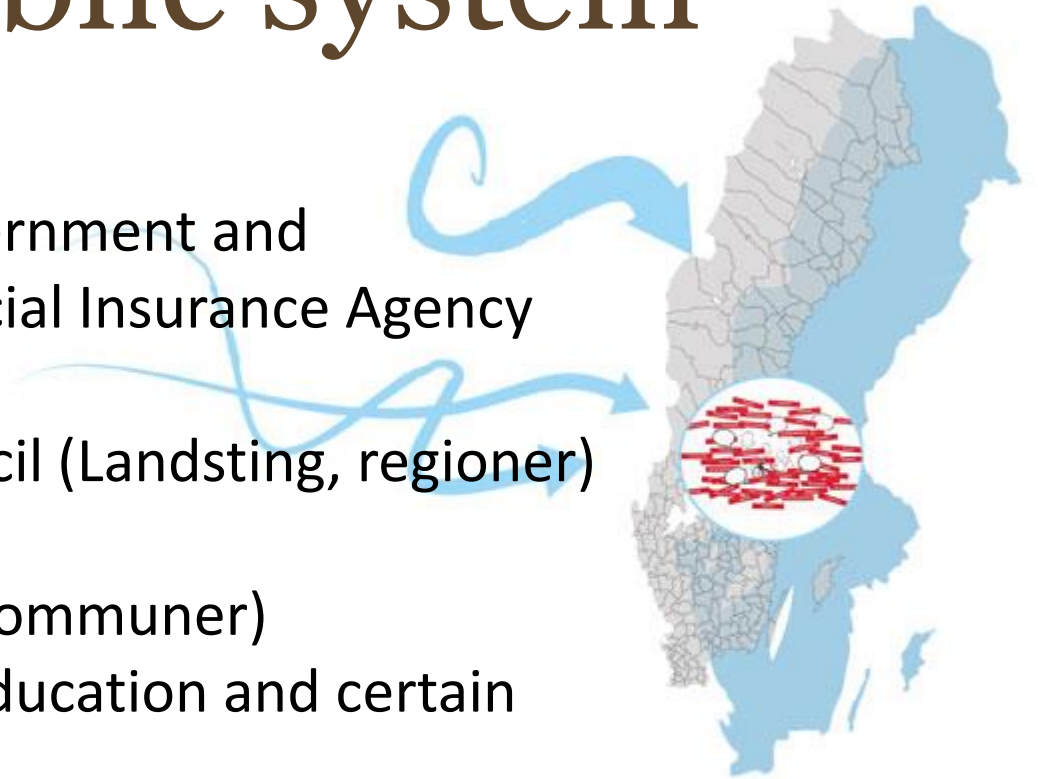
Rare disease definition

- Less than 1/10 000
- Mostly syndrome with rare and complex combination of functional impairments
- Mostly genetic
- Mostly chronic
- Incurable



The Swedish public system

- **The state level** Parliament, government and authorities, eg. The Swedish Social Insurance Agency (Försäkringskassan)
- **The regional level** County Council (Landsting, regioner)
- Health care responsibilities
- **The local level** Municipalities (Kommuner)
Responsibilities in social care, education and certain health care.
- Autonomy in the regional and local level.
- Legislation required collaboration when the need exists.
- Large regional and local differences!



Legislation



- The Social Service Act (SoL)
- The Act on Support and Service for Persons with certain Functional Impairments (LSS)
- The Education Act
- The Health and Medical Service Act (HSL)
- The Patient Act
- The Discrimination Act
- The Act on Social Insurance

The Act on Support and Service for Persons with certain Functional Impairments (LSS)



An entitlement law that guarantees good living conditions for people with extensive and permanent functional impairment, ensuring that they receive the help they need in daily life and that they can influence the support and services they receive.

The Act on Support and Service for Persons with certain Functional Impairments (LSS)



Applies to people

1. With an intellectual disability, autism or a disorder within the autism spectra.
2. Who have considerable and permanent mental impairment following brain damage sustained as an adult, as a result of external force or physical illness.
3. Who have some other lasting physical or mental impairment that is clearly not due to normal aging, if such impairments are substantial and cause considerable difficulties in daily life and consequently, an extensive need for support and service.

Must need assistance in activities of **daily living** and their **needs may not be met in any other way**

Those who qualify for measures pursuant to LSS are entitled to.....



1. Advice and other personal support
 2. Personal assistance
 3. Companion Service
 4. Contact Person
 5. Respite care services (in the home, away from home, supervision for schoolchildren over the age of 12)
 6. Family home/residence with special services for children, adolescents and adults (in 2013: 22 339 persons)
 7. Daily activities
- In principle, no costs for the individuals.
 - Run under both municipal council and private management (# 2,5,6 and 7)

Resource Centres and Therapeutic Recreation Programmes

- Ågrenska
- Mo Gård
- EX-Center
- Spinalis



Coordination



- **Permanent coordination contact** in Health Care if a patient need it or ask for it. The contact shall coordinate the health care contacts and other stakeholders. (The Health and Medical Service Act and The Patient Act)
- **Individual coordinating plan** in order to get an overview of needs and coordination of stakeholders, treatments and services. (The Health and Medical Service Act, The Social Service Act and The Act on Support and Service for Persons with certain Functional Impairments)

Education



- The school should take into account the students different needs. **The school must adapt to the students potential – Not the other way around.**
- The students may require special assistance, special support etc in order to achieve the goals.
- **Individual needs – Individual support**

The basic idea behind the Swedish system

- The individual needs, not the diagnosis



Does it work?

Support from Society*

Do you /your members feel that you are getting enough support from the community?
(the State, county councils, municipalities)

Yes	0%
Pretty good	14%
Pretty bad	57%
No	20%
Don't know	3%



* NFSD survey among 99 organizations

Does it work?

- **The permanent coordination contact** is not known among health care professionals and therefore not offered.
- Few patients know about the possibility.
- Few municipalities (37%) have routines for **individual plans**.
- Approx. 40% of primary and secondary schools and 20% of high schools do not offer **special support in school** to the extent and in the manner that students need and are entitled to.

Almost but not completely...



Challenges

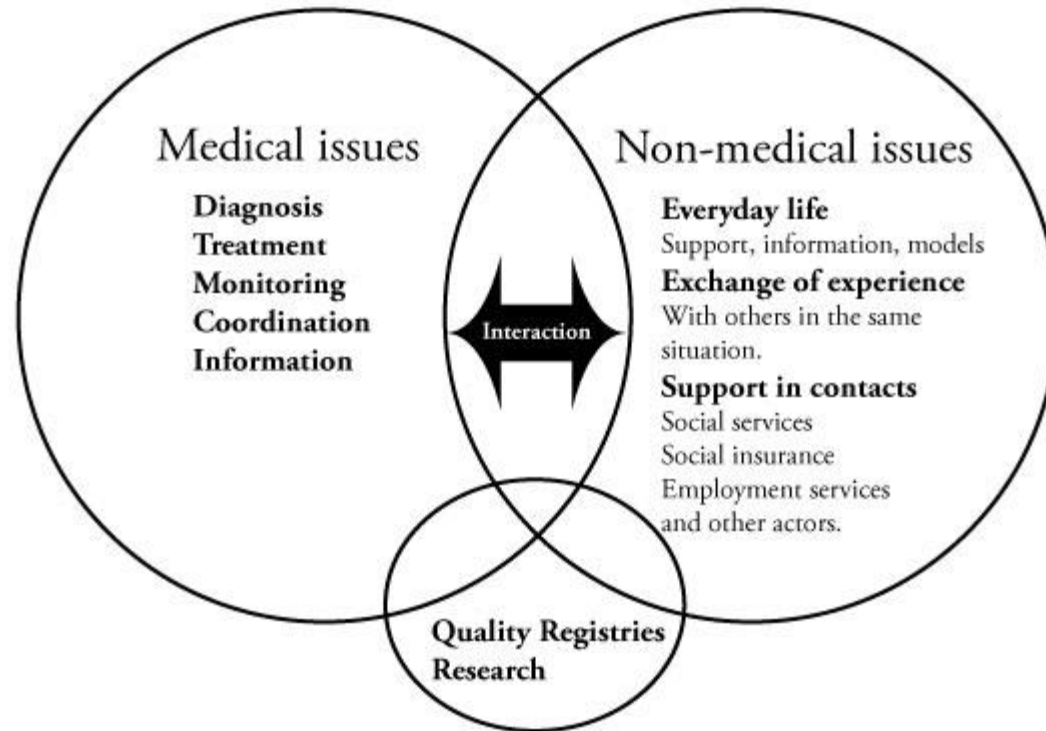
Lack of ...

- holistic view.
- knowledge about rare diseases and needs among professionals.
- knowledge about legal obligations among the professionals.
- knowledge about legal rights and available support from the society among PLWRD and their families.
- practical structures for interaction between professionals in the society.
- patient involvement and evaluation.
- long time perspective.

- The decision-makers, the local politicians have very limited legal liability for their decisions.

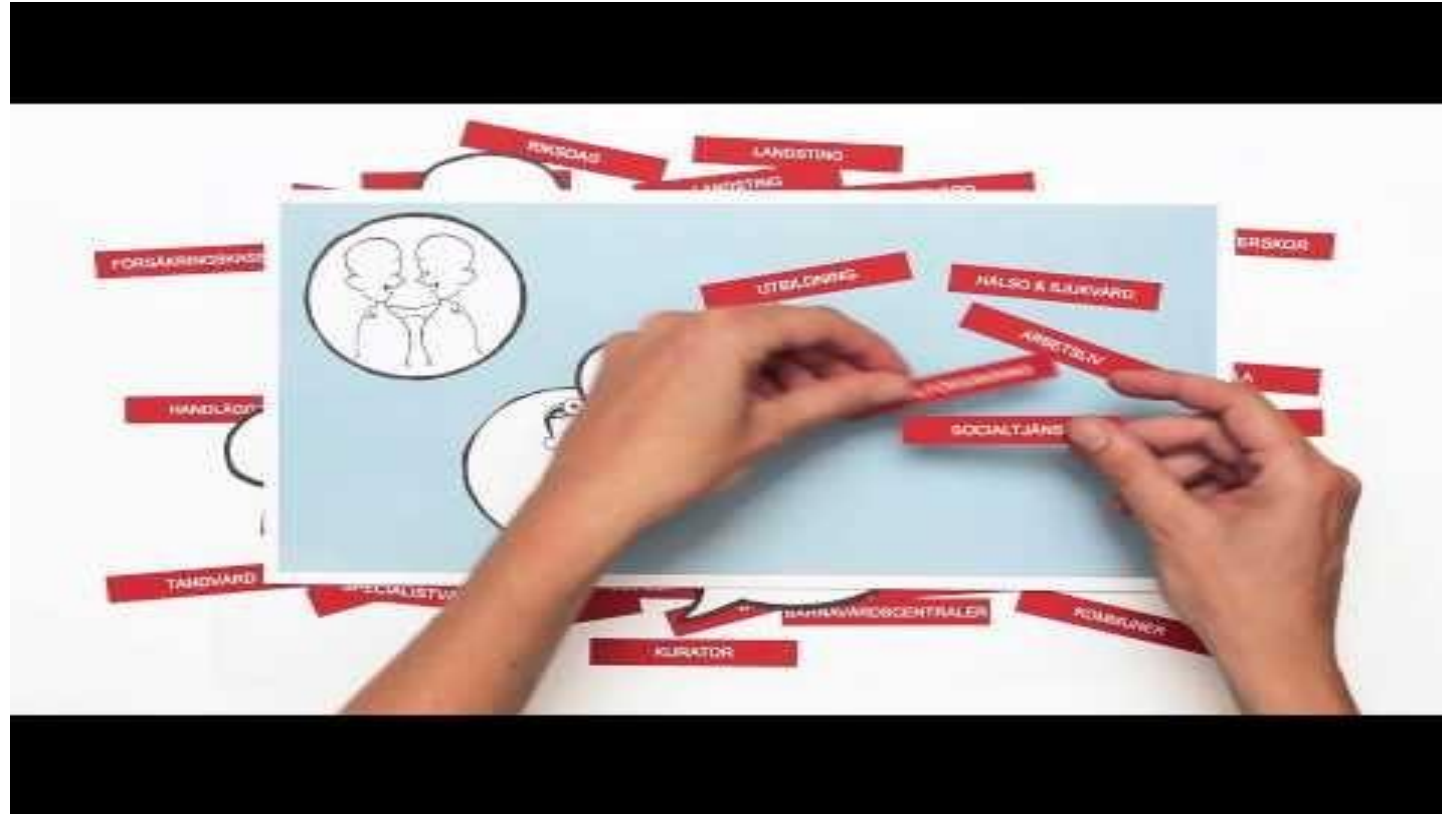
On going work

Centres of Expertise



On going work

- National treatment and care programs, with a holistic and “whole-life” approach
- Rare Disease Sweden, projects “Structures for patient involvement” & “Managing the transition. From child to adult care for PLWRD.”
- Workshops and seminars with/for professionals (decision-makers and administrators)
- Training programs about RD for professionals within respite care services and the Swedish Social Insurance Agency
- Collaboration between information providers to find synergies and coordinate communication.
- www.nfsd.se - legal obligations and rights, - best practice, - films, - training, - news etc.
- Twitter, LinkedIn, Facebook, magazines, seminars and workshops



YouTube: “Rare diseases are leading the way in future medical provision and health care.”

Gracias!

