

# State of the Art of Social Care Pathways, Sweden

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# Context

- Definition of rare diseases in Sweden. Plan or way..
- Welfare model and UN disability convention
- Who has the right to social support and service? Rare-perspective.
- Laws, structure and systems, how they inter-act around the individual.
- Does this work?
- Actors and processes of importance for future developments of the situation.

# Rare disease definition

- Population fewer than 1/10 000
- Mostly a syndrom with a **rare and complex combination of functional impairments**
- Mostly genetic
- Mostly cronic
- Incurable

# Fundamentals

## **Welfare model**

- Inclusion of all citizens
- Universal rights
- Generous support to vulnerable groups
- "from cradle to grave"

## **UN-konvention on rights for persons with disabilities**

- Article 19 on independent living
- Pushes for high living standards, equality compared with the rest of the **national** population

# The Swedish way..



NATIONELLA FUNKTIONEN SÄLLSYNTA DIAGNOSER



**SÄLLSYNTA  
"DIAGNOSER**  
RARE DISEASES SWEDEN

## Legal Framework

Both health care and social care is supervised by the national Health and Social Care Inspectorate. The national Board of Health and welfare provides knowledge and guidelines

### **Medical needs. Aim: health**

Health care Law

(Patient Law from 2015)

including habilitation, rehabilitation and adaptation of every day environments, technical aids and sign language interpretation. More patient centredness in the new Law)

Patient protection Law

### **Social needs. Aim: independance, participation**

Social service Law

Municipality Law

Law on Support and Service for certain groups of persons with disabilities

School Law

Law on Social Insurance  
(Discrimination Act etc)

# Structures and what they provide in terms of social **service** and **support**

- State-level. Regulations, Finance, Some health care, some social support and service is financed by the National Agency of Social Insurance. Labour market steering.
- Regional / County council level. Most health care including habilitation etc.
- Municipality level. Most social service and support for persons with disabilities, all ages. Some health care. Education.
- Combination common.

# Social service Law provides:

- A range of kinds of service and support to persons of **all ages** with disabilities with the aim of contributing to independant living and **reasonable living conditions** with respect of integrity etc.
- Needs are assessed by social workers according to ICF-influenced methods, not diagnosis
- The municipalities are also also required to provide different kinds of **support to family members** who give care and support to a person, no matter the age, with an illnes or functional impairment whatever the reason.

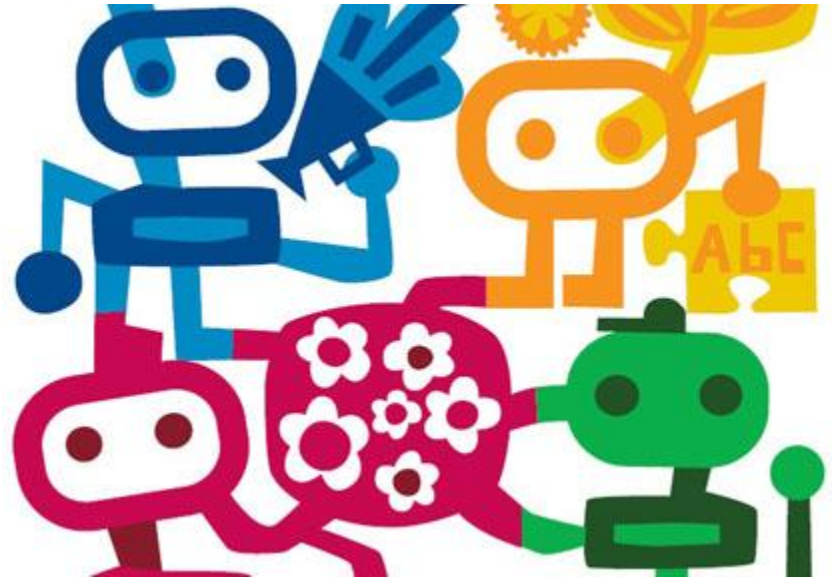


# Law of Service and Support for certain groups of persons with disabilities, aim is to **ensure good living conditions** and entitles:

- 1 counseling and other personal support that requires specific knowledge of the problem and the conditions of life for people with severe and permanent disabilities,
2. personal assistance or financial support for the reasonable cost of such assistance, to the extent that the need for support is not covered by granted assistance hours in accordance with Chapter 51. Social Code,
- 3-10. escort service, assistance of contact person, relief service in the home, short-term stay outside the home, short-term supervision for school children over 12 years outside the home adjacent to the school day and during school holidays, accommodation in foster or residential care activities for children or young people who need to live outside the parental home, housing with special services for adults or other specially adapted housing for adults, daily activities for people of working age who are not gainfully employed and do not educate themselves.

# Education

- According to the Swedish school law the school should take into account children's and students' different needs. The school must therefore adapt to the student's potential - **not the other way around!**
- In addition to the guidance and encouragement that all students should get. Some students may require special assistance, special support, in order to achieve the goals.
- Special support can differ. The starting point is the individual needs.
- Material on implementation of accessibility in terms of physical environment, educational and social aspects from [Disability Federation](#) an [National Agency of Special need Education](#)



# Work and labour market support

- Right to reasonable accomodation and assistant technology
- Sheltered/protected work including day time activities
- Social cooperations and entrepreneurship
- Support to employees
- Support to employers
- Anti discrimination Act. Reasonable accomodation
- Awareness raising, National Agency for participation  
[one two](#)

# Coordination

- **Permanent coordinating contact** in the health care situation (according to Health Care Law and Social service Law for **coordination of actors, treatments, service on different levels**)
- **Individual plan** when needs are complex (according to Health Care Law and Social service Law for **overview of needs and coordination of actors, treatments, service on different levels**)
- Individual plan is also to be offered when service and support is provided by the Law on Service and Support for certain groups of persons with disabilities

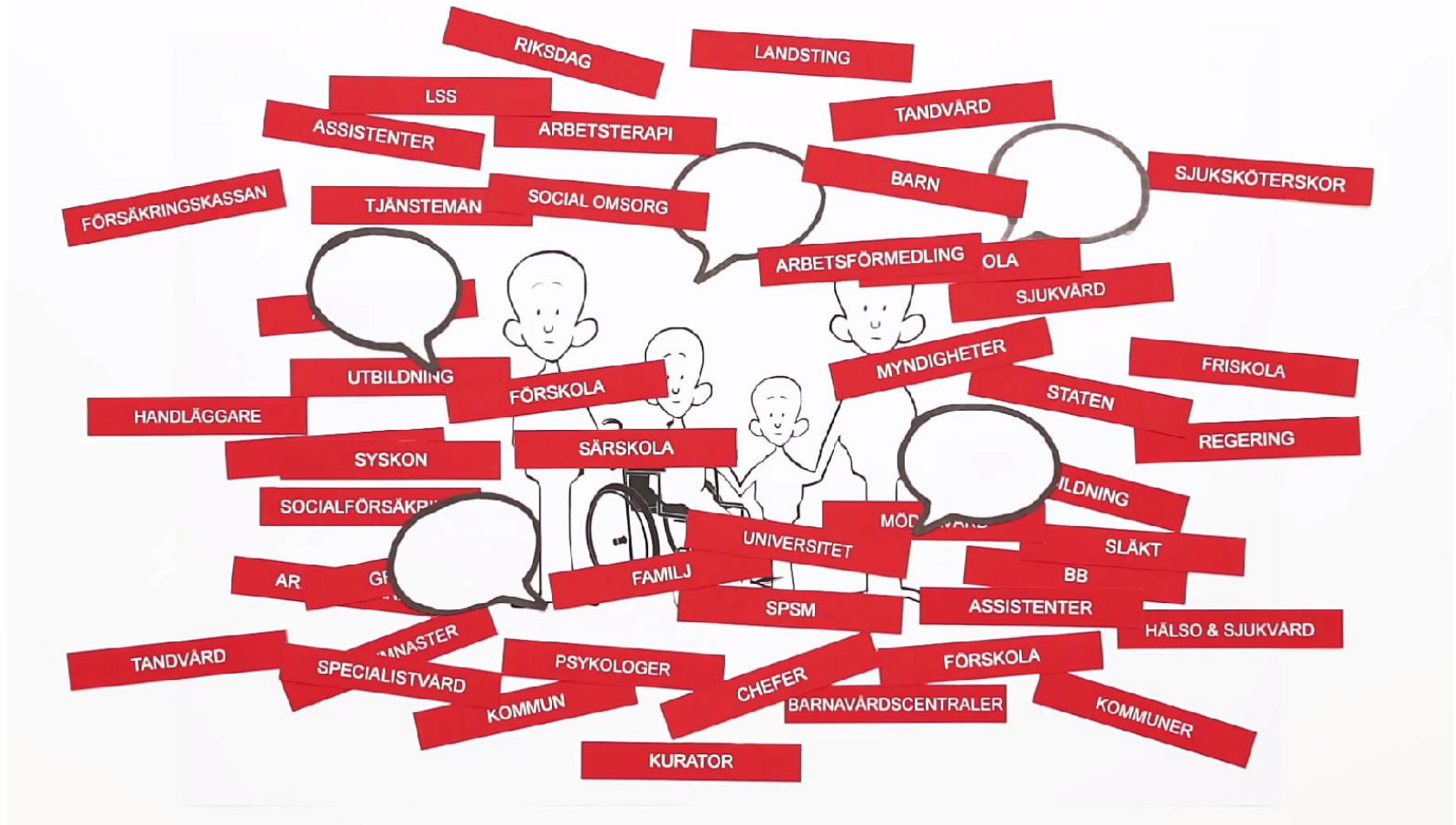
# But..

- According to the National board of Health and Welfare, the permanent **coordination contact is not known** among health care personnel and therefore not offered. **Few patients know about the possibility. Social workers are not motivated to use it.**
- Few municipalities and County councils actually have **rutines for individual planning.**
- Only about 60% of the municipalities coordinate support and service according to Law of Service and Support of certain groups.
- Only about 60% of primary and secondary schools have a substandard work in special needs.
- About 50% of primary and secondary schools do not investigate students' needs promptly when it is feared that she or he will not reach the knowledge needs.
- Approximately 40% of primary schools and 20% of high schools do not offer special support to the extent and in the manner that students need and deserve
- Unemployment is still distinctively higher among persons with lower working capacity due to disability, than in the rest of the population.
- Lack of user/citizen/patient/client-reported data on satisfaction

Almost but not completely..



# Structures and rare combination of, complex needs. National Agency of Rare diseases information film

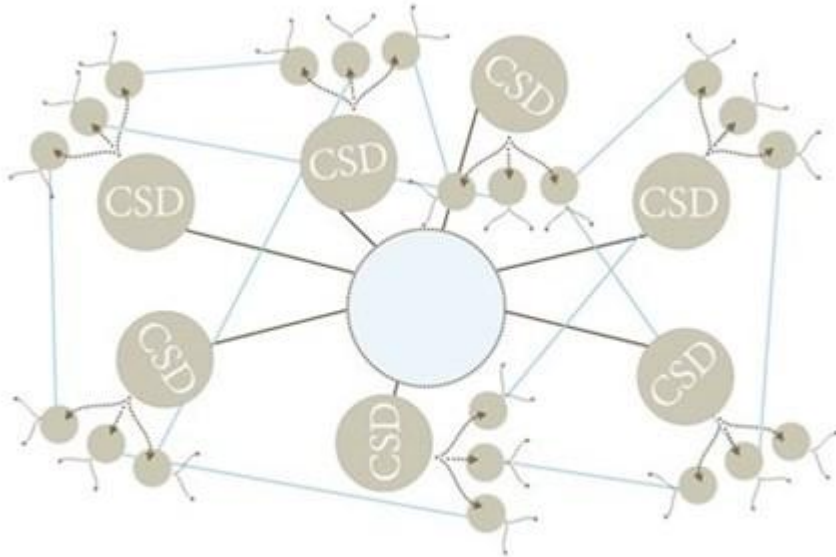


# Challenges

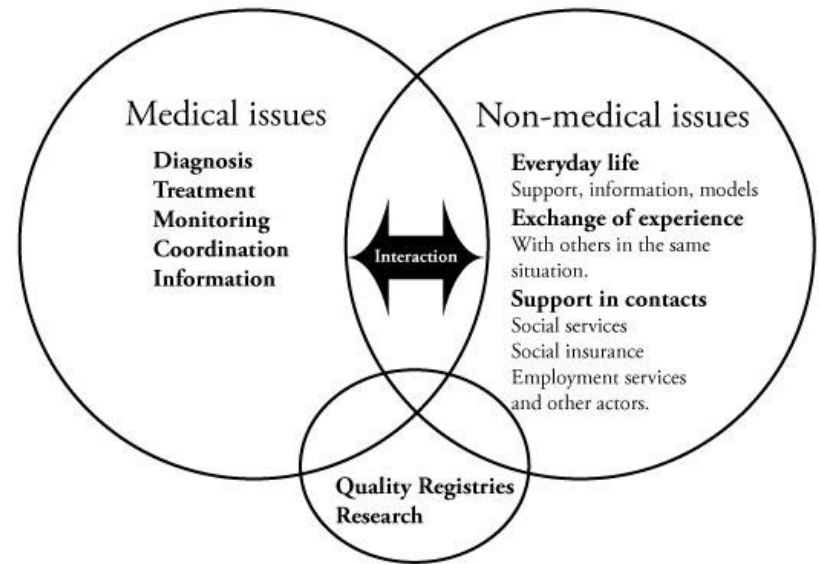
- Get the **systems and actors** of society working **more efficiently together** for persons with complex needs, person centeredness not system/production centeredness
- More of **patient/user-evaluation** and steering accordingly



# Positive future through further co-operation co-ordinated by the RD Agency



## Centres of Expertise



# RD Sweden's strategic networking around the university hospitals' processes



# Thank you!

