



# Breaking down barriers to live independently with a rare disease

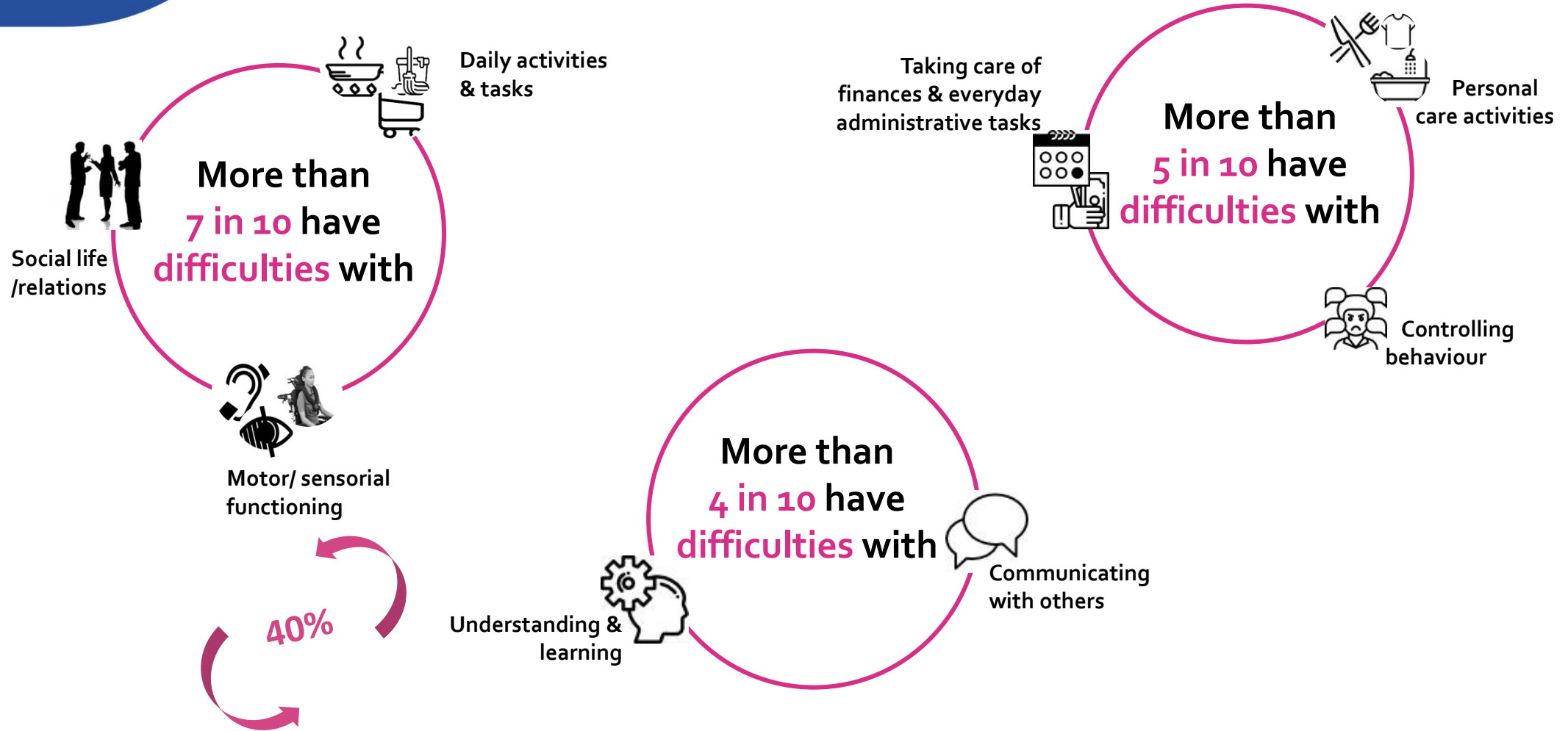
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EURORDIS-Rare Diseases Europe

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**Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others**

UNCRPD Art. 1



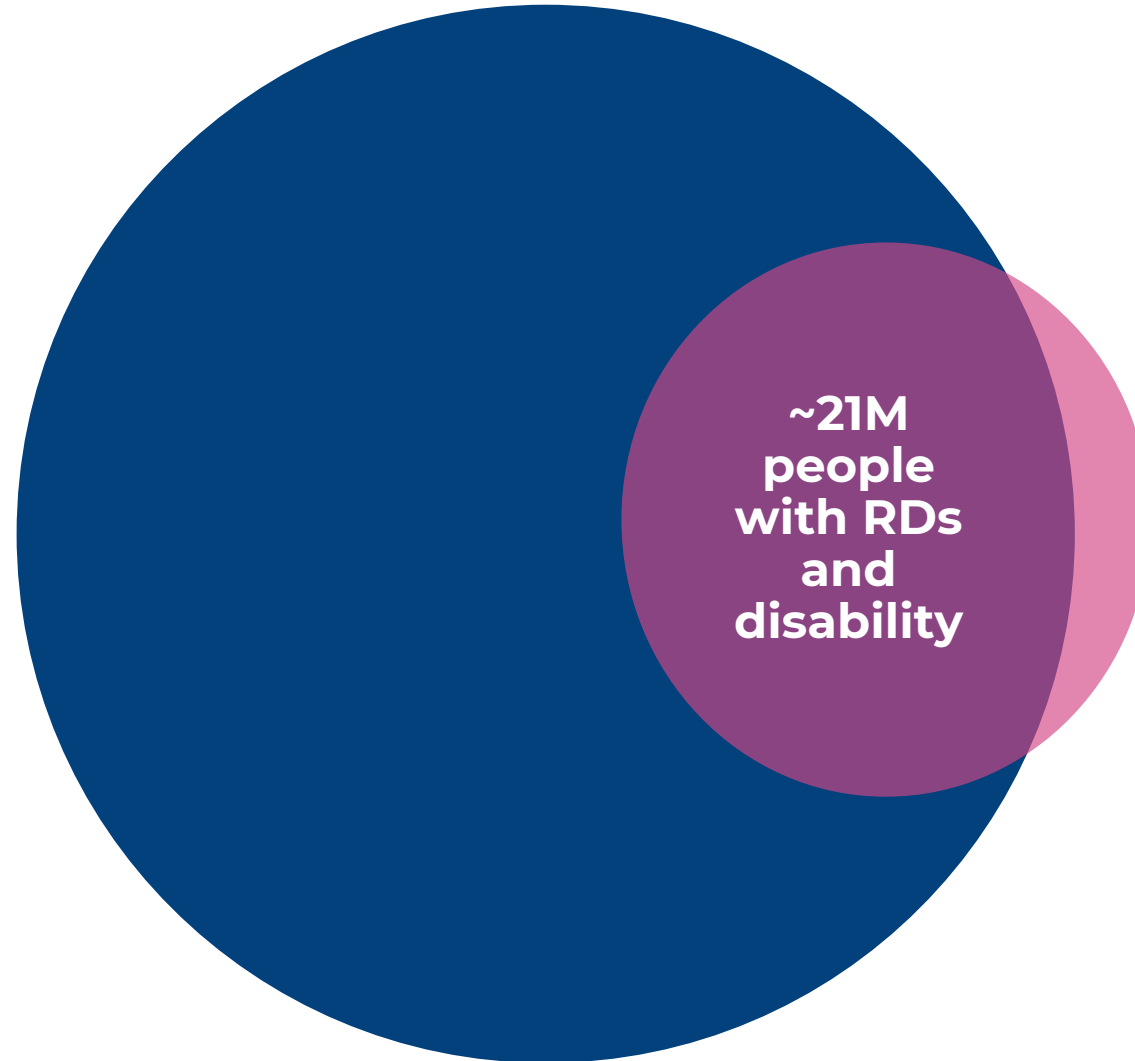
**The majority of people with rare diseases  
live with disabilities.**

**These can be visible, invisible, degenerative  
or vary over time.**

**Some of them live with multiple disabilities.**

# In Europe:

**101M people  
with disabilities**



**~21M  
people  
with RDs  
and  
disability**

**30M people with  
rare diseases**

# Independent living

*Individual dimension*



*social dimension*



UNCRPD Art. 19

# Independent living

**equal right to live in the community**

**full inclusion and participation in the community**

Opportunity to **choose where and with whom they live**

**access to a range of in-home, residential and other community support services**

**Community services and facilities available** and **responsive to their needs.**

**It's all  
human rights!  
Right?**

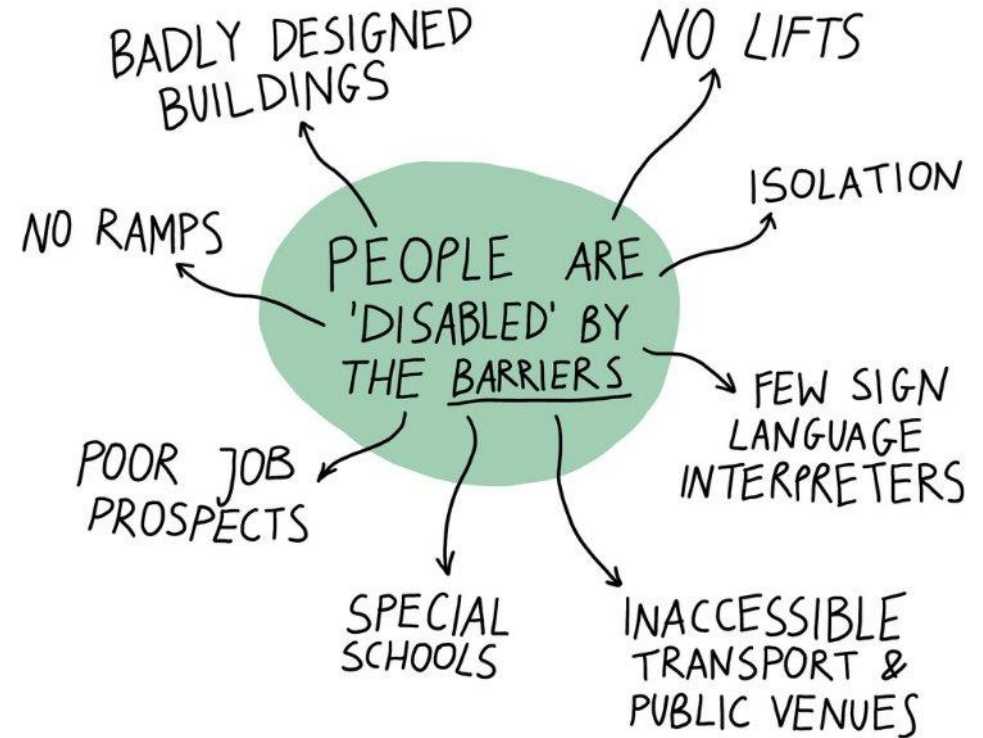




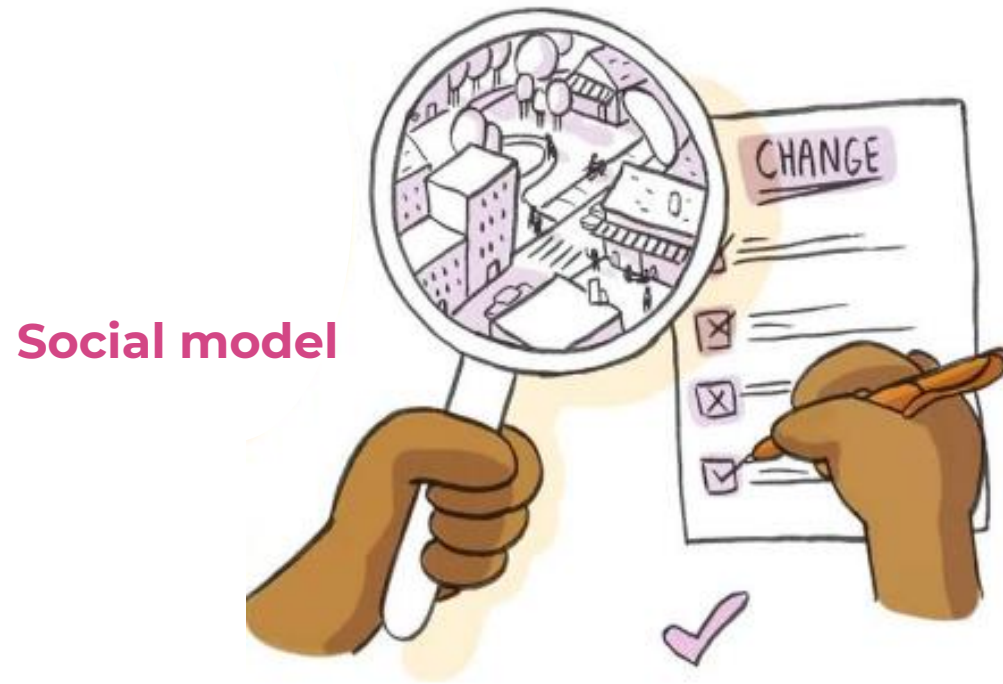
# The Medical Model



# The Social Model



**Charitable model:** Helpless people who need to be cared for



Social model

The problem is not our disabilities,  
but a society and a system that leaves out people with disabilities.  
There is nothing wrong with us. We just experience the world differently.  
It's up to society to change.



Goes further than the social model.  
The disability cannot be used as an excuse to discriminate  
or deny access to equal opportunities.

## Some of the issues we face...

**Disabilities are not always recognised.**

**Many barriers to independent living and social support.**

**Unable to access the support they need.**

# How are we working on disability?



**Our vision  
and needs**

**How we  
advocate for it**



**What we  
need to get  
there**

**Who can  
help us get  
there**

## Our vision

EURORDIS' vision is a world where all people living with a rare disease can have longer and better lives and can achieve their full potential, in a society that values their well-being and leaves no one behind.



# EURORDIS Position: Holistic Care



[See the full position paper](#)



# What are we advocating for?

**All people living with rare diseases and disability must access:**

- ⊕ **Adequate disability assessment and recognition\***
- ⊕ **Adequate social protection and independent living support**

European Strategy for Persons with Disabilities provides some advocacy opportunities.  
EURORDIS is also a member of the EU Disability Platform.



Approach by special rights for people with rare diseases or by rights for people with a single disease is rarely the solution!

# The power of words!

Fighting for healthcare, social, human rights.

People, person (patient, if healthcare related)

Rare disease advocates, people with lived experience (not always patient advocates)

Family member (who are often the main carers)

Holistic care and full participation in society

Disability (vs functionality, impairment)

What the person wants, what the family wants, what others think they want

# Representation matters!

Let's get evidence! Stay tuned for the last presentation...!

Let's show the diversity of the community!

# EURORDIS Social Policy Action Group



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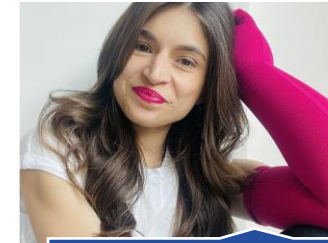
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# Connection, connection, connection!

How are you working with disability organisations?

How are you involved in disability activism?

How are you involved in shaping policies for persons with disabilities?



# Thank you

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