



DISABILITY ADVOCACY: Update and Next Steps

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[EURORDIS.ORG](https://eurordis.org)



Agenda

1. Rare Diseases and Disability
2. Past actions related to Disability
3. Disability advocacy priorities 2023
4. EU Disability Card
5. Next steps

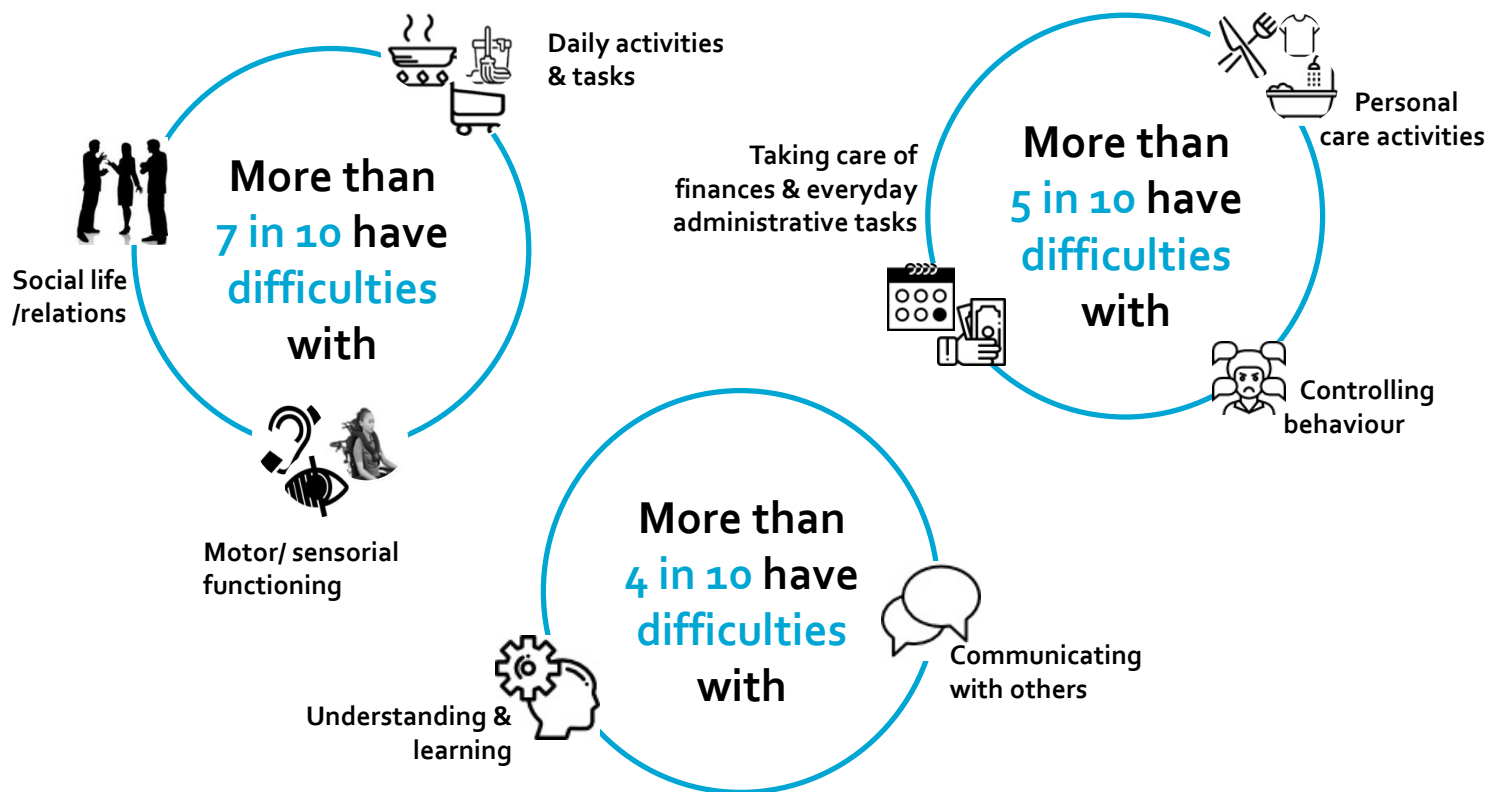


1. RDs & Disability

The majority of people with a rare disease have motor, sensorial or intellectual impairments, which can occur simultaneously.

72% of people living with a rare disease involved in EURORDIS' European survey on the impact of rare diseases on daily life, declared having difficulties with motor or sensorial functioning.

People living with a rare disease face serious limitations in everyday activities:



Impact of Rare Diseases on Activities of Daily Living (ADLs).
Survey "Juggling care and daily life: The balancing act of the rare disease community", 2017.

Disabilities of people living with rare diseases can be **visible, invisible, degenerative** or **vary over time**

One day you appear completely healthy, the next day you are sick, and two days later you appear completely normal again” Female, Spain

I don't look ill but am very ill with a condition which no one understands or has heard of” Female, United Kingdom

Main obstacles: Adequate Disability Assessment



Methods for assessing disability, granting disability status,
disability allowance and providing social protection to citizens
with disabilities

Main obstacles: Adequate Disability Assessment

Affecting 53% of people living with a rare disease

34% who face inadequate assessments

19% who do not receive an assessment at all despite needing one.

Consequence: Inadequate social support

50% have inadequate access to disability benefits

28% have access, but find them insufficient to cover their needs

22% do not have access and consider that they would need to.

2. Previous Advocacy Actions



Previous advocacy actions

- [EURORDIS Position Paper on Holistic Care, Pillar 3 \(2019\)](#)
- [EURORDIS Contribution to EC consultation on EU Disability Strategy \(2020\)](#)
- [EURORDIS Statement welcoming EU disability Strategy \(2021\)](#)

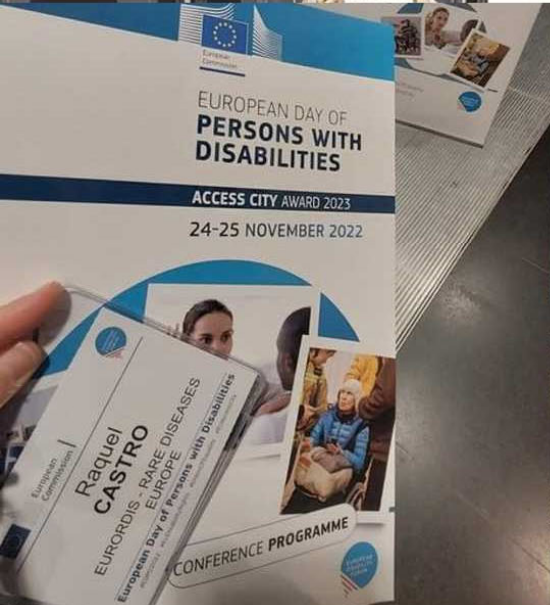
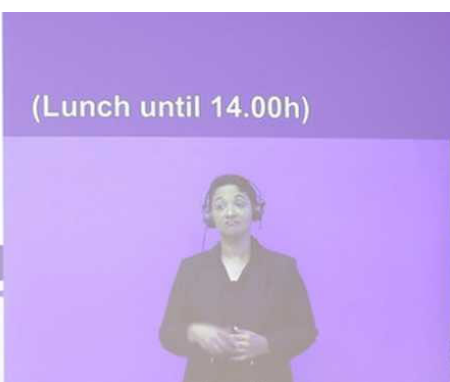
EURORDIS is a member of the European Disability Forum since 2019

Successful contribution to the EU Disability Strategy

In line with our advocacy actions, the strategy calls for:

- **More awareness and support for patients with disabilities related to rare diseases;**
- **Reforms of social protection (...) and disability assessment frameworks;**
- **Improved labour market outcomes, including reasonable accommodation at work.**

EURORDIS joined the event alongside EDF & other civil society organisations



3. Disability advocacy priorities 2023



Disability advocacy priorities

1. Join EU Disability Platform
2. Contribute to EC guidelines to MS on improving national disability assessment frameworks
3. Contribute to work on EU Disability Card

In line with EURORDIS Strategic Objective 2 and 3:
priority area on 'Integrated care & inclusion' and 'Inclusive of all RDs & regions'



4. EU Disability Card

EU Disability Card

<https://ec.europa.eu/social/main.jsp?catId=1139>

What will it do (EU Jargon version):

Support free movement for people with disabilities by facilitating their access to some services across the EU, which offer preferential conditions for persons with disabilities (e.g., leisure, culture, sports, transport).



EU Disability Card

What will it do (translated!):

- ⊕ If you have disability status in your EU country, you will be able to apply for the Card.
- ⊕ When you travel abroad and access one of the services included in the Card, you can show your Card and will be granted the same conditions offered to national persons with disabilities.

EU Disability Card

What it won't do:

- ⊗ Oblige any services to provide accommodations for persons with disabilities.
- ⊗ Interfere with national disability assessment frameworks which grant disability status.
- ⊗ Replace national disability Cards.
- ⊗ Facilitate access disability benefits (social security/protection) in another country.

It must fully respect the subsidiarity principle and national powers

EU Disability Card: EURORDIS contribution to EC Call for Evidence

Closed 9 Jan: https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/13517-European-disability-card_en

We called for the Card to:

- Cover as many services as possible.
- Be based on binding legislation - regulation, to avoid implementation differences at national level.
- Be accessible, accompanied by a website and an awareness campaign.

And called on the EC to:

- Allocate EU-funding to support its the implementation.
- Closely collaborate with organisations of persons with disabilities, at EU and national level.

Read our full contribution: <https://www.eurordis.org/publications/eu-disability-card-call-for-evidence/>

EU Disability Card: EURORDIS contribution to EC Call for Evidence

**Only those who have disability status in their country can apply for the Card.
Obtaining disability status is one of the main challenges for people living with RDs.**

**We also called for the improvement of national disability assesment frameworks,
as a complementary priority to ensure all persons with disabilities can benefit from the Card.**

EU Disability Card: EURORDIS contribution to EC Call for Evidence

Regarding the improvement of disability assessment frameworks, we called on the EC to:

- ✓ Ensure that the **EC guidance to MS on improving disability assessment methodologies is duly informed by:**
 - **Disaggregated data**, by disability types and by sub-population groups e.g. people with rare diseases.
 - **Data collected by organisations** of persons with disabilities.

- ✓ Support a **greater harmonisation of disability assessment principles** and tools across MS, by:
 - **Supporting the development of a EU common core standard for disability assessment.**
 - **Assisting MS in establishing and sharing good practices on disability assessment**, drawing on the findings of EU-funded technical assistance.



5. Next steps

EU Disability Card: next steps

12-week online public consultation to be launched shortly

Opportunity to:

- ⊕ Provide further evidence on our challenges
- ⊕ Continue to advocate for the improvement of national disability assessment frameworks

Action Point: do you have relevant evidence to share?

EC Guidance to MS on Improving Disability Assessment

Done via the European Semester

Opportunity to:

- ⊕ Provide country-specific evidence on our challenges
- ⊕ Specific country recommendations to improve national disability assessment frameworks

To be discussed later on...

5th European Parliament of Persons with Disabilities

When: 23 May 2023

Where: European Parliament, Brussels

How to get involved:

- Delegations of national disability councils, sponsored by the national MEPs
- EURORDIS and/or NAs can only join as part of a national delegation

Action point: any volunteers to approach their national disability organisation?



Thank you

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