



Call for Evidence: European Disability Card

Response from EURORDIS-Rare Diseases Europe

January 2023

EURORDIS-Rare Diseases Europe welcomes the procedure to establish a [EU Disability Card](#) and would like to offer the following input, to contribute to the inclusion of all voices of the disability community in the future Card:

We call for a **EU Disability Card that allows for mutual recognition of disability status across EU countries and is accepted by all areas of services which offer preferential conditions to persons with disabilities.**

Additionally, the Card should be:

- **Based on binding legislation, preferably a Regulation**, to avoid implementation differences at national level.
- **Accessible and accompanied by a website**, in all EU languages and accessible communication formats, with details for each MS (where to get the Card, how it works, database of benefits).

The Commission (EC) should also consider:

- The **allocation of EU-funding to support the implementation of the Card** e.g., under the ESF+, as recommended by the European Parliament (EP)¹.
- An **accessible awareness-raising campaign** in all EU countries to inform users, service providers, and general public.
- **Close collaboration with persons with disabilities, and their representative organisations at EU and national level**, throughout the Card's implementation.

Regarding the exemption of **social security/protection**, we believe that **the Card should provide the possibility of granting such services on a temporary basis** when the person with a disability has moved to work or study (e.g., Erasmus+) in another Member State (MS), while they await their disability re-assessment in the new MS.

To effectively allow all persons with disabilities to exercise their right to free movement and residence across the EU, **the implementation of the Card must be coupled with the improvement of disability assessment and determination at national level.** If persons with disabilities cannot see their disability status recognised in their MS, they will not be able to benefit from the Card.

People with rare diseases are amongst those at risk of being left behind. Evidence from a European survey² shows that although the majority live with disabilities, obtaining an adequate disability assessment remains a major obstacle for people living with a rare disease, who face inadequate assessments (34%) or do not receive an assessment at all despite needing one (19%). This not only affects their access to social rights at national level, but it will also prevent them from benefiting from the Card.

¹ European Parliament Resolution of 13 December 2022 'Towards Equal Rights for Persons with Disabilities (2022/2026(INI))': https://www.europarl.europa.eu/doceo/document/TA-9-2022-0435_EN.pdf.

² EURORDIS. 2017. Juggling care and daily life: The balancing act of the rare disease community. 3071 respondents from 42 European countries. Survey conducted in 23 languages within the EU-funded (East) project INNOVCare. <https://www.eurordis.org/publications/juggling-care-and-daily-life-the-balancing-act-of-the-rare-disease-community/>.

As such, we welcome the upcoming EC guidance to support MS with improving disability assessment methodologies, via the European Semester and the Technical Support Instrument. For such a process to be duly informed, we join the EP in calling on the EC and on MS to collect disaggregated and reliable data, ensuring that EU-wide statistics have data disaggregated by the types of disability. Data by relevant population groups, e.g., persons with a rare disease, should also be collected. In addition, the EC must ensure that self-reported data collected by organisations of persons with disabilities can feed into such processes.

Lastly, we call on the EC to support a greater harmonisation of disability assessment principles and tools across MS:

As noted by the recent EP resolution (2022/2026(INI))³ and the EP study on issues relevant to the Card⁴, the lack of a common EU definition of disability and the variations in disability assessment and determination across MS, both in terms of methods as well as of outcomes, are major obstacles to mutual recognition of national decisions on disability issues. As such, they are great barriers for persons with disabilities exercising their freedom of movement.

In line with the study's recommendations, we call on the EC to commit their support to:

- 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 projects and evaluations.

About Rare Diseases and EURORDIS-Rare Diseases Europe

There are 30 million people living with a rare disease in Europe, with rare diseases affecting at least 3,5% to 5,9% of the worldwide population⁵. The European Union considers a disease as rare when it affects less than 1 in 2000 citizens. Over 6,000 rare diseases have been identified to date, less than 6% of which have a treatment⁶.

Rare diseases are often chronic and highly complex. Most people who live with a rare disease, live with disabilities which can be visible, invisible, degenerative, or vary from one day to the next. Evidence demonstrates that they and their families continue to face serious every day and social inclusion challenges, to a large extent linked to disability².

EURORDIS-Rare Diseases Europe, a member of the European Disability Forum, is a non-profit alliance of over 1000 rare disease patient organisations from 74 countries that work together to improve the lives of over 300 million people living with a rare disease globally.

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.

Contact:

Raquel Castro
Social Policy and Initiatives Director
raquel.castro@eurordis.org

³ European Parliament Resolution of 13 December 2022 'Towards Equal Rights for Persons with Disabilities (2022/2026(INI))': https://www.europarl.europa.eu/doceo/document/TA-9-2022-0435_EN.pdf.

⁴ Policy Department for Citizens' Rights and Constitutional Affairs Directorate-General for Internal Policies, European Parliament. November 2022. Disability assessment, mutual recognition and the EU Disability Card: Progress and opportunities. PE 739.397. [https://www.europarl.europa.eu/RegData/etudes/STUD/2022/739397/IPOL_STU\(2022\)739397_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/STUD/2022/739397/IPOL_STU(2022)739397_EN.pdf).

⁵ Nquengqanq Wakap, S., Lambert, D.M., Olry, A. et al. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. *Eur J Hum Genet* 28, 165–173 (2020). <https://doi.org/10.1038/s41431-019-0508-0>

⁶ Monaco L, et al. Research on rare diseases: ten years of progress and challenges at IRDiRC. *Nat Rev Drug Discov.* 2022 May;21(5):319-320. doi: <https://doi.org/10.1038/d41573-022-00019-z>. PMID: 35079160; PMCID: PMC7613920.