All people living with a rare disease and disability must have access to:

- Adequate disability assessment and recognition
- Adequate social protection and independent living support (e.g. sick leave, disability benefits, community based services, adapted housing)

The majority of people living with a rare disease live with disabilities. These can be visible or invisible, cumulative, and can vary over time.
## Disability rights advocacy

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EU Disability Card

What, why:

- A Card that makes it easier for people with disabilities to access some services while travelling within the EU.

- Focused on services offering preferential conditions for persons with disabilities.

- For people who have disability status in a EU Member State.

- When travelling abroad within the EU and accessing one of the services offering preferential conditions, the person can their Card and will be granted the same conditions offered to national persons with disabilities.
EU Disability Card: EC consultations
Flagship initiative of EU Disability Strategy

We asked for the Card to:

- Be based on binding legislation
- Cover as many services as possible

We also called for the Card to be accompanied by improvement of national disability assessment frameworks, to ensure all persons with disabilities can benefit from it.

Only those who have disability status in their country can apply for the Card, and obtaining disability status is one of the main challenges for people living with RDs.
EU Disability Card Proposal: positive points

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- It is binding legislation, so all EU countries will have to implement it.
- Not based on a list of services, but on mutual recognition of disability statutes. Cardholders visiting another EU country will have access to the same conditions as nationals (discounts, preferential access).
- Foresees both physical and electronic versions.
- Respects the person’s privacy.
- European Disability Card and Parking Card are separate.
- It will complement national cards (not substitute them).
- Foresees measures to avoid forgery and fraud.

Our statement to welcome the proposal
https://www.eurordis.org/eurordis-response-disability-card/
We want to be sure that all people living with disabilities being able to access the Card

- Countries might want to establish that only those with severe disabilities can get the Card.

We don’t want the scope of services to be narrowed.

- The proposal is large on all services offering preferential conditions. But MS could try to limit the scope.

A Directive can lead to differences in transposition to national level.

- We want to be sure there is a monitoring framework which keeps track of whether eligible individuals can access the card and can indeed enjoy preferential conditions thanks to the card when using services.

There will be inequalities in accessing the Card due to differences in national disability assessments. This is being accepted as a side effect, but it opens the door to a step-wise approach to improve and harmonise disability assessment.

- Someone who with a certain disability in France might be entitled to disability status and to the Card in France. However, a person with the same disability and situation in Spain, might not be entitled to disability status. When the French person travels to Spain, and use their Card, they will effectively access preferential conditions that the nationals with the same disability do not get.
EU Disability Card Proposal: what else is missing

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- Access to social security and disability allowances when moving abroad, especially during the "re-assessment" period of disability status.
- Provisions to support persons doing EU Mobility Programmes (Erasmus+, EU Solidarity Corps).
- Mention to non-EU nationals that reside in an EU country being able to get the Card.
- Measures to build a EU-wide database and implement an awareness campaign about the Card.
- EU Funding to support the Card’s production and implementation.
- Clear steps to involve persons with disabilities and their representative organisations in the Card’s implementation and evaluation.
- Card to be automatically issued – EDF is advocating for no direct issuing unless the person asked for it.
EU Disability Card Proposal: EU-decision making

Timeline is not clear but with the elections ahead, the procedure could be fastened.

EU Disability Card - the EU legislative process.

Proposal by the European Commission

Establishing positions
European Parliament and the Council

Negotiations
“Trilogues”

Final approvals
and publication in
the Official Journal
of the EU

Implementation
Since the law is a Directive, EU countries must transpose it into national law and begin issuing the Cards.

Transposition period: 18 months.
Rules shall apply within 30 months from entry into force.
EU Disability Card Proposal: next steps

European Commission:

- Consultation for feedback on the proposal.
- Open feedback (4000 characters) + option to attach a file.
- Deadline 13 November 2023.

We will prepare a response, based on our contributions to the previous consultations, now in context of the proposal.
EU Disability Card Proposal: next steps

European Parliament:

- Committee responsible: EMP - Committee on Employment and Social Affairs. Opinions by
- Rapporteur: Lucia ĎURIŠ NICHOLSONOVÁ [Renew], Slovakia. Shadow rapporteur(s): Elżbieta RAFALSKA [ECR], Poland.
- Report that will represent the Parliament’s demands – Before this step, opinions from other Committees will be prepared and voted on (IMCO, PETI).

We might prepare amendments to submit ourselves or to be included in EDF’s suggested amendments

- Vote on the report at the Committee.
- Submission to the entire Plenary – at this stage, other MEPs not directly involved can submit amendments.
- Vote by the Plenary of the EP on the report and amendments.
- Then, the report will become the European Parliament’s negotiation position.
EU Disability Card Proposal: next steps

Council of the EU, the steps are the following:

- Establish which configuration is responsible.
- Technical and political meetings, led by the Presidency of the Council of the EU, to establish the Council’s position.
- Adoption of the position.

Spanish Presidency is very engaged, so is Belgium; and there is quite a positive reaction with the Council.

16 November, Palma de Mallorca: High-level meeting on the rights of people with disabilities. We’re trying to attend, but no feedback from ES Presidency team.

EDF is meeting with some permanent representations: ES, BE, DK, FI, LV, SE, NL

Nordic countries and Germany have raised issues with including transport.

Netherlands has raised issues with automatic emission of the Card, due to concerns with stigma.
Event on the European Disability Card! From proposal to reality

9 November | Online | 14:00 h (Brussels time)

Join us to understand what the European Disability Card will be and what you can do to support a strong legislative proposal.

This event will be an opportunity for you to learn:

- The journey until the Card becomes a reality
- Key players
- The demands from the disability movement
- How the Card might look like
- What will it cover
- Experiences from the use of the Cards made during the pilot projects

More information about the event

Register to the event on the Disability Card