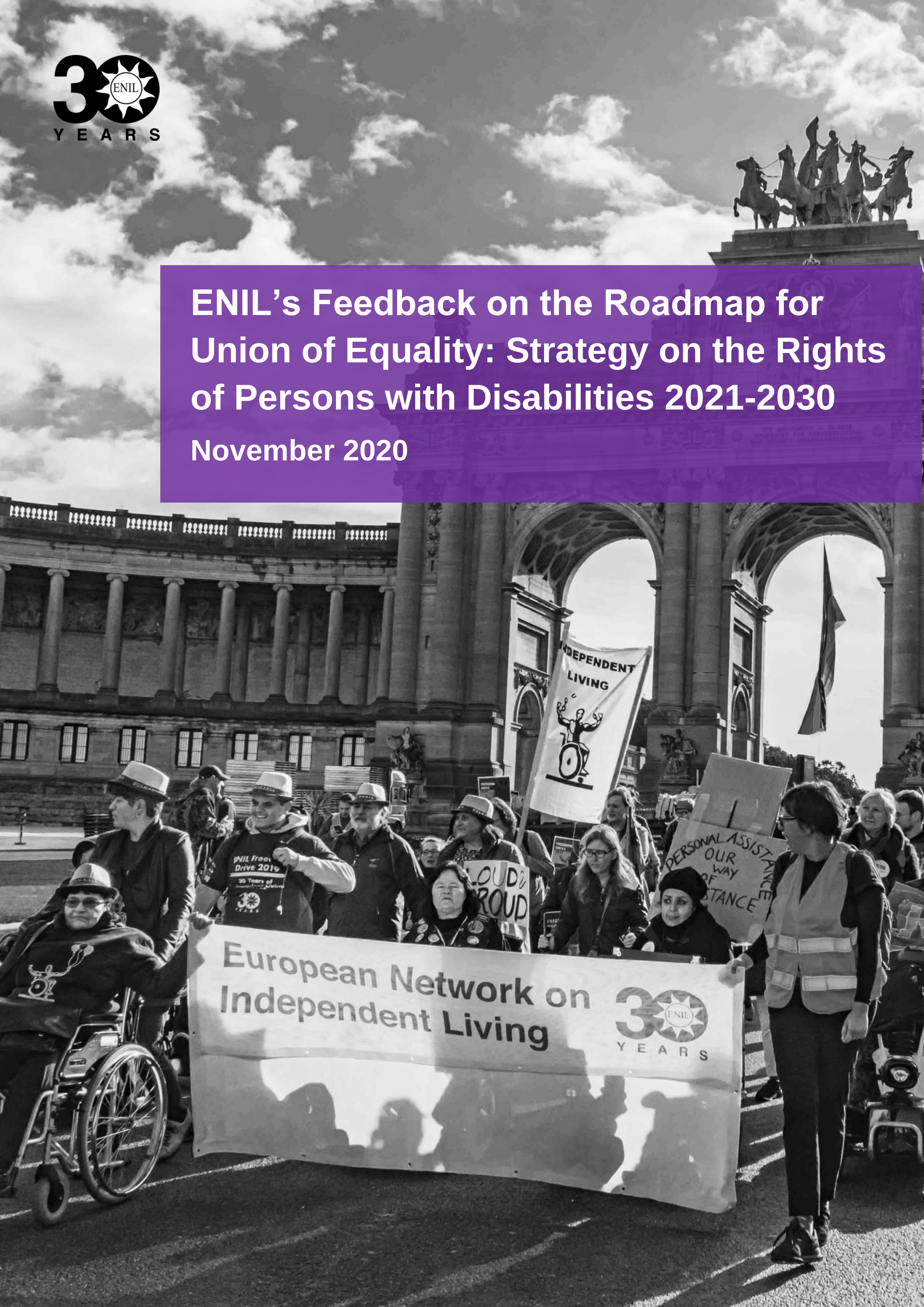


ENIL's Feedback on the Roadmap for Union of Equality: Strategy on the Rights of Persons with Disabilities 2021-2030

November 2020

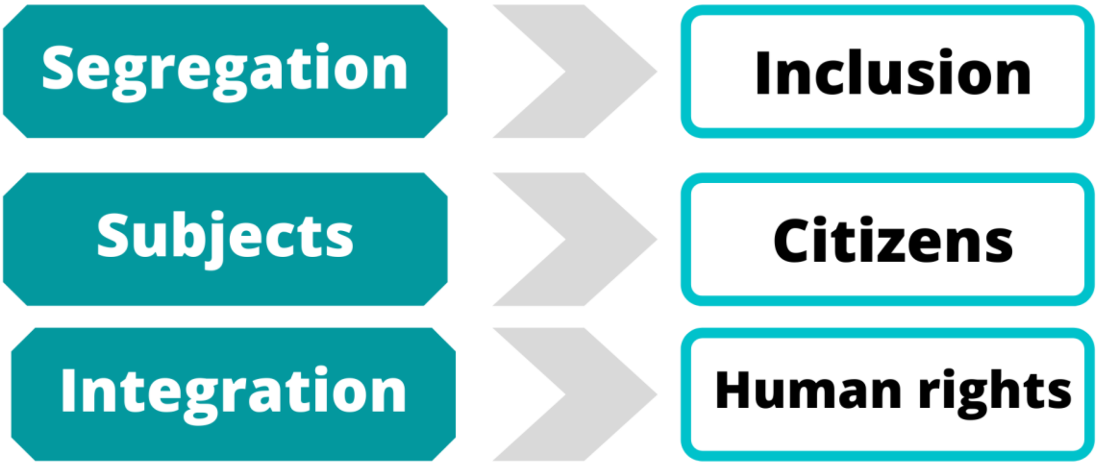
Introduction

The recent European Commission's Roadmap on the 2021-2030 Disability Strategy rightly states that "all persons with disabilities have a right to decent quality of life and to living independently". The right to Independent Living, as defined in Article 19 of the UN Convention on the Rights of persons with disabilities (CRPD) and General Comment 5, is key for unlocking the full enjoyment of Human Rights for disabled people across Europe.

Recognising the right of disabled people to control their lives and have equal and real choices on where, with whom and how to live is a prerequisite for full inclusion.

Against this background, the European Network on Independent Living (ENIL), highlights 3 essential shifts which are crucial for a successful post 2020 European Disability Strategy (EDS). First, the shift from segregation to inclusion; secondly, the shift from disabled subjects to disabled citizens; and finally, the shift from integration to human rights.

Within each of these shifts, this position paper will identify concrete actions to advance the right to independent living and the other specific goals set out in the roadmap.



I. Shift from segregation to inclusion

In the roadmap for the new European Disability Strategy (EDS), the Commission states the aim to ensure inclusion and participation of disabled people[1]. Furthermore, the roadmap confirms that all people have the right to live independently. Modernisation and consolidation of community-based services (CBS) are mentioned as key to achieve this goal.

Being able to live your life independently according to your own choices is indeed essential for participation and inclusion. A recent survey among ENIL members showed that this right to Independent Living is far from realized in the European Union and the neighbourhood[2].

Throughout all Member States, disabled people are still segregated into large or small institutions. The current COVID-19 crisis has only confirmed the fact that isolating people in institutional care settings is a danger to both their physical and mental health.[3]

Access to mainstream services, such as education or the open labour market, is described as inadequate by ENIL members. Segregating services like sheltered workshops, special schools or special transport are often the only option for disabled people, because mainstream services are not available or accessible on an equal basis.

While recognising that some progress has been made, the European Union continues to perceive disability as a separate ('special') area, isolated from other policy fields. For example, the quality of education in Europe is measured by the OECD PISA test, which in turn influences the countries' education policies. However, a recent ENIL report showed that the PISA testing excludes, rather than includes, disabled students[4]. To realize the goal of inclusive education and other rights presented in the roadmap, the ambition of the next EDS must reach beyond the social field and approach disability inclusion as a cross cutting human right.

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[1] ENIL prefers the term 'disabled people' over 'persons with disabilities' or 'people with disabilities', in order to reflect the fact that people are disabled by the environmental, systemic and attitudinal barriers in society, rather than by their impairment. This is in line with the social model of disability.

[2] The Independent Living Survey was open from June until September 2020 and covered 44 countries in Europe, including all 27 EU Member States. Full results will be published on 10 December 2020.

[3] COVID Disability Rights Monitor: https://enil.eu/news/covid-19-disability-rights-monitor-report-highlights-catastrophic-global-failure-to-protect-the-rights-of-persons-with-disabilities/

[4] https://enil.eu/news/how-inclusive-is-pisa/

New European funding tools, like Invest EU or the Resilience and Recovery Facility (RFF) do not have safeguards against investments in institutional care. In general, EU Funds are still used to move disabled people from large into small institutions, instead of developing community-based services, in line with the CRPD. Furthermore, the development of genuine community-based services, such as personal assistance, is not supported by EU legislation in other fields, like for example, environment, health or employment.

Giving people the opportunity to tailor their support specifically to their needs gives them independence and the autonomy necessary to actively participate in all aspects of society. This is in line with Article 19 of the CRPD (the right to live independently and be included in the community) and principles 1,3,4,17,18 and 20 of the European Pillar of Social Rights.

The next European Disability Strategy should include **the following key action points to facilitate the shift towards a European society that enables people to live independently, take control over their lives and live according to their own choices and requirements**.

- The EU should adopt a strong position to make it clear that the **availability of community-based services (CBS), controlled by the user, is essential for the transition towards an inclusive European Union**, where not a single disabled person is forced into institutional care due to the lack of community-based alternatives.
- The Roadmap calls for a clear action plan to realize the right to Independent Living across Europe. This **action plan should be developed with the active involvement of disabled people**, and should include definitions of the key terms, based on the UN CRPD and its General Comments.
- All European Funds and funding instruments (such as Invest EU and RRF) should have **provisions to fully prohibit investments into the building, renovation or modernization of any segregating settings** (including small institutions, such as group homes) for disabled children, adults and older people.
- EU funding instruments and European legislation across policy fields, like the **Working Time Directive, the proposed Directive on Adequate Minimum Wages, or the Renovation Wave for Europe should support, rather than obstruct, the development of innovative CBS** like personal assistance.
- The European Union should **update the social scoreboard to actively monitor progress** towards inclusion and UN CRPD implementation in all Member States.

- Similarly, the EU should monitor and stimulate progress towards inclusion and UN CRPD implementation in **international cooperation and negotiations with partner and candidate countries**.
- In line with the EU legislation, the UN CRPD and European Social Pillar, the EU should **apply sanctions and launch infringement proceedings** against Member States that make investments in segregating services, such as sheltered workshops, special education or special transport
- As a state party to the UN CRPD, the **EU should engage with other international organisations**, such as the OECD, to promote the implementation of UN CRPD (by, for example, improving the inclusiveness of the PISA tests).

II. Shift from disabled subjects to disabled citizens

The Roadmap rightly points out that disabled persons need to be able to fully participate in the democratic process and the European Parliament elections. Furthermore, the Roadmap suggests to build on the EU Parking Card and the EU Disability Card pilot project to start the debate on mutual recognition of disability between Member States. These are important steps towards recognising disabled people as full citizens of the EU, and facilitating their freedom of movement.

Today, disabled people in the EU still face discrimination in accessing their rights as EU citizens. The right to move, live, study or work freely throughout the EU remains largely inaccessible for disabled people. This is illustrated by the fact that only 0.17% of the participants in mobility programmes like Erasmus+ are disabled people.[5] When crossing the border of another EU Member State, disabled people lose their access to the social support services in both their home and host country. This includes access to essential services like physiotherapy, personal assistance or sign language interpretation. The current EU framework, with the Regulation on Social Security Coordination[6], and the Council Recommendation on Access to Social Protection[7], only covers a part of the sickness and health care benefits, and does not allow people to access social support services across borders. This is problematic, as access to

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[5] See: https://mapped.eu/inclusive-mobility-alliance

[6] Procedure 2016/0397(COD) to amend Regulation 883/2004/EC: https://oeil.secure.europarl.europa.eu/oeil/popups/ficheprocedure.do?reference=2016/0397(COD)&l=en

[7] https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.C_.2019.387.01.0001.01.ENG&toc=OJ:C:2019:387:TOC

personal assistance or sign language interpretation is essential for disabled people to work, study and fully access their right to free movement as active citizens.

Civic engagement is another essential part of citizenship. Disabled people in the EU are regularly consulted, but rarely actively engaged in the policy process. This has three main reasons: accessibility, visibility and capacity (i.e. resourcing).

In terms of accessibility, European public consultations are often not easily accessible nor available in easy read or sign languages. Disabled people who want to contribute actively to EU policy, to report a violation of their rights, misuse of EU Funds, or breaches of EU law in their country, do not have a straightforward way to notify the European Commission of their situation or seek remedy.

Disabled EU citizens are often also invisible citizens. The most noticeable example of this is the denial of legal capacity for many disabled people[8]. Furthermore, people living in institutions are often not seen as citizens at all, let alone involved in policy making or even counted in official education or employment statistics.

A precondition for participation is capacity and, in this respect, activities to empower disabled people (through peer support) and funding to support the work of organisations of disabled people are needed. This must include those that are most marginalised, such as people living in institutions or those with the highest support needs.

Recognising disabled people as full and active citizens instead of passive subjects of care is vital to achieve inclusion and counter discrimination in education, employment and society in general. This would be in line with the EU's UN CRPD obligations (in particular article 8 and 12), the CRPD Committee recommendations to the EU, the EU Charter of Fundamental Rights and the 3rd principle of the European Pillar of Social rights.

Therefore, the next **EDS should include the following actions to enable full citizenship for all disabled people in the EU**:

- The EU should urgently work towards the adoption of the **horizontal non-discrimination directive** or propose a new directive to this effect.

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[8] https://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf

- The new EDS should support the **expansion of the European Disability Card project and the mutual recognition of disability** in all Member States.
- Building on the Council Recommendation on Access to Social Protection and the negotiations around the Regulation for Coordination of Social Security Systems, the European legislators should adopt **binding legislation to ensure all disabled people can exercise their right of free movement**, with automatic access to equivalent social benefits and services across Member States.
- The new EDS should invite the Member States to start the **process towards a revision of Article 153 of the TFEU**. This will give the EU the tools to contribute to a progressive, effective and consistent European social policy.
- The new EDS should have **the objective to actively involve disabled citizens that are most excluded** – such as those in institutions and with the highest support needs - in EU policy. Disabled Peoples Organisations (DPOs) should play a key part in this process.
- The EU should set up an **easily accessible platform** where people can directly interact with European institutions, ask for information, file complaints or seek remedies for breaches of EU law.
- The new EDS should include **clear goals for national and European data collection**, in order to make those disabled citizens that are currently invisible, visible in official statistics. This would help unveil persistent discrimination and segregation in the Member States, among other.
- The new EDS should ensure that **funding available to Member States, neighbourhood countries or through international cooperation is accessible to local organisations** of disabled people, in order to increase their capacity and ability to participate in decision-making processes in their countries and at EU level.
- The EU should **ratify the Optional Protocol to the UN CRDP**, in order to allow citizens to use the individual or collective complaint mechanism, if they feel that EU actions or legislation are not compatible with the Convention.

III. Shift from integration to human rights

The Roadmap successfully lays out a framework aimed at inclusion of disabled people. To reach this goal, the Roadmap takes into account different fields, from education and employment, to health, sports and culture. Throughout the Roadmap, disabled people are, however, mainly approached as a separate category in need of protection and support. Links to other groups, like women and children, are only made to confirm the "fragility" of disabled people, not to emphasize the universal nature of human rights.

In order to reach its full potential, the next EDS should take the additional step and approach disabled people as (human) right holders. The UN CRPD does not create new rights, it rather clarifies how States Parties should realize and protect existing human rights for people '*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'*. As a consequence, the Convention applies to all people who face barriers to fully participate in society.

Therefore, the next European Disability Strategy should aim to remove policy silos, in order to give all people in Europe the confidence and the support to fully access their human rights.

Starting from this clear vision, the EDS should formulate concrete goals to make the EU more inclusive during the 2021-2030 period. This should be done with respect to, but not in fear of, EU competences. The **next EDS should stimulate, rather than shy away, from public debates with the Member States and European citizens on key topics around inclusion and human rights**.

- The next EDS should take into account the EU's obligations under the UN CRPD and **systematically address the issues raised in the CRPD Committee's recommendations to the EU, and the Member States** (when reviewing plans for the use of EU funds, for example).
- EDS actions should **cover the broad diversity of disabled people**, including women and girls, and children with disabilities, but equally important - older people with disabilities, who are also rights holders under the UN CRPD. Older persons with disabilities have been excluded until now from Europe's disability agenda.
- The EU should **urgently update its declaration of competences** to ensure all its obligations under the UN CRPD can be fully addressed. This revision of competences should be done without fear of encroaching on Member States' competences.

- To reflect the fact that disability right are human rights, the next EDS should **include a provision to move the disability unit from DG Employment to DG Justice.**
- All European Commission DGs, Parliamentary Committees, Council configurations, European institutions and agencies, and EU delegations, should set up **disability focal points**, which should be adequately trained. The main focal point should be located at the Secretariat-General of the European Commission.
- Regular **training on UN CRPD and its general comments**, developed and delivered together with disabled people and their organisations, should be rolled out across the Commission DGs, in order to ensure that the Convention can be operationalised in the internal and external activities of the Commission.
- EDS should include **measurable progress indicators**, and foresee a mechanism for continuous monitoring and evaluation, with annual reports to the Secretariat-General.

For additional information, please contact: Frank Sioen, Advocacy and Policy Coordinator, ENIL, frank.sioen@enil.eu