

ENIL's Proposals for the Post 2020 European Disability Strategy January 2020

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European Network on Independent Living

ENIL's Proposal for the Post 2020 European Disability Strategy

Introduction

Independent Living and social inclusion are not checkboxes in policy documents. They are key to disabled people being able to enjoy their human rights, as set out in the UN Convention on the Rights of Persons with Disabilities (CRPD) and other human rights standards, in the European Union (EU) and across the globe.

The European Disability Strategy (EDS) is an important programmatic document for disabled people in Europe, highlighting those areas in which the European Union can most effectively advance the rights of disabled people. In this document, the European Network on Independent Living (ENIL) outlines a set of recommendations to ensure that the new European Disability Strategy, for post 2020, can meaningfully contribute to the realisation of these rights.

This position paper begins with the overall need to mainstream the right to Independent Living, as set out in Article 19 of the CRPD, and social inclusion, across all EU policy areas. It then goes on to discuss three key areas where the upcoming EDS must play a role to ensure all disabled people in Europe can fully access their human rights.

Mainstreaming disability across all policy areas

Social inclusion and Independent Living are not only about access to social services; they concern all areas of life. This includes **access to health care, education and employment, public transport, housing, culture, sports and leisure, and other areas.**

Similarly, the need to be included and fully participate in society is not limited to any particular target group. All children need support to fully participate in school. All employees need breaks during the day and flexible working arrangements from time to time. Everyone benefits from an accessible built environment.

With this in mind, ENIL expects the EDS to:

- Recognise the **universal nature of social inclusion** and the need to mainstream disability across all policy fields.
- Facilitate connections between different policy areas at the EU level to make sure that processes like the transition from residential and institutional care to living in the community, with access to community-based services, are addressed by actions across policy fields.
- In line with the <u>General Comment No. 7</u>, on participation of disabled people in implementation and monitoring of the Convention, promote the need to fund the work of disabled people and their organisations in the Member States and at EU level.
- Promote implementation of the **CRPD in all external actions** of the European Union. This includes promoting the transition from institutionalisation to living in the community in all partner countries, including by only funding projects fully in line with the CRPD.

With regard to specific actions, this can be achieved by:

- Implementing the first EU-wide awareness-raising campaign to highlight the importance of mainstreaming disability across all policy areas.
- Linking the actions of the new EDS to <u>recommendations of the</u> <u>Committee on the Rights of Persons with Disabilities</u> to the EU from 2015, with deadlines for implementation and a framework in place to allow for ongoing evaluation of EDS at the EU level, involving organisations of disabled people.
- Considering moving the **unit for disability rights** to the Secretariat-General of the European Commission, in order to ensure mainstreaming of disability across policy areas.

Three key objectives for the next European Disability Strategy

1. End institutional care. Promote access to communitybased support services and Personal Assistance.

All actions to advance the right to Independent Living and social inclusion in general should be accompanied by a shift away from the traditional model of care based on institutional and residential care. This means that **Community-Based Services (CBS) and access to Personal Assistance (PA) must be made available across the EU**.¹

Being able to live your life according to your own choices is essential for participation and social inclusion. Therefore, all disabled people should be in control of the support they receive. Giving people the opportunity to tailor the support they receive to their needs gives them independence and the autonomy necessary to actively participate in all aspects of society.

In line with Article 19 of the CRPD (the right to live independently and be included in the community), the **EU should facilitate the shift towards a system of support that enables and empowers people to take control over their life** and to live it according to their own choices and requirements.²

Personal Assistance, paid for by direct payments/personal budgets, controlled by the person, is a perfect tool to give people control over their own life. This is in line with both the CRPD and Article 26 of the EU Charter of Fundamental Rights. Additionally, Personal Assistance makes economic sense, because it allows people to get exactly the right support for their needs. This reduces costs and reliance on other services, such as health care.

The 2014 **Multiannual Financial Framework (MFF)** has played a vital role in putting deinstitutionalisation and the transition to Community-Based

¹ For more information on the concepts of CBS and PA, see <u>http://enil.eu/independent-living/definitions/</u>

 $^{^{\}rm 2}$ For more information on Article 19 of the UN CRPD, see General Comment No 5 by the CRPD Committee

https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/ GC/5&Lang=en

Services (CBS) and access to Personal Assistance (PA) on the agenda. However, despite good intentions, EU Funds have not been used in compliance with Article 19 of the UN CRPD. Many disabled people in the EU are being moved from large into small institutions, without adequate support to live independently or without being involved in decisions concerning their lives.³

Therefore, it is essential that the next EDS:

- Includes **definitions of the key terms**, in line with Article 19 and its <u>General Comment No. 5</u>, to prevent the continued segregation and exclusion of disabled people under the guise of community living.
- Adopts a strong position to make clear that the **general availability** of (mainstream) CBS is essential for the transition from institutional care to living in the community.
- Promotes the closure of residential institutions for disabled people and a moratorium on the building of new institutions, as well as actions to ensure that not a single European citizen is forced into residential or institutional care because of the lack of Community-based Services (CBS).
- Promotes the transition from institutional care to CBS and Personal Assistance (PA) in all EU policy tools and initiatives.

With regard to other law and policy initiatives, the EDS should ensure that:

- <u>The European Semester</u> is used to monitor and ensure that austerity does not damage social protection.
- The availability and quality of CBS and PA are included as an indicator in the **EU Social Scoreboard.**
- The European and national rules regarding **working time and working conditions** recognise the importance of the transition towards CBS and PA. This includes working with Member States to make sure that the national social security systems provide sufficient funding to allow PA users to comply with EU regulations.

³ See the 2018 ENIL Briefing on the Use of EU Funds for Independent Living, at <u>http://enil.eu/wp-content/uploads/2018/04/EU-Funds-Briefing_web0903.pdf</u>

2. Involve European citizens to improve the transparency and effectiveness of EU Funds.

The European Structural and Investment Funds (ESI Funds) are one of the most important tools the EU has to reduce inequality between regions and to promote social inclusion. Yet, **many European citizens are not aware of the existence or possibilities of these Funds**. This makes it more likely they will be misused, by supporting projects that go against common European values.

Fully involving (disabled) Europeans in the funding cycle - from programming, through implementation, to monitoring will **improve the effectiveness, transparency and legitimacy of the EU.**

Full involvement should go beyond consultation. European citizens, including disabled people, should get an equal seat at the table. This includes physical access, but also getting the support and time you need to acquire the knowledge necessary to participate on an equal basis with policy makers or social partners. People who contribute to the discussion should also receive (financial) compensation for their time. This will ensure that decisions about European funding are co-produced by policy makers, civil society and EU citizens. This will greatly improve the transparency and legitimacy of EU projects.⁴

Therefore, it is essential that the next EDS:

- Makes it clear that the European Structural and Investment Funds (ESI Funds) can only be used for genuine deinstitutionalisation and independent living, as set out in Article 19 and its <u>General Comment No. 5</u>.
- Promotes initiatives to ensure that the support services funded by ESI Funds start from the needs of individuals, not the interests of service providers or the authorities.
- Promotes an independent monitoring and complaints system for the use of ESI Funds to ensure that no public or private funds

⁴ For more information on co-production see: <u>'Co-production – enhancing the role of citizens</u> in governance and service delivery'

in the EU are spent on building, maintaining and/or renovating institutions of any type.

With regard to other law and policy initiatives, the EDS should ensure that:

 The current <u>European Code of Conduct on Partnership</u> is replaced with a new one for 2021 – 2027 and is fully implemented. This should include using co-production to fully involve (disabled) citizens in the set-up, monitoring and evaluation of projects.

3. Promote freedom of movement for all disabled Europeans.

Freedom of movement of goods, people, services and capital is a basic EU principle enshrined in the <u>Treaty on the Functioning of the European</u> <u>Union (TFEU)</u>.⁵ The freedom to travel around the EU is an opportunity for people to feel European. Seeing and experiencing different cultures and ways of life fosters a diverse and inclusive society.

Today, businesses in the EU already make use of the possibilities offered by the right to free movement. Private citizens, on the other hand, often cannot fully enjoy their right to live, work or study in another EU Member State. The reason for this is simple: **there is no European social framework to support the right to free movement.**

Principles 12, 14 and 20 of the Social Pillar state that everyone has a right to, respectively, social protection, an adequate income and access to essential services, including transport.⁶ Yet, in practice, many European citizens cannot access these rights while traveling or living in another Member State. This prevents people from discovering the possibilities of European Citizenship and perusing opportunities to work or study across the EU. **This is especially true for disabled EU citizens**.⁷

⁵ Art 45-66 TFEU

⁶ See the Social Pillar principles, at <u>https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en</u>

⁷ See the Report of the European Day Of Persons With Disabilities 2015, at <u>http://ec.europa.eu/social/BlobServlet?docId=15129&langId=en</u> and the 2016 Report on intra- EU Labour Mobility, at <u>http://ec.europa.eu/social/BlobServlet?docId=17165&langId=en</u>

Article 153, paragraph 4 of the Treaty limits EU's competence in the social field. Paragraph 2 of the same article, however, allows the Parliament and Council to promote good practices to enhance social inclusion and remove administrative barriers.⁸

Therefore, it is essential that the next EDS:

- Promotes the need to revise Article 153 of the TFEU to give the EU the tools to contribute to a progressive, effective and consistent social policy.
- Promotes better **coordination of support services** between countries and **the setting up of contact points** in all Member States to inform (disabled) EU citizens about social rights and support services across Europe.
- Expands the pilot project of the <u>EU Disability Card</u> beyond culture and sport, to ensure that disabled people across Europe can access disability support without the need for separate assessments in each Member State.
- Puts in place actions to ensure that mainstream accessible **public transport becomes an enforceable right** for all EU citizens.⁹

With regard to other law and policy initiatives, the EDS should ensure that:

- The European transnational programmes like Erasmus+ and the European Solidarity Corps are fully accessible and inclusive to all EU citizens, whatever their support needs are.
- Build on the Commission Proposal for a Council Recommendation on access to social protection, to expand its scope and enable all EU citizens to access (social) support services across the EU. This is in line with a recommendation of the UN CRPD Committee.¹⁰
- Use the European Accessibility Act (EAA) as a basis to adopt a strong European framework for an accessible and inclusive (built) environment with fully accessible services, including transport, communication and financial services.

⁸ See Art.153 TFEU, at <u>https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A12008E153</u>

⁹ One of the initiatives in this area that could be expanded is <u>Eurokey.</u>

¹⁰ See §48-49 of the UN CRDP Concluding observations on the initial report of the European Union, at <u>https://daccess-ods.un.org/TMP/6056394.57702637.html</u>

About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

ENIL has Participatory Status with the Council of Europe, Consultative Status with ECOSOC, is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform, and on the Advisory Council on Youth at the Council of Europe.

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