



# ENIL 2017 Freedom Drive Declaration

## Introduction

From the 24<sup>th</sup> to 28<sup>th</sup> September, Independent Living activists and allies from across Europe will meet in Brussels for ENIL's 2017 Freedom Drive. Delegations from the European Union and neighbouring countries will march from the European Parliament to the European Commission, demanding rights, not charity, for disabled people in Europe. Many will meet their Members of the European Parliament (MEPs), to discuss barriers disabled people face in their country and to learn what the EU institutions can do to improve their situation.

This Freedom Drive Declaration outlines the main barriers disabled people are facing, and which the European Network on Independent Living - ENIL is campaigning on. Specific recommendations are set out for MEPs, to be used by country delegations to help them formulate their own demands. In addition to MEPs, this Freedom Drive Declaration is aimed at the European Commission, which will also participate in different Freedom Drive events.

ENIL will use the two years between the Freedom Drives to monitor progress in these areas, and will continue with advocacy and campaigning activities in Brussels, and together with our members, at the national level.

## ENIL's Message to Members of the European Parliament

### 1. IMPLEMENTATION OF CRPD ACROSS THE EU

The European Union and all the Member States, apart from Ireland, have ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). ENIL is concerned, however, about the many barriers that exist across Europe, and which prevent disabled people from enjoying their right to independent living. These are highlighted in our recent report on barriers to independent living around the world.<sup>1</sup>

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<sup>1</sup>The European Network on Independent Living (2017) *The Right to Live Independently and Be Included in the Community – Addressing Barriers to Independent Living across the Globe*, available at: <http://enil.eu/news/enil-publishes-report-on-the-barriers-to-independent-living-across-the-globe/>

ENIL has issued a statement<sup>2</sup> on the 7<sup>th</sup> June about the millions of Euros to be invested into institutional care in Wallonia, Belgium. In our report for the Petitions Committee at the European Parliament<sup>3</sup>, we highlighted the concerns raised by the Committee on the Rights of Persons with Disabilities (CRPD Committee) in respect of different Member States. These include the lack of community-based services, the lack of progress towards deinstitutionalisation and the continued investments into institutional care in a number of countries. With regard to the EU, the CRPD Committee expressed concern about the fact that many disabled people, especially those with intellectual or psychosocial disabilities still live in institutions, and that the European Structural and Investment Funds (ESIFs) continue to be used for maintenance of institutions, rather than to develop community-based services.

### Recommendations:

- We urge MEPs to call on the Irish Government to **ratify the CRPD** without further delay.
- In its role as a member of the CRPD monitoring mechanism under Article 33 CRPD, we urge the European Parliament to call on the European Commission to **implement the recommendations of the CRPD Committee** without delay, and to regularly report on progress. In respect of Article 19 CRPD, the Commission was asked to: develop an approach to guide and foster deinstitutionalisation, to strengthen the monitoring of the use of ESIFs and to ensure they are used strictly to develop community-based services, and to withdraw and recover payments if the obligation to respect fundamental rights is breached. The Parliament's reports on the implementation of the CRPD in the EU must highlight to what extent disabled people in different Member States can access independent living, and whether ESIFs are used to support personal assistance, accessible housing and other community-based services.
- We urge MEPs to strongly and unequivocally **condemn any attempts to strengthen the system of institutional care** in the Member States, including the recently announced plans in Wallonia. Moreover, MEPs should encourage deinstitutionalisation reforms *in their own* Member State, and urge the Government to implement recommendations of the CRPD Committee on Article 19. MEPs should also promote awareness raising campaigns or other

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<sup>2</sup>Disability Watchdog: Wallonia to Invest Millions into Institutions for Disabled People, 7 June 2017, available at: <http://enil.eu/news/disability-watchdog-wallonia-to-invest-millions-into-institutions-for-disabled-people/>

<sup>3</sup>Directorate General for Internal Policies, Policy Department C: Citizens' Rights and Constitutional Affairs. (2016) *European Structural and Investment Funds and people with disabilities in the European Union*, available at: [http://www.europarl.europa.eu/RegData/etudes/STUD/2016/571386/IPOL\\_STU\(2016\)571386\\_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/STUD/2016/571386/IPOL_STU(2016)571386_EN.pdf)

activities in the European Parliament, and their own Member State, to improve knowledge of the CRPD among policy and decision makers, service providers, disabled people and other stakeholders.

- In line with Article 32 CRPD (International cooperation), the MEPs should ensure that the European Union, as the biggest donor, complies with the CRPD, and also work towards the **implementation of the Sustainable Development Goals**.<sup>4</sup> The European Parliament should monitor the Member States' and the EU's progress in this area, and include the relevant information in their own reports.

## 2. A STRONG EUROPEAN ACCESSIBILITY ACT

In December 2015, the European Commission launched a proposal for a European Accessibility Act (EAA). While the proposal was not overly ambitious - as pointed out in the *ENIL Position paper on the EAA*<sup>5</sup> - it provided a starting point for addressing the lack of accessible mainstream products and services in the EU. However, since the initial proposal, the negotiations in the European Council and the European Parliament have resulted in weakening of the provisions. A weak EAA will do nothing to improve accessibility of products and services in the Member States, and we need the MEPs to stand up, not for business and other interests, but for the rights of disabled people.

### Recommendations:

- The European Council and the European Parliament have tried to delete or to water down the requirement to make the built environment, in which the product or service is provided, accessible. As a result, one could have an accessible ATM in an inaccessible bank; this would both be useless for the disabled person and a waste of resources for the bank. In order to have a meaningful Accessibility Act, it is **crucial to have a strong obligation, or at least a commitment, to a fully accessible built environment**.
- Instead of limiting disability to a strict medical interpretation, the EAA should, in line with the CRPD, define disability as any 'long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder [...] full and effective participation in society on an equal basis with others'. As a consequence, **the main aim of the EAA should be the removal of barriers which hinder the full functional use of products and services in the EU**.

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<sup>4</sup>See: <http://www.un.org/sustainabledevelopment/sustainable-development-goals/>

<sup>5</sup>See ENIL Position on the Proposal for a European Accessibility Act, available at: [http://enil.eu/wp-content/uploads/2016/03/ENIL\\_position\\_EAA\\_final.pdf](http://enil.eu/wp-content/uploads/2016/03/ENIL_position_EAA_final.pdf)

- The European Parliament's report on the EAA included a proposal to limit the impact of the EAA to fields not yet covered by existing legislation (thus excluding areas like transport, for example). In other fields, EAA would only be used to define accessibility. Accessibility can only be achieved when all parts of the chain are fully accessible (this includes physical accessibility of services, buildings and environment, but also user friendly communication and access to information). **The EAA will only be useful if it recognizes this need for integral accessibility in its scope and has the ambition to influence existing EU legislation.**
- The Accessibility Act should define 'accessibility' as **"enabling equal use of a product or service for all users"** and NOT as "products and services... operated and understood by persons with disabilities and are sufficiently robust for them to use".

### 3. NO MORE CUTS TO INDEPENDENT LIVING

Together with our partners in the Alliance against Disability Cuts (AADC), ENIL has been raising awareness about the devastating effect of austerity on disabled people's right to independent living across Europe<sup>6</sup>. As highlighted in the first in our series of articles on Sweden<sup>7</sup>, disabled people have suffered a tightening of criteria for personal assistance, a reduction in the hourly rate, a redefining of their basic needs, needless assessments and hostile rhetoric – all of which have affected their right to live independently in the community. Our member in the UK – Disabled People against the Cuts – has prompted the first UN inquiry under the Optional Protocol to the CRPD, resulting in the condemnation of austerity in the UK<sup>8</sup>.

#### Recommendations:

- MEPs must be aware of **the devastating effect of austerity on the lives of disabled people around Europe** and raise their concerns in the European Parliament. AADC has been campaigning since 2011 for a European Parliament Resolution against the cuts, but so far, this initiative has not received enough support. We need the **support for of MEPs from all political groups for the Resolution**, in order to prevent disabled people from continuing to be disproportionately affected by budget cuts in the Member

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<sup>6</sup>See, for example, European Foundation Centre (2012) *Assessing the impact of European governments' austerity plans on the rights of people with disabilities*, available at: [http://efc.issuelab.org/resource/assessing\\_the\\_impact\\_of\\_european\\_governments\\_austerity\\_plans\\_on\\_the\\_rights\\_of\\_people\\_with\\_disabilities](http://efc.issuelab.org/resource/assessing_the_impact_of_european_governments_austerity_plans_on_the_rights_of_people_with_disabilities)

<sup>7</sup>Independent Living Under Threat in Europe: Sweden, 5 May 2017, available at: <http://enil.eu/news/independent-living-under-threat-in-europe-sweden/>

<sup>8</sup>CRPD Committee (2016) *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention*, available at: [www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc)

States. Moreover, any financial sanctions imposed by the EU on the Member States must ensure that disabled people are not affected as a result.

- The European Parliament is part of the independent monitoring mechanism under Article 33 of the CRPD and it must make sure that Member States **do not take retrogressive measures**, which would undermine implementation of the CRPD.

## 4. A VOICE FOR ALL

ENIL's *EU Funds for Our Rights Campaign* has found a number of problems in how the European Structural and Investment Funds (ESIFs) are used in the Member States<sup>9</sup>. Although we haven't found evidence of large institutions for disabled people being built or renovated in the current programming period (2014 – 2020), many of the services (such as family-type homes or group homes) still fail to provide disabled people with the opportunity to live independently. We are also concerned that user-led personal assistance schemes, accessible mainstream housing and other services and facilities that facilitate social inclusion, are not receiving ESIF support. There are also major gaps in monitoring the use of ESIF in the EU, with many organisations that promote independent living excluded from the Monitoring Committees and other processes. Despite the European Code of Conduct on Partnership<sup>10</sup> providing for involvement of disabled people, including those most marginalised, the Member States are not doing enough to facilitate the involvement of disabled people and their organisations.

### Recommendations:

- We urge MEPs to ensure that **ESIFs are not used to support any form of institutional care in the Member States** – regardless the size of the settings – and to promote the use of ESIFs to support personal assistance schemes and other community-based services, as well as to make mainstream services and facilities accessible.
- We call on MEPs to ensure that the **priority on the 'transition from institutional to community-based care' and the ex ante conditionalities on disability and the CRPD** are kept in the ESIF Regulations for the next programming period (2021 – 2028). The **provisions on monitoring and complaints** should be strengthened to prevent future investments into institutional care services, and ESIFs funding for technical assistance should

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<sup>9</sup>ENIL has sent a letter to the Romanian Minister of Labour and Social Justice on 26 May, raising concerns about the plans to build protected units (group homes) and day care centres for disabled people – with the support of ESIFs - as the only alternatives to large long-stay institutions.

<sup>10</sup>See: [http://ec.europa.eu/regional\\_policy/en/policy/what/glossary/e/european-code-of-conduct](http://ec.europa.eu/regional_policy/en/policy/what/glossary/e/european-code-of-conduct)

be used to build the capacity of disabled people's organisations to act as partners in the process of ESIFs programming and implementation.

- We urge the Petitions Committee (PETI Committee) at the European Parliament to **adequately investigate any complaints into the use of ESIFs for institutionalisation of disabled people**, and to carry out field visits, such as the one to Slovakia in 2016. Moreover, we call on the PETI Committee to ensure the Commission and the Member States implement any recommendations by the PETI Committee as a result of these investigations.
- The principle of '*Nothing about us, without us*' requires meaningful involvement and consultation with disabled people and their representative organisations in all the decisions that affect them. As the best experts on their lives, disabled people are an invaluable resource to policy and decision makers, at the European and local level. MEPs should therefore urge the European Commission and Member States to **financially support organisations of disabled people** - through both the EU and national funding – so that they are better able to undertake this role.
- Importantly, MEPs, the European Commission and the Member States should ensure that they actively involve **groups of disabled people whose voices are not always heard** – such as children, young people, women with disabilities and people with intellectual disabilities. MEPs should provide leadership in this area by, for example, promoting employment, internship and apprenticeship opportunities for young disabled people in the European Parliament.

## 5. AN ENFORCEABLE PILLAR OF SOCIAL RIGHTS

On 26 April 2017, the European Commission published its proposal for a European Pillar of Social Rights (Social Pillar). The Pillar will be formally adopted in November and will take the form of a European Commission Recommendation to the Council and the Parliament. While it is good to see that some elements mentioned in the ENIL Position paper on the Social Pillar<sup>11</sup> have been taken into account, there is still a lot of work to be done in order to make sure the Pillar will have a real impact on the life of EU citizens.

### Recommendations:

- Taking into account that the Social Pillar will be a recommendation, its principles **will not be directly enforceable or create new obligations for the Member States**. Rather than listing existing principles, **the Pillar should**

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<sup>11</sup> ENIL Position paper on the Social Pillar, available at: [http://enil.eu/wp-content/uploads/2016/06/ENIL\\_position\\_Social-Pillar\\_Final.pdf](http://enil.eu/wp-content/uploads/2016/06/ENIL_position_Social-Pillar_Final.pdf)

**set out enforceable social commitments and targets, on which Member States should report on a regular basis.** A dedicated and **obligatory social section in the EU Semester** reports (with disability-specific indicators) and recommendations could be an easy way to establish such a follow up mechanism.

- While some progress has been made (for example, the chapter on education now includes inclusive education), disability remains confined to the chapter on social protection. **Disability rights are human rights and, as a consequence, should be mainstreamed throughout the Pillar (in areas such as employment, working conditions and social protection).**
- One of the Commission's flagship initiatives to translate the principles of the Pillar in practice is the proposal on **Work Life Balance (WLB)**. This Proposal consists of a legislative part in the form of a directive<sup>12</sup> and a non-legislative communication.<sup>13</sup>

The directive proposes to introduce 5 days of carer's leave for relatives. While this is a good first step for emergency situations, **carer's leave should not be used as a substitute for the development of individualised community-based services.** Furthermore, **the right to take carer's leave should be open not only to relatives, but to everyone.** This will allow for real choice, both for the person providing and requiring the assistance.

One of the non-legislative proposals is to support the development of accessible, affordable and quality long-term care services with EU Structural Funds. However, investments in long-term care services are still mainly defined as investments in infrastructure. **The EU should take its UN CRPD commitments seriously and stop the focus on residential long-term care services.** Instead, the WLB initiative should promote investment in setting up Personal Budget schemes and other personalised community-based services.

## 6. FREEDOM OF MOVEMENT FOR DISABLED PEOPLE

Discrimination of disabled people in exercising one of the main freedoms in the EU – the freedom of movement – has been on the agenda of the Freedom Drives for at least a decade. We are concerned that not much progress has been made in this respect. Disabled people who have support packages in their home countries (which include personal assistance) are still unable to access support if they move to another EU country to study, work or to join a family member. There is also a lot of uncertainty for disabled people on what to expect if they were to move to another EU country – when it comes to having their disability status recognised, and the benefits

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<sup>12</sup> See: [http://eur-lex.europa.eu/resource.html?uri=cellar:84205176-2b39-11e7-9412-01aa75ed71a1.0001.02/DOC\\_1&format=PDF](http://eur-lex.europa.eu/resource.html?uri=cellar:84205176-2b39-11e7-9412-01aa75ed71a1.0001.02/DOC_1&format=PDF)

<sup>13</sup> See: <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52017DC0252&from=EN>

and supports they are entitled to. With the European Disability Strategy ending in 2020, there is still time left for the Member States to start putting in place systems to facilitate disabled people's freedom of movement.

#### **Recommendations:**

- We urge the European Parliament to **address discrimination of disabled EU citizens wanting to exercise their right to move to another country to work**, study or to join a family member; MEPs should urge the European Commission to propose legal and policy solutions that will ensure disabled people have the same rights as other EU citizens when moving around. As a start, the European Commission should promote EU standards for the recognition of disability status, to apply in all Member States.

## **7. PROTECT DISABILITY RIGHTS DURING BREXIT**

ENIL is concerned about the impact Brexit will have on disabled people in the UK<sup>14</sup>. Many disabled people employ personal assistants from the EU and are worried about what will happen after Brexit to their assistants, and whether they will be able to recruit new PAs. Disabled people and carers from the EU, who have been living in the UK, are worried about being able to meet the criteria for staying in the country – as many of them do not work full time or have been caring for their relatives. There are many other concerns, including whether disabled people will lose the rights they had as EU citizens, as well whether they will be able to access EU funding to support research, capacity building and the work of disabled people's organisations.

#### **Recommendations:**

- We call on MEPs to **ensure that the rights of disabled people are safeguarded during the Brexit negotiations** – disabled people, whether they are EU citizens in the UK, or UK citizens (including those living in other EU countries), must not be used as bargaining chips in the negotiations by the UK Government or the EU.

## **8. SAFEGUARD THE RIGHTS OF ASYLUM SEEKERS AND REFUGEES WITH DISABILITIES**

As a member of the European Expert Group of the Transition from Institutional to Community-based Care (EEG), ENIL has become aware of the precarious situation of disabled asylum seekers and refugees in the EU. In the past months, we have seen a worrying trend in the way that the EU and its Member States have responded to the needs of people that require additional support – including children and disabled people - seeking refuge in Europe. Among other, we are concerned about the conditions in asylum centres that jeopardise the social inclusion and integration

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<sup>14</sup> See, for example, ENIL's Briefing on the impact of Brexit, available at: <http://enil.eu/news/enil-edf-and-ecas-launch-report-from-brexit-workshop/>

of the new arrivals. Our Serbian member – the Centre for Independent Living Upright – has made us aware of the lack of accessible accommodation, personal assistance and basic technical aids that disabled asylum seekers and refugees face in Serbia, and the difficulties in reaching their final destination. Adequate accommodation and support services, provided in line with the European legal standards (such as the Reception Conditions Directive) are key for the well-being of asylum seekers and refugees. It is also important that camps are used in exceptional circumstances only, as a temporary measure, in line with the UN High Commissioner for Refugees standards.

### **Recommendations:**

- The EU must ensure **safe passage** to all people fleeing armed conflicts and persecution.
- The European **legal framework on asylum**, including provisions on persons in ‘vulnerable situations’, should be fully implemented. **Adequate training**, involving disabled people’s organisations, should be provided to all staff who work with asylum seekers and beneficiaries of international protection.
- The European Union (EU) and its Member States should ensure that **reception centres, hotspots and camps are provided only as a short-term solution**, and where provided, respect human rights, while family and community-based solutions, including housing and emergency foster care for unaccompanied minors, are prioritised in the long-term.

### **About ENIL**

The **European Network on Independent Living** (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination. For more information, see: [www.enil.eu](http://www.enil.eu)

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