

# Realising the Right to Independent Living:

## Is the European Union Competent to Meet the Challenges?





# Realising the Right to Independent Living: Is the European Union Competent to Meet the Challenges?

**ENIL–ECCL Shadow report on the implementation of  
Article 19 of the UN Convention on the Rights of Persons  
with Disabilities in the European Union**

**October 2014**

© European Network on Independent Living – European Coalition for Community Living, October 2014

Written by: Camilla Parker, Mental Health and Human Rights Consultant and Ines Bulic, Policy Officer and Coordinator of the European Coalition for Community Living at the European Network on Independent Living (“ENIL–ECCL”)

Cover photo: © European Network on Independent Living

Design, layout: Judit Kovács | Createch Ltd.

Printed in Dublin, Ireland

# Acknowledgments

ENIL–ECCL would like to thank the individuals who provided answers to the questionnaire on access to independent living in their countries. They are: Kapka Panayotova and Dilyana Deneva (CIL Sofia, Bulgaria), Gary Lee (CIL Carmichael House, Ireland), Debbie Jolly (Disabled People Against Cuts, UK), Miro Griffiths (UK), Mari Siilsalu (Estonia), Jose Smits (Inclusion Netherlands, the Netherlands), Ieva Leimane-Veldmeijere (ZELDA, Latvia), Dovile Juodkaite (Lithuanian National Forum for the Disabled, Lithuania), Stelios Kypouropoulos (Greece), Milan Šveřepa (the Czech Republic) and Mathilde Fuchs (Gre a Gre, France). We would also like to thank members of the ECCL Advisory Council, namely Luke Clements, Tina Coldham, John Evans, Orla Kelly, Camille Latimier, Maria Nyman and Michael Stein for providing us with information and guidance, as well as Stelios Charitakis, a researcher at the University of Maastricht for his helpful comments. Finally, we would like to thank officials at the European Commission, at the Directorate-General (DG) for Justice, DG Employment, Social Affairs and Inclusion and DG Regional Policy, as well as the Secretariat of the Petitions Committee at the European Parliament for their willingness to answer questions in relation to this report.

The drafting and publication of this shadow report would not have been possible without a generous grant from the Open Society Foundations – Mental Health Initiative, for which we are thankful.



# Table of Contents

<b>Acknowledgements</b> .....	3
<b>Executive Summary</b> .....	7
<b>List of abbreviations</b> .....	11
<b>Article 19 – Living independently and being included in the community</b> .....	12
<b>Introduction</b> .....	13
Scope and purpose of this report.....	13
Context: the situation of people with disabilities and the role of the EU .....	13
<b>Article 19 and the Right to Independent Living in the EU: Key Areas</b> .....	16
1. Ascertaining the extent of the EU’s obligations under the CRPD .....	16
2. Understanding the current situation of people with disabilities living in the EU .....	18
3. Using Structural Funds to promote independent living.....	25
4. Promoting personal assistance as an essential element of independent living .....	33
Conclusion.....	36
<b>Annexes</b> .....	37
Annex I: European Union initiatives with the potential to promote Independent Living.....	37
Annex II: Determining the EU’s obligations under the CRPD .....	39
Annex III: Glossary .....	40
Annex IV: Resources.....	42
<b>Endnotes</b> .....	45



# Executive Summary

This report considers the action taken by the European Union (“EU”) to implement the rights of people with disabilities under Article 19 (living independently and being included in the community) of the UN Convention on the Rights of Persons with Disabilities (“CRPD”). It seeks to provide the Committee on the Rights of Persons with Disabilities with information that will be of assistance when assessing the extent to which the EU has complied with its obligations under Article 19. It does so by considering the initial EU report to the CRPD Committee, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*<sup>1</sup> (“the EU report”) and providing comments under the following four broad areas:

1. Ascertaining the extent of the EU’s obligations under the CRPD
2. Understanding the current situation of people with disabilities living in the EU
3. Using Structural Funds to promote independent living
4. Promoting personal assistance as an essential element of independent living

Under each of these areas, key issues of concern are identified and discussed. They are followed by a set of proposed questions, which the CRPD Committee may wish to raise with the EU when considering the EU’s compliance with the CRPD. The two specific areas – the use of “Structural Funds” (European Structural and Investment Funds) to promote independent living and the promotion of personal assistance as an essential element of independent living are the focus of this report. This is because ENIL–ECCL consider these areas to be crucial elements of the work that must be undertaken by the EU to enable people with disabilities to exercise their right to independent living.

## 1. Ascertaining the extent of the EU’s obligations under the CRPD

Given that the CRPD is a “mixed agreement”, it is necessary to ascertain the extent of the EU’s responsibility to ensure compliance with the CRPD. The key issues of concern are as follows:

- Lack of clarity on the scope of the EU’s competence in relation to the CRPD
- Lack of clarity on action to be taken by the EU to ensure overall compliance with the CRPD
- Lack of clarity on EU’s competence and specific action to be taken in relation to Article 19 of the CRPD

### The extent of the EU’s obligations under the CRPD: Proposed questions

**Question 1:** *In which areas of the CRPD does the EU have exclusive competence (i.e. areas for which it is solely responsible for meeting the obligations under the CRPD) and in which areas does it share competence with the Member States?*

**Question 2:** *Has the EU undertaken a review of EU legislation and policies for compliance with the CRPD and, if such a review has been undertaken, what is the outcome of this review (i.e. what recommendations have been made and to what extent have they been implemented)?*

**Question 3:** *Given that the EU shares competence with the Member States in relation to Article 19, what specific actions are being taken by the EU to promote Article 19, how does the EU work with Member States towards meeting the obligations under Article 19, and how is progress assessed?*

## 2. Understanding the current situation of people with disabilities living in the EU

People with disabilities living in the EU face significant barriers to independent living and being included in the community. For example, large numbers of people with disabilities continue to be placed in long-stay residential care – settings in which serious human rights abuses are known to occur. There is a disproportionate adverse impact on people with disabilities of governments’ austerity measures and the progress towards achieving the transition from institutional care to community-based alternatives remains slow and uneven. Despite their relevance to the CRPD and the significant negative impact on the lives of people with disabilities, the EU report gives too little attention to these areas. This raises the following key issues of concern:

- Insufficient data on the situation of people with disabilities in the EU
- Insufficient information on people with disabilities living in institutions
- Adverse impact of austerity measures on people with disabilities
- Insufficient action to raise awareness about the institutionalisation of people with disabilities
- Slow progress in developing community-based alternatives to institutional care that ensure independent living for people with disabilities

### The current situation of people with disabilities living in the EU: Proposed questions

**Question 4:** *What action does the EU propose to take to address the lack of comprehensive and up to date information on the situation of people with disabilities in the EU, including people with disabilities living in long-stay residential care?*

**Question 5:** *What action does the EU propose to take to ensure that Member States are aware of their obligations under the CRPD, including the obligation to promote independent living?*

**Question 6:** *What action is being undertaken by the EU to encourage Member States to promptly identify and address the reasons for the continued institutionalisation of people with disabilities, including the increase in the institutionalisation of people with disabilities as a result of austerity measures?*

## 3. Using Structural Funds to promote independent living

Structural Funds can play a significant role in the promotion of the right to independent living. They have the potential for facilitating the systemic reforms that governments need to make, if they are to achieve the goal of moving from institutional care to a range of community-based services and supports that enable people with disabilities to live and participate in the community as equal citizens. Their use must comply with EU law, including the CRPD. However, in the past, there has been a failure to use Structural Funds to support the development of a properly planned strategy for the transition from institutional care to community-based services. The key issues of concern are as follows:

- Clear leadership required at EU level to ensure Structural Funds support deinstitutionalisation reforms in the Member States
- The use of Structural Funds to maintain institutional care should be prohibited
- If such failures are to be avoided in the future, the significant negative consequences of past failures to ensure that Structural Funds support the development of community-based must be acknowledged
- Concerted action is required to avoid any future misuse of Structural Funds
- Clear monitoring mechanisms are required to ensure the effective use of Structural Funds to promote the right to independent living

## The use of Structural Funds: Proposed questions

**Question 7:** *Where the need for “measures for the shift from institutional to community-based care” is identified as a funding priority by the EU, what action does the EU take to ensure that the Member State allocates a sufficient amount of Structural Funds for this purpose?*

**Question 8:** *How will the EU ensure that all projects funded by Structural Funds accord with the CRPD, including the requirement under Article 19 that all people with disabilities have the right to “choose where and with whom they live”?*

**Question 9:** *What action will the EU take if a Member State uses Structural Funds to support programmes that do not promote the right to independent living under Article 19, or otherwise do not comply with the EU or Member State’s obligations under the CRPD?*

**Question 10:** *What monitoring mechanisms within the EU are in place to ensure the effective use of Structural Funds to promote the right to independent living and how does this involve people with disabilities and their representative organisations?*

## 4. Promoting personal assistance as an essential element of independent living

Personal assistance is one of the core elements of independent living. Article 19(b) requires State Parties to ensure that people with disabilities have access to “community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”. However, to date, too little attention has been given to the importance of ensuring that personal assistance schemes are available to all people with disabilities living in the EU. The key issues of concern are as follows:

- Lack of attention given to promoting personal assistance schemes
- Lack of portability of personal assistance schemes

### Personal assistance as an essential element of independent living: Proposed questions

**Question 11:** *What action will the EU take to ensure that personal assistance schemes are sufficiently supported by the Structural Funds, along with other community-based services?*

**Question 12:** *What action will the EU take to ensure that people with disabilities have access to essential independent living services, including personal assistance, when taking up residence in another EU Member State?*

**Question 13:** *How does the EU plan to use existing policy initiatives, such as those related to reaching Europe 2020 targets, to promote access to personal assistance for people with disabilities?*

## Conclusion

The EU report gives insufficient attention to the problems and challenges faced by people with disabilities living in the EU, in relation to the right to independent living (Article 19). It fails to provide a realistic picture of the current situation of people with disabilities, with the corresponding problem that there is little discussion on how the continuing widespread and weighty barriers to achieving the goals set out in the EU Disability Strategy 2010 – 2020 might be addressed. In particular, while the action by the European Commission to highlight, in both policy and legislation, the need for Member States to ensure the shift from institutional care to community-based services is very welcome,

more effective action is required to ensure that people with disabilities can exercise their right to independent living in accordance with Article 19.

ENIL–ECCL hopes that the range of comments and questions it has posed will assist the CRPD Committee in assessing the extent to which the EU has complied with its obligations under the CRPD, in particular Article 19, and to consider what further action the EU should take to address any areas in which it falls short in meeting its obligations.

# List of abbreviations

ANED	Academic Network of European Disability Experts
CIL	Centre for Independent Living
CoE	Council of Europe
CPT	Committee for the Prevention of Torture
CRC	Convention on the Rights of the Child
CRC Committee	Committee on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CRPD Committee	Committee on the Rights of Persons with Disabilities
DOTCOM	Disability Online Tool for the Commission
DPO	Disabled Persons' Organisation
EC	European Commission
ECCL	European Coalition for Community Living
EEG	European Expert Group on the Transition from Institutional to Community-based Care
EESC	European Economic and Social Committee
ENIL	European Network on Independent Living
ERDF	European Regional Development Fund
ESF	European Social Fund
ESI Funds	European Structural and Investment Funds
EU	European Union
FRA	European Union Agency for Fundamental Rights
UN OHCHR	United Nations Office of the High Commissioner for Human Rights

## Article 19

### – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

# Introduction

## Scope and purpose of this report

The purpose of this report is to consider the action taken by the European Union (“EU”) to implement the rights of people with disabilities under Article 19 (living independently and being included in the community) of the UN Convention on the Rights of Persons with Disabilities (“CRPD”). ENIL–ECCL consider Article 19 (referred to in this report as “the right to independent living”) to be of fundamental importance and have for many years campaigned to promote independent living<sup>2</sup> for all people with disabilities.

By becoming a State Party to the CRPD in December 2010, the EU made a commitment to recognising the rights of all people with disabilities living in the EU and to taking action to ensure that these rights, including the right to independent living are realised. This report focuses on two areas that are of particular importance when assessing the EU’s compliance with the CRPD. They are both crucial elements of the work that must be undertaken by the EU to enable people with disabilities to exercise their right to independent living. The two areas are as follows:

- *The use of Structural Funds:* The EU’s role in ensuring that EU funds (more specifically, the European Structural and Investment Funds, referred to in this report as “Structural Funds”) support projects that promote the right of people with disabilities to live and participate in the community, in accordance with Article 19.
- *The availability of personal assistance schemes:* The EU’s role in highlighting the importance of personal assistance schemes, and that such schemes are an essential element of the range of community-based services that Member States are expected to provide in accordance with Article 19.

The report seeks to provide the Committee on the Rights of Persons with Disabilities (referred to as “CRPD Committee”) with information that will be of assistance when assessing the extent to which the EU has complied with its obligations under Article 19 in relation to these two areas. It does so by considering the initial EU report to the CRPD Committee, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*<sup>3</sup> (“the EU report”) and comparing it with information about the situation of people with disabilities living in the EU Member States. This is important because, although this report is concerned with the EU’s role, and not that of individual Member States, an understanding of the extent to which people with disabilities living in the EU are able to exercise their right to independent living, and how this varies across the Member States, is a significant factor when considering whether the EU is meeting its obligations under the CRPD.

## Context: the situation of people with disabilities and the role of the EU

“Despite a heightened degree of sensitivity at policy level, people with disabilities across Europe still report that they are not included in the community and big challenges remain”.<sup>4</sup>

It is difficult to disagree with the EU’s observation that there are “big challenges” to realising Article 19. This article, entitled “Living Independently and being included in the community”, makes explicit that all people with disabilities have the right to “live in the community, with choices equal to others” and requires States Parties to “take effective and appropriate measures to facilitate full inclusion and participation in the community”. Significant changes in law, policy and practice are needed if this right is to become a reality for all people with disabilities living in the EU.

ENIL–ECCL welcomes the range of initiatives taken by the EU since its ratification of the CRPD, to promote the implementation of the CRPD, such as the work to be undertaken by the European Commission (“EC”) to meet the goals set out in the European Disability Strategy 2010–2020, *A Renewed Commitment to a Barrier-Free Europe*. Annex I of this report summarises the EU initiatives that are of particular relevance to the implementation of Article 19. Although

these are important steps in the much-needed work to promote independent living for people with disabilities in the EU, ENIL–ECCL are concerned that the EU gives too little attention to how to ensure that these policies and goals are put into practice in the Member States. The implementation of these initiatives is crucial if they are to have a positive impact on the everyday lives of people with disabilities. This requires an understanding of the current situation of people with disabilities, including the significant barriers that limit the extent to which people with disabilities can exercise their rights under the CRPD.

### *Article 19 – the right to independent living and institutional care*

A major barrier to realising the rights set out in Article 19 is that an estimated 1.2 million people with disabilities across the EU<sup>5</sup> are living in institutions and in some Member States “the ethic and practice of institutional segregation seems deeply embedded”.<sup>6</sup>

This report uses the term “institution” and “institutional care”<sup>7</sup> when referring to settings in which residents are excluded from the wider community and/or are compelled to live together, and do not have control over their lives or decisions which affect them.<sup>8</sup> Although the size of the premises in which people live is an important factor in determining whether it is institutional in character, these other aspects are as relevant. While the traditional, large long-stay residential settings that are still common in many parts of Europe, particularly Central and Eastern Europe, are clearly “institutions”, smaller settings, such as “group homes” can also replicate a negative culture of institutional care. For example, this might be because residents have no choice about living in such homes, or they remain subject to a rigid daily regime designed around the convenience of staff, rather than their needs, wishes and aspirations.

#### **BOX A: Article 19 (Living independently and being included in the community)**

Although Article 19 does not create a new right,<sup>9</sup> it is the first time that the right to live independently and be included in society has been made explicit in a human rights treaty. This right, which applies to all persons with disabilities, regardless of the type or degree of the impairment or the level of support necessary, provides a clear vision for the future – that people with disabilities can live in the community as equal citizens. In addition, the themes of inclusion and participation are integral to the CRPD as whole. Thus, the CRPD requires that action is taken to ensure that all people with disabilities can live and receive the support they need to participate in society as equal citizens.

The right to live independently and being included in the community has been described as “the key portal to living a fuller life”. It is “much celebrated since it is the one that delivers on ‘choice’ where it matters most to people – where to live and with whom”.<sup>10</sup> The vision, encapsulated by Article 19 is in stark contrast to the situation of people with disabilities who in parts of the EU (in particular, but not exclusive to, Central and Eastern Europe), are placed in large, often remote institutions, and have very little contact with the outside world. Thus, segregation of individuals solely on the basis of their disability is in itself a violation of their rights under Article 19, as they are prevented from engaging with family or friends or being involved in community life.

In his Issue Paper on Article 19, the former Council of Europe (“CoE”) Commissioner for Human Rights, Thomas Hammarberg, noted that Article 19 is closely linked to other rights such as equality and non-discrimination, as well as to “how health, education, social support systems and the labour market are shaped”. It also “embodies a positive philosophy, which is about enabling people to live their lives to their fullest within society”. The Commissioner emphasises the crucial importance of this right in addressing the social exclusion of people with disabilities:

“The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one’s life, wrought on people with disabilities because of their need for support against the background of an inaccessible society. ‘Neutralising’ is understood as both removing the barriers to community access in housing and other domains, and providing access to individualised disability-related supports on which enjoyment of this right depends for many individuals.”<sup>11</sup>

## *Structural Funds and institutionalisation of people with disabilities*

The institutionalisation of people with disabilities has been exacerbated by the use of Structural Funds by some Member States to maintain a system of institutional care that excludes people with disabilities, rather than to develop community-based alternatives that promote their inclusion. That this remains a fundamental barrier to the realisation of the right to independent living and participation in the community for people with disabilities is emphasised by the CoE's Commissioner for Human Rights, Nils Muižnieks, who has stated that he will "continue to monitor very closely deinstitutionalisation and the implementation of the right to live in the community".<sup>12</sup> In his keynote speech to the International Symposium "Human Rights and Disability" in Vienna in April 2014, the Commissioner stated:

"Unfortunately, Europe still has a long way to go even to eradicate the most obvious violations of this right; that is, the segregation of persons with disabilities in large institutions. The human rights violations such institutions engender are well documented, including in the case-law of the European Court of Human Rights and the reports of the Council of Europe anti-torture Committee (CPT), yet they continue to blight the European landscape. There are still European countries refurbishing existing institutions or even building new ones – sometimes, shamefully, with EU structural funds."<sup>13</sup>

## *Lack of community-based services*

Often the reason for the prevalence of institutionalisation is the lack of community-based services. In such circumstances, even those people with disabilities who are not institutionalised are likely to "live disconnected and lonely lives because the infrastructure of inclusion – especially open and accessible services as well as personalised services – is insufficiently developed".<sup>14</sup>

Article 19 requires that people with disabilities are able to choose where and with whom they live and that they have access to a range of community support services that "support living and inclusion in the community" and "prevent isolation or segregation from the community". Thus, although not all residential care settings are "institutions" or provide "institutional care", it is essential that the providers of such services adhere to the principles of Article 19. This includes the requirement that residential care services are part of a range of options that support independent living – residential care should never be the only option.

## *The impact of austerity measures on people with disabilities*

There is also a growing concern that the austerity measures introduced by many Member States have caused additional hardship to people with disabilities and other marginalised groups. Of particular concern is that, as a result of the cuts to public services, services are becoming more institutional and more people with disabilities are being placed in long-stay residential settings, rather than being supported in their own homes.<sup>15</sup>

## *The importance of the EU in promoting independent living*

The above comments illustrate the importance of the EU in supporting the development of community-based services (of which personal assistance schemes will be a crucial component) in the Member States and ensuring the Structural Funds are used to support the development of such services, so that institutional care becomes obsolete.

# Article 19 and the Right to Independent Living in the EU: Key Areas

ENIL–ECCL consider the following four areas to be of particular relevance when evaluating EU’s implementation of Article 19:

1. Ascertaining the extent of the EU’s obligations under the CRPD
2. Understanding the current situation of people with disabilities living in the EU
3. Using Structural Funds to promote independent living
4. Promoting personal assistance as an essential element of independent living

For each of these areas, a number of key issues are identified. These are considered by first, setting out the relevant paragraphs of the EU report and then, providing ENIL–ECCL’s comments. A set of questions that the CRPD Committee may find helpful to raise with the EU are then suggested.

ENIL–ECCL’s comments on the EU report are based upon information received from organisations of disabled people<sup>16</sup> and other civil society groups, as well as published reports and commentaries from the United Nations, Council of Europe and EU bodies in relation to the 27 Member States of the EU for the period covered by the EU report (January 2011–December 2013).<sup>17</sup> ENIL–ECCL have sought to include information on all Member States, albeit, as discussed below, the availability of information is not consistent across the EU, particularly in relation to people with disabilities placed in institutional settings.

## 1. Ascertaining the extent of the EU’s obligations under the CRPD

Given that the CRPD is a ‘mixed agreement’, covering “fields that fall in part within the competence of the EU, in part within that of the Member States and in part within the shared competence of the EU and its Member States”<sup>18</sup>, it is necessary to ascertain the extent of the EU’s responsibility to ensure compliance with the CRPD. ENIL–ECCL are concerned that there is a lack of clarity on the extent of the EU’s obligations under the CRPD, both generally and specifically, in relation to Article 19. (Further background information is provided in Annex II.)

**The following key issues are considered below:**

1.1	Lack of clarity on the scope of the EU’s competence in relation to the CRPD
1.2	Lack of clarity on action to be taken by the EU to ensure overall compliance with the CRPD
1.3	Lack of clarity on EU’s competence and specific action to be taken in relation to Article 19 of the CRPD

1.1	<b>KEY ISSUE: Lack of clarity on the scope of the EU’s competence in relation to the CRPD</b>
-----	---

### EU report:

**Paragraph 4:** states that Annex II to the Council Decision “illustrates the extent of the Union competence with respect to matters governed by the CRPD”.

#### ENIL–ECCL comment:

- *Council Decision is unclear:* Annex II of the Council Decision does not distinguish between those areas that fall within the exclusive competence of the EU and those where the EU shares competence with Member States.
- *Recognition that EU competence will change over time:* the Council Decision notes that the “scope and the exercise of Community competence are, by their nature, subject to continuous development”.<sup>19</sup> However, Annex II has not been updated since EU’s ratification of the CRPD in 2010, so it is unclear whether and how the scope and exercise of EU’s competence has changed.

### 1.2 KEY ISSUE: Lack of clarity on action to be taken by the EU to ensure overall compliance with the CRPD

#### EU report:

**Paragraph 29:** states that “the Commission is conscious of the need to analyse the extent to which current laws or policies are aligned to the CRPD” and refers to funding a study on this issue. (The findings of this study were published in 2010 in a report entitled *Study on Challenges and Good Practices in the Implementation of the UN Convention on the Rights of Persons with Disabilities* (“the CRPD study”).<sup>20</sup>)

#### ENIL–ECCL comment:

- *The CRPD study recommended action to be taken to ensure CRPD compliance:* Although the CRPD study identified various challenges to the implementation of the CRPD, for the EU as well as Member States, the EU report makes no mention of what action the Commission has taken, or is intending to take, in the light of them.
- *The need for a review of EU law and policy:* One of the recommendations made by the CRPD study is that “the EU and Member States should conduct a comprehensive ‘screening exercise’ of EU and national legislation and, if necessary, should modify or abolish existing instruments in order to ensure full compliance with the UN CRPD”. It concluded that the screening of EU legal instruments would need “to evaluate EU legislation towards the requirements of the UN CRPD and consider the EU competence to act in the fields covered by the Convention”. It adds that the consideration of EU competence “will be important to determine the type of measure that the EU would need to take in order to meet the requirements of the Convention”.<sup>21</sup> The need for the EC to carry out an impact assessment of the CRPD has also been highlighted by the European Economic and Social Committee (EESC).<sup>22</sup> In addition, the European Parliament called on the EC to “carry out a comprehensive review of EU legislation and policies” in order to assess their compliance with the CRPD.<sup>23</sup>

### 1.3 KEY ISSUE: Lack of clarity on the EU’s competence and specific action to be taken in relation to Article 19

#### EU report:

**Paragraph 92:** states that “competence for the promotion of independent living in the community is shared with the Member States” and that the EC “has undertaken to promote the use of EU Structural Funds to assist Member States in the transition from institutional to community-based services”.

#### ENIL–ECCL comment:

- *Investment of Structural Funds in institutional care contrary to CRPD:* The EU’s stated commitment to promote the use of Structural Funds for the transition from institutional care to community-based services, thereby making the link between the use of these funds and the realisation of Article 19, is very welcome. However, in some Member States,<sup>24</sup> Structural Funds have been used to reinforce outmoded systems of institutional care, rather than supporting the development of community-based alternatives, which is contrary to the CRPD.<sup>25</sup> This means – as discussed below under “Using Structural Funds to promote independent living” – that concerted action will be required to ensure that such misuse of funds does not occur in the current financial period (2014–2020).

- *Consider action to be taken to ensure compliance with Article 19:* There are wide-ranging obligations under Article 19, but the EU report provides little information on how it intends to take action, with Member States, to address these extensive obligations. For example, the CRPD study noted that several EU legal instruments concerning indirect taxation and state aid were relevant to Article 19. Such instruments “could positively contribute to the elimination of barriers (such as inaccessible, or insufficient, goods and services) for persons with disabilities to fully enjoy the right to independent living”. The CRPD study recommended that the EU should ensure that “any indirect tax reliefs for goods and services, or any funding to be given” should encourage and promote independent living, and “should not support any residential, medical, or other institution that restricts the autonomy of persons with disabilities”.

#### Questions to ascertain the extent of the EU’s obligations under the CRPD:

- Question 1:** *In which areas of the CRPD does the EU have exclusive competence (i.e. areas for which it is solely responsible for meeting the obligations under the CRPD) and in which areas does it share competence with the Member States?*
- Question 2:** *Has the EU undertaken a review of EU legislation and policies for compliance with the CRPD and, if such a review has been undertaken, what is the outcome of this review (i.e. what recommendations have been made and to what extent have they been implemented)?*
- Question 3:** *Given that the EU shares competence with the Member States in relation to Article 19, what specific actions are being taken by the EU to promote Article 19, how does the EU work with Member States towards meeting the obligations under the Article 19, and how is progress assessed?*

## 2. Understanding the current situation of people with disabilities living in the EU

People with disabilities living in the EU face significant barriers to independent living and being included in the community. The European Economic and Social Committee (EESC) provides a general summary of the situation of people with disabilities in its recent report on the implementation and monitoring of the CRPD:

“There are around 80 million persons with disabilities in Europe and, according to Eurostat figures, they are two to three times more likely to be unemployed than non-disabled people; only 20% of people with severe disabilities have a job, compared to 68% of those without disabilities. Persons with disabilities are more than 50% less likely to reach third-level education than non-disabled persons. Only 38% of persons with disabilities aged 16–34 across Europe have an earned income, compared to 64% of non-disabled people.”<sup>26</sup>

In many parts of the EU, people with disabilities do not have the choice of where, or with whom to live. Of particular concern to ENIL–ECCL is the high number of people with disabilities who continue to be placed in long-stay residential care, in some cases for life, and the serious human rights abuses that occur within these closed residential settings. For example, the CRPD study states:

“[R]esearch in this field has revealed that the existence of national laws that still permit institutionalisation of persons with disabilities hampers significantly their social inclusion and full participation in their society. Several national policies are focused on improving institutional care, instead of moving residents of such institutions into the community. In cases where national policies promote independent living for persons with disabilities, the frequent absence of direct payments, or individualised funding schemes, to allow persons with disabilities to manage their own affairs is a significant challenge to the effective implementation of the UN CRPD.”<sup>27</sup>

That there is a strong link between the high prevalence of institutionalisation and the lack of community-based services is highlighted in a recent EU Parliament resolution, which:

“...deplores the fact that certain persons with disabilities have no choice but to live in special homes, given the lack of community-based alternatives, and calls on the Member States to champion arrangements which enable more persons with disabilities to live independently.”<sup>28</sup>

Furthermore, ENIL–ECCL is concerned that the measures undertaken by governments across Europe as a means of addressing the economic and financial crisis that began in 2008, have had a disproportionate adverse impact on people with disabilities. Together with the European Disability Form and the European Foundation Centre’s Consortium of Foundations on Human Rights and Disability, ENIL has created an online resource to highlight the impact of European governments’ austerity measures.<sup>29</sup>

Despite the clear policies of the EU and Member States that highlight the need for action to ensure the social inclusion of people with disabilities, progress towards achieving the transition from institutional care to community-based alternatives has been slow. While recognising that this process (often referred to as ‘deinstitutionalisation’), will take time and requires careful planning,<sup>30</sup> ENIL–ECCL are concerned that governments fail to make this a priority, so that little or no action is taken to implement deinstitutionalisation policies.

Little attention is given to these areas in the EU report, despite their relevance to the CRPD and the significant negative impact on the lives of people with disabilities.

**The following key issues are considered below:**

<b>2.1</b>	Insufficient data on the situation of people with disabilities in the EU
<b>2.2</b>	Insufficient information on people with disabilities living in institutions
<b>2.3</b>	Adverse impact of austerity measures on people with disabilities
<b>2.4</b>	Insufficient action to raise awareness about the institutionalisation of people with disabilities
<b>2.5</b>	Slow progress in developing community-based alternatives to institutional care that ensure independent living for people with disabilities

**2.1 KEY ISSUE: Insufficient data on the situation of people with disabilities in the EU**

**EU report:**

**Paragraphs 16–17, 107 and 192–199:** provide some statistical information in relation to people with disabilities, in relation to Article 19 and Article 31 of the CRPD.

**ENIL–ECCL comment:**

- *No uniform standards for data collection:* There are no standards for data collection agreed at the EU level in relation to services for disabled people generally, nor to measure progress in the transition from institutional care to community-based support.
- *Data collected is limited in scope:* As noted by the EU report (**paragraph 196**), the EU Statistics on Income and Living Conditions (EU-SILC) – the reference source on income distribution and social inclusion at European level – only interviewed those aged 16 and older. In addition, those living in “collective households and institutions are generally excluded”. This means that children and disabled people (both children and adults) in residential care are excluded from these statistics, thereby making a reliable evaluation of the level of social inclusion in the Member States and at the EU level very difficult, if not impossible.

- *Lack of up to date information:* The European Foundation Centre’s 2012 study, *Assessing the impact of European governments’ austerity plans on the rights of people with disabilities* (“EFC’s Austerity report”) highlights a concern about the lack of data, at EU level, in relation to people with disabilities.
  - The report notes that “the absence of up-to-date statistics on poverty, social services and disability is persistently being reported as the principal obstacle for an adequate monitoring of the social impacts of the austerity measures in the Member States”. It adds that “information and data in the Member States are fragmented, outdated, not recorded or not made public, which makes an accurate analysis of the country situation difficult and a cross-country comparison almost impossible”.<sup>31</sup>
  - A report published in 2012 on mental health services across 32 European countries, including the 27 Member States, *Mapping Exclusion – Institutional and community-based services in the mental health field in Europe* (“Mapping Exclusion”), also raised concerns about the limited availability of data at a national level.<sup>32</sup>
- *Lack of information about children with disabilities:* The Committee on the Rights of the Child has noted the lack of data in relation to children with disabilities and children in alternative care in the majority of EU Member States reviewed since 2011 (for example, Finland, Italy, Cyprus, Greece, Slovenia and Germany).

## 2.2 KEY ISSUE: Insufficient information on people with disabilities living in institutions

### EU report:

**Paragraph 100:** refers to the EC funded study “on progress towards community living across Europe”. The findings of this study were published in the report *Deinstitutionalization and community living – outcomes and costs* (“the DECLOC report”).<sup>33</sup>

### ENIL–ECCL comment:

- *Insufficient information about people living in long-stay residential care:* The insufficient data in relation to people with disabilities (highlighted above at 2.1) also relates to long-stay residential care. It is not known how many people with disabilities live in such settings across the EU. The DECLOC report estimated that almost 1.2 million people with disabilities were living in institutions across the EU and Turkey in 2007. This figure is likely to be an underestimate given that three of the countries provided no data to the researchers.<sup>34</sup> The study also found that 16 countries of the 25 countries that provided data had institutions for 100 or more residents.
- *Need for standardised data:* The DECLOC report found that there were no “existing sources providing comprehensive information about the number and characteristics of people in residential institutions in Europe”.<sup>35</sup> Although noting that the DECLOC report “called for standardised data to be collected on residential institutions across the EU to report on progress”, the EU report gives no further information.
- *DECLOC recommendations on the collection of data:* The DECLOC report made a number of recommendations to the EC on the collection of data<sup>36</sup>, including the following, but it is not clear whether any steps have been taken to implement them:
  - The EC should promote joint work between the Member States and Eurostat<sup>37</sup> to define “a minimum data set for residential services for people with disabilities”;
  - There should be regular publication of statistics by Eurostat demonstrating progress in the transition from institutional care to alternatives in the community;
  - The EC should work with Member States to identify a single source in each country competent to provide the needed information, and this information should be publicly available.
- *Information about people with mental health problems is incomplete:* The Mapping Exclusion report noted that the official data on the number of people with mental health problems in institutional care often excluded people with mental health problems placed in social care homes. Furthermore, the report noted that Eurostat data on the declining number of psychiatric beds in hospitals is not indicative of an increase in the availability of community-based services.<sup>38</sup>

**EU report:**

**The EU report:** includes no specific reference to the austerity measures introduced by some Member States and their impact on the enjoyment of the right to independent living in the EU.

**ENIL–ECCL comment:**

- *Insufficient attention given to austerity measures:* The EU report does not refer to the concerns that the austerity measures undertaken by many Member States have had a disproportionately adverse impact on people with disabilities.<sup>39</sup> Despite reports (see below), both from civil society groups and institutions within the EU, that provide detailed accounts of this problem, the EU has thus far provided no response on how this unwanted consequence of the measures taken to address the financial crisis should be addressed.
- *Austerity measures – negative impact on independent living:* Significant concerns have been raised by the European Parliament, other bodies and organisations:
  - In June 2013, the Committee on Employment and Social Affairs of the European Parliament raised concerns that, across the EU, people with disabilities “are being disproportionately affected by cuts in public spending”. The Committee notes that as a result, people with disabilities “are losing the support services which allow them to live independently in the community”. In turn “...this is leading to an increase in the number of people living in long-term institutional care and the further social exclusion of persons with disabilities in the EU”, which is in breach of the CRPD.
  - The European Economic and Social Committee (EESC) stated in December 2012 that it “is worried about the negative impact that the austerity measures that have been put in place in many EU Member States are having also on persons with disabilities and their families leading to further social exclusion, discrimination, inequality and unemployment”. It added that “the crisis cannot be used to postpone implementation of the UN CRPD”.<sup>40</sup>
  - The European Parliament adopted a resolution in 2011 that stressed that it was “unacceptable” for “unjustified cuts to be made to services for persons with disabilities or to projects for their social inclusion”<sup>41</sup> and continues to raise this issue, for example by raising parliamentary questions addressed to the European Commission.<sup>42</sup>
  - The Council of Europe’s Commissioner for Human Rights, Nils Muižnieks, has highlighted significant concerns about the adverse consequences of governments’ austerity measures on people with disabilities following his visits to Portugal (2012),<sup>43</sup> Spain (2013)<sup>44</sup> and Romania (2014).<sup>45</sup>
  - EFC’s Austerity report of 2012, which focused on Greece, Hungary, Ireland, Portugal, Spain and the UK, concluded that there was “a substantial body of evidence at EU level and from country reports” that the right to live independently in the community has been placed under severe threat as a result of the economic crisis and resulting austerity measures.<sup>46</sup> EFC’s Key Findings document notes that in Ireland, Portugal and the Netherlands service providers are being forced into providing more standardised services as a result of the crisis and to deliver more services with fewer resources. In relation to the UK, “in some areas there is no budget allocated to community services, only for residential services”.<sup>47</sup>

**EU report:**

- **Paragraph 93:** states that “In the Disability Strategy, the Commission has undertaken to promote the use of EU Structural Funds to assist Member States in the transition from institutional to community-based services and to raise awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people”.

- **Paragraph 100:** refers to the DECLOC report, which “provided evidence in support of transition from institutional care to community-based alternatives, as they can provide better results for users, their families and staff while the costs are comparable when based on comparable quality standards”.
- **Paragraphs 97–98 and 101–102:** note the important role of Structural Funds in supporting the transition from institutional care to community based services and refer to the EC’s role in promoting this transition.
- **Paragraph 106:** refers to a report that “highlighted the need for further efforts on de-institutionalisation accompanied by reforms in the areas of education, healthcare, employment, culture and support services”. (This is a report published by the European Union Fundamental Rights Agency (FRA) in 2012, entitled *Choice and control: the right to independent living – Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*<sup>48</sup> (“the FRA report”).)

#### ENIL–ECCL comment:

- *Continuing prevalence and increase in institutionalisation in some countries:* While there is recognition of the importance of promoting the transition from institutional care to community-based services across the EU, in many countries institutional care remains the predominant form of care. This is especially true for Central and Eastern Europe and the Baltic countries (which became EU members in 2004), with a strong legacy of institutional care and very few community-based services in place.<sup>49</sup> For example, in Romania, the CoE Commissioner for Human Rights noted in his country visit report of 2014 that “the number of residential social care institutions for adult persons with disabilities has more than doubled in the past eight years, from 141 at the end of 2005 to 335 at the end of December 2013”.<sup>50</sup>

Furthermore, notwithstanding the lack of reliable data (discussed above at 2.1 and 2.2), reports suggest that the number of people with disabilities being placed in institutional care has increased in some of the more developed EU Member States.<sup>51</sup> In Austria,<sup>52</sup> Belgium, Denmark, Germany,<sup>53</sup> Italy,<sup>54</sup> Luxembourg<sup>55</sup> and Spain<sup>56</sup>, people with disabilities are being placed in residential care, rather than provided with services and supports that promote independent living. Lack of services in one Member State can also result in people with disabilities being sent to institutions across the border. For example, in France, it has been reported that families of people with intellectual disabilities send their family members to institutions in Belgium. The French Government estimates that approximately 1,500 minors and 5,000 adults from France reside in institutions in Wallonia, while the Wallonian authorities put the number at 8,000.<sup>57</sup>

- *The need for legal and policy reform:* the FRA report (noted at **paragraph 106**) highlights the need for “further efforts on deinstitutionalisation” and the need for reform in a range of areas. However, the EU report provides no information as to whether the EU has considered these findings and assessed what action could be taken to help Member States address the barriers to independent living identified in the report. For example, the FRA report notes the need for measures “to ensure that adequate, good quality and freely chosen personalised support for independent living is made available independently of the type of living arrangement”<sup>58</sup>.
- *The link between guardianship and independent living:* Another report by FRA, *Legal capacity of persons with intellectual disabilities and persons with mental health problems* (2013)<sup>59</sup> emphasised that while the EU does not have specific competence to address legal capacity, it can play a major role in assisting Member States to ensure compliance with the CRPD. It also notes that the concept of legal capacity is increasingly being linked with the principles of non-discrimination and equality and is therefore relevant to EU law and policy, particularly non-discrimination. Legal capacity is also relevant to Article 19, in particular the right of people with disabilities to exercise their right to choose where and with whom to live.<sup>60</sup> Concerns about the system of guardianship, particularly plenary guardianship, whereby a person is held to lack capacity and require another person (“the guardian”) to make all decisions on behalf of that person, have been raised in connection with Austria,<sup>61</sup> the Czech Republic,<sup>62</sup> Denmark,<sup>63</sup> Latvia,<sup>64</sup> Lithuania,<sup>65</sup> and Romania.<sup>66</sup> The CoE’s Commissioner for Human Rights highlighted particular concerns about the use of guardianship for people with mental health problems or intellectual disabilities in Slovakia<sup>67</sup> and Spain.<sup>68</sup>
- *Specific concerns about people with mental health problems and people with intellectual disabilities:* The DECLOC report found that the two largest groups living in institutions were people with mental health problems

and people with intellectual disabilities. It would appear that this continues to be the case. ENIL–ECCL’s partner organisations highlight the particular vulnerability of these two groups of people to institutionalisation in Bulgaria, Latvia<sup>69</sup> and Lithuania.<sup>70</sup> The CoE’s Commissioner for Human Rights has also raised concern about the institutionalisation of people with mental health problems (also referred to as psycho-social disabilities) and the lack of protection of their human rights following his country visits in the Czech Republic (2013),<sup>71</sup> Denmark (2014) and Spain (2013).<sup>72</sup> The Mapping Exclusion report provides information on the types of residential services for people with mental health problems in 32 countries, including all the EU Member States<sup>73</sup>.

- *Specific concerns about the institutionalisation of children with disabilities:* have been raised by the CoE’s Commissioner for Human Rights in the Czech Republic (2013), Estonia (2013) and Romania (2014)<sup>74</sup> and the CRPD Committee in relation to Hungary.<sup>75</sup> The Committee on the Rights of the Child has raised concerns about the institutionalisation of children in Austria (2012), Greece (2012), Lithuania (2013), Portugal (2014) and Hungary (2014).<sup>76</sup> As noted above, at least 1,500 children from France have reportedly been placed in institutions in Belgium.<sup>77</sup>

## 2.5 KEY ISSUE: Slow progress in developing community-based alternatives to institutional care that ensure independent living for people with disabilities

### EU report:

- **Paragraph 107:** includes statistics that demonstrate a) the lack of community based services and b) the inadequacy of services and supports in meeting a person’s individual needs:
  - Of severely disabled people 23% consider that they are not included in society (EQLS 2011-2012).
  - Similarly, many people with disabilities consider that their life lacks opportunities for social engagement and other opportunities (SHARE 2011).
  - People with disabilities express a dissatisfaction concerning their social life: about 46% of persons with severe disabilities aged 18 or more declare a score between 1 to 5 (where 10 is the maximum satisfaction) compared to 14.6% of persons without disabilities (EQLS 2011-12).
  - About 45.8% of persons aged 50 or more with difficulties in everyday life receive help. Among those who receive help, about 8.8% consider that help received ‘sometimes’ or ‘hardly ever’ meets their needs (SHARE 2007).
  - The 2011 SHARE survey provided similar results concerning the percentage who received help from others (44.5%).

### ENIL–ECCL Comments:

- *Problems with the inadequate development of community-based services:* this has been noted in Austria,<sup>78</sup> Bulgaria, Belgium, Denmark,<sup>79</sup> Estonia,<sup>80</sup> Greece, Hungary,<sup>81</sup> Italy,<sup>82</sup> Lithuania,<sup>83</sup> Romania<sup>84</sup> and Spain.<sup>85</sup> For example:
  - ENIL–ECCL partner organisations from Bulgaria and Greece report that disabled people whose family cannot or does not want to support them, are most likely to be placed in institutional care.
  - During his visit to Romania, the CoE Human Rights Commissioner was informed that at the end of 2013 only 1,669 adults with disabilities were receiving community-based care (provided by 57 non-residential institutions), whereas more than 17,000 adults were placed in institutional care. He noted that “67% of persons with disabilities placed in an institution remain there for life, while 14% are transferred at some point to other centres”.<sup>86</sup>
  - The CoE Human Rights Commissioner also raised similar concerns to that of the CRPD Committee<sup>87</sup> about the situation in Denmark, noting that that “clusters of about 20 to 80 housing units” have been built for people with disabilities, and adding that “the average number of persons living in a residence was 15,2, while the largest residence hosted 233 persons”. He was also informed that “20 residences for more than 20 residents have been built between 2011 and 2013”.<sup>88</sup> The Commissioner draws attention to the situation in

Denmark when highlighting his concern that even in countries where there has been some progress towards deinstitutionalisation, there are major setbacks to achieving full inclusion:

“Even in a relatively wealthy country such as Denmark, which abolished institutions in 1998, many municipalities have built large blocks of up to 80 or even more apartments away from city centres, accommodating exclusively persons with disabilities. The material conditions in these facilities may be of a high standard, but I am convinced that clustering persons with disabilities together in such settings runs against the full inclusion and control over one’s living arrangements required by the CRPD.”<sup>89</sup>

- *Lack of clear plans for the transition from institutional care to community-based supports (deinstitutionalisation strategy):* based on the available information, in Austria,<sup>90</sup> Belgium,<sup>91</sup> Estonia,<sup>92</sup> Poland,<sup>93</sup> and Romania<sup>94</sup> there are, as yet, no finalised national programmes for deinstitutionalisation, or, as in the case of Lithuania, have only recently been approved.<sup>95</sup>
- *Plans for deinstitutionalisation are in place but there are problems with their implementation:* ENIL–ECCL are informed that in Cyprus, there are no structures for the transition from institutional care to community living, while in Slovenia, the national action programme states that “for many persons with disabilities institutions are still needed”.<sup>96</sup> In the Czech Republic, deinstitutionalisation includes “humanisation” of institutions, which allows for renovation and building of smaller institutions,<sup>97</sup> while in Hungary, the government has set itself a 30-year time frame. (There are also significant concerns with Hungary because, although the government prohibits the use of institutions, it defines institutions as a residential setting of 50 beds or more.<sup>98</sup>)
- *The lack of accessible mainstream services:* Concerns about inaccessible mainstream services have been raised in Bulgaria,<sup>99</sup> Denmark (concern that social housing is not accessible to people with disabilities), Spain (mainstream services are less accessible to disabled people in rural areas than in the cities),<sup>100</sup> and Romania (very poor accessibility of public spaces and services to persons with disabilities).<sup>101</sup>
- *Lack of access to mainstream education:* The CoE Commissioner for Human Rights has raised concerns about disabled children’s lack of access to mainstream education in the Czech Republic,<sup>102</sup> Spain,<sup>103</sup> and Romania.<sup>104</sup> Similar concerns have been raised in Bulgaria.<sup>105</sup> The Committee on the Rights of the Child has raised concerns in relation to Austria, Cyprus, Finland, Germany, Greece, Italy, Malta, Portugal, Slovenia, and Hungary.<sup>106</sup>
- *Lack of development of personal assistance schemes:* research carried out by ENIL on the availability of personal assistance in Europe<sup>107</sup> has shown that there are still many barriers to disabled people being able to live independently with personal assistance. These include:
  - The lack of adequate legislation on personal assistance in many countries;
  - Failure to interpret personal assistance in line with the independent living philosophy and the CRPD; and
  - Insufficient resourcing of personal assistance schemes, resulting in people with disabilities receiving a limited amount of personal assistance, the scheme being limited to people with specific impairments or certain local authorities; the scheme being limited to supporting people with disabilities with their most basic needs; disabled people having no option but to be supported by their family members.

#### Questions about the current situation of people with disabilities living in the EU:

- Question 4:** *What action does the EU propose to take to address the lack of comprehensive and up to date information on the situation of people with disabilities in the EU, including people with disabilities living in long-stay residential care?*
- Question 5:** *What action does the EU propose to take to ensure that Member States are aware of their obligations under the CRPD, including the obligation to promote independent living?*
- Question 6:** *What action is being undertaken by the EU to encourage Member States to promptly identify and address the reasons for the continued institutionalisation of people with disabilities, including the increase in the institutionalisation of people with disabilities as a result of austerity measures?*

### 3. Using Structural Funds to promote independent living

Structural Funds can play a significant role in the promotion of the right to independent living. They have the potential for facilitating the systemic reforms that governments need to make if they are to achieve the goal of moving from institutional care to a range of community-based services and supports that enable people with disabilities to live and participate in the community as equal citizens. Their use must comply with EU law, including the CRPD.

The two main funds that can be utilised in this work are the European Regional Development Fund (ERDF), which can finance investments in health and social care infrastructure, and the European Social Fund (ESF), which can support employment initiatives, such as the provision of training of staff working in community-based services or supporting personal assistance schemes. Thus, these funds have a particularly important role in helping to address the institutionalisation of people with disabilities. They can support the development of new services, including services that prevent institutionalisation. They can also provide technical support for reforming legislative and financial frameworks to underpin and support community-based services that promote independent living, so that such services can replace outmoded models of institutional care.<sup>108</sup>

Accordingly, the use of Structural Funds is an important factor when considering the EU's and Member States' obligations under Article 19, in particular the development of community-based alternatives to institutional care. This point was made by the European Parliament in 2009, when it highlighted the importance of ensuring that Structural Funds are used to promote independent living, in compliance with the CRPD and urged the EC to ensure that funding is "provided for appropriate community/family based services and options for independent living."<sup>109</sup> Similarly, the European Expert Group on the Transition from Institutional to Community-based Care ("the EEG") notes that:

"The EU and its Member States, within their respective competencies, have an obligation arising from Article 19 of the CRPD [...] and Structural Funds should be used as a key tool to comply with this obligation".<sup>110</sup>

Despite the potential of Structural Funds to promote independent living, the opposite has happened in some Member States. During the previous programming period (2007–2013), Structural Funds were invested in institutional care, rather than the development of community-based alternatives.<sup>111</sup>

Another concern is that, in many cases, Structural Funds have supported the development of different residential settings (such as "small group homes"), which have replicated the institutional culture. Save for an improvement in the physical environment, little else has changed.

The overriding concern, therefore, is the failure to use Structural Funds to support the development of a properly planned strategy for the transition from institutional care to community-based services.

Failure to use Structural Funds to facilitate independent living and prevent institutionalisation is a wasted opportunity on the part of Member States and the EU, especially considering the 'transition' or 'double running costs' of moving from the system of institutional care to community-based alternatives.<sup>112</sup> This point is also relevant when determining how the concept of progressive realisation applies to this situation. The concept recognises that account may be taken of the time needed to put in place the necessary arrangements and that some States Parties may have limited available resources.

The EU is a wealthy economy and Structural Funds provide Member States with considerable additional resources (347,410 billion EUR in 2007–2013)<sup>113</sup> that can be used to develop community-based services, as well as plan and implement the legal, financial and other necessary reforms to support a new model of services based upon Article 19. Accordingly, ENIL–ECCL consider that the EU must be more proactive in encouraging Member States to use Structural Funds in order to promote the right to independent living. For example, while the EC is not in a position to prescribe actions that should be funded by the EU, the EC could make clear that where it has identified transition from institutional care to community-based services as a priority area,<sup>114</sup> those Member States will be expected to invest a sufficient amount of Structural Funds into genuine community-based alternatives to institutions.

The box below provides a summary of relevant actions taken in relation to the use of Structural Funds and the promotion of independent living since 2007.

**BOX B: Structural Funds and the transition from institutional care to community-based services: Key actions and developments<sup>115</sup>**

- **2007:** ECCL raises concerns with the European Commission about Structural Funds being used to build and renovate institutions in Romania.
- **2009:** Commissioner for Employment Spidla establishes the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. The group issues a report which highlights the need for the EC to make clear that Structural Funds are not to be used to renovate existing, or build new, institutions.
- **2009:** The European Commission asks the Bulgarian government to redirect EU funds from institutions to family-based care for children after pressure from civil society organisations.<sup>116</sup>
- **2010:** ECCL publishes the Wasted Lives report, highlighting the misuse of Structural Funds in Central and Eastern Europe.
- **2012:** The European Expert Group on the Transition from Institutional to Community-based Care (“the EEG”, formerly the Ad Hoc Expert Group) publishes the Common European Guidelines and Toolkit on the Use of EU Funds for the Transition from Institutional to Community-based Care.
- **2012:** the Open Society Foundations – Mental Health Initiative (“OSF-MHI”) and UN OHCHR Regional Office for Europe publish reports on EU’s obligations under the CRPD and EU law to invest Structural Funds into services and supports with facilitate independent living.
- **2012:** EC Position Papers identify de-institutionalisation for one or more user groups as one of the priorities for the programming period 2014–2020 in 12 countries.
- **2013:** OSF-MHI submit a petition to the European Parliament’s Petitions Committee, raising concerns about the misuse of Structural Funds for the building and renovation of institutions for people with disabilities in Central and Eastern Europe.
- **2013:** In cooperation with national NGOs, ENIL–ECCL produce *Briefing on Structural Funds Investments for People with Disabilities*, covering Bulgaria, Hungary, Latvia, Lithuania, Romania and the Slovak Republic, and highlighting continued misuse of Structural Funds.
- **2013:** EEG launches a series of seminars on the use of Structural Funds to support deinstitutionalisation in Member States where EC highlighted deinstitutionalisation as one of the priorities for 2014–2020.<sup>117</sup>
- **2013:** The new Structural Funds Regulations introduce provisions that promote ‘transition from institutional care to community-based services’.
- **2014:** Al Jazeera documentary reveals that human rights abuses were found in two institutions in Romania funded by Structural Funds. The Mental Disability Advocacy Center (MDAC) calls on the EC to take action to address this.
- **2014:** European Ombudsman writes to the EC, asking what action the EC is taking to ensure that Structural Funds are not used to violate the rights of people with disabilities in the Member States.

The following key issues are considered below:

3.1	Clear leadership required at EU level to ensure Structural Funds support deinstitutionalisation reforms in the Member States
3.2	The use of Structural Funds to maintain institutional care should be prohibited
3.3	If such failures are to be avoided in the future, the significant negative consequences of past failures to ensure that Structural Funds support the development of community-based need to be acknowledged
3.4	Concerted action is required to avoid any future misuse of Structural Funds
3.5	Clear monitoring mechanisms are required to ensure the effective use of Structural Funds to promote the right to independent living

3.1	<b>KEY ISSUE: Clear leadership required at EU level to ensure Structural Funds support deinstitutionalisation reforms in the Member States</b>
-----	--

#### EU report:

- **Paragraph 93** states that the EC “has undertaken to promote the use of EU Structural Funds to assist Member States in the transition from institutional to community-based services and to raise awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people”.
- **Paragraph 101** refers to the report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, which set out common basic principles for transition from institutional to community-based care.
- **Paragraph 102:** refers to the national seminars organised by the EEG in co-operation with the EC in Member States to support the use of Structural Funds to promote “effective transition to community-based living”.

#### ENIL–ECCL comment:

- *More concerted action from the EU is required:* The EU report’s emphasis on promoting the transition from institutional care to community-based services is very welcome, but more needs to be done to achieve this goal. The Ad Hoc report was significant (**paragraph 100**), because it highlighted the need for action to be taken to develop community-based alternatives to institutional care and the role of Structural Funds in supporting such work. However, the report was not an official EC communication, therefore neither the EC nor the Member States are obliged to implement its recommendations. The national seminars referred to in **paragraph 101** have helped to raise awareness of this issue and to publicise the EEG’s *Common European Guidelines on the Transition from Institutional to Community-based Care* (“the EEG Guidelines”) and accompanying Toolkit describing how Structural Funds can be used to facilitate this transition.<sup>118</sup> But this is only a start. The transition to a model of community-based support is a complex process, which requires careful planning, in consultation with a range of stakeholders, including organisations of people with disabilities. It will need sufficient resources, which can be provided by Structural Funds, but also careful monitoring, to ensure that the projects funded are in line with Article 19 of the CRPD.
- *The potential leadership role of the European Commission (EC):* Through Structural Funds programming, the EC is in a position to provide leadership and guidance for Member States, particularly for those that lack the commitment and/or expertise to implement the necessary systemic reforms. For example, the EC can ensure that Commission staff are familiar with the EEG Guidelines and Toolkit, and promote these materials when negotiating Partnership Agreements and Operational Programmes with Member States. Using such materials, on behalf of the EU, the EC could:
  - Take action to obtain a better understanding of the situation of people with disabilities who live in the Member States that are eligible for Structural Funds.
  - Based on this information, work with the relevant Member State to ensure that the Member State’s plan for the transition from institutional care to community-based services (often referred to as “a deinstitutionalisation

strategy”) provides a comprehensive response to the country’s assessed needs. For example, the EEG Guidelines highlight the importance of the strategy addressing the need to establish national standards for service provision and a system for the inspection of these services.

- Keep the implementation of the Deinstitutionalisation Strategy under review (in consultation the Member State and national DPOs and other civil society groups).
- Take action to investigate where there are concerns that the Structural Funds are being used for projects that do not accord with Article 19 and suspend/withdraw funding in cases where the funds have been inappropriately used.
- *Clear commitment to act to prevent inappropriate use of EU funds:* In the past, the Commission was reluctant to take action even where concerns were raised that significant amounts of EU funds were being invested in institutional care (the renovation of existing institutions and building new long stay facilities). It is therefore imperative that the Commission takes action in cases where there are concerns that Structural Funds are supporting projects that maintain institutional care. Where the funding is for infrastructure projects, this principle should apply regardless of the size of the setting.

### 3.2 KEY ISSUE: The use of Structural Funds to maintain institutional care should be prohibited

#### EU report:

- **Paragraph 94:** states that Structural Funds are to be applied in accordance with principles of equality, non-discrimination, inclusion and accessibility.
- **Paragraph 95:** explains that Member States and the Commission are required to “take appropriate steps to prevent any discrimination based on disability during the preparation and implementation of programmes and that accessibility for persons with disabilities is taken into account throughout the preparation and implementation of programmes”.
- **Paragraph 98:** states that Structural Funds should not be used “for building new residential institutions or the renovation and modernisation of existing ones”, save in exceptional cases “where urgent and life-threatening risks to residents linked to poor material conditions need to be addressed, but only as transitional measures within the context of a de-institutionalisation strategy.”

#### ENIL–ECCL comment:

- *Clear statement on prohibiting Structural Funds investment in institutional care:* The EU’s statement in **paragraph 98** that Structural Funds should not be invested in institutional care is very welcome. This position was set out in the report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009).<sup>119</sup> It is also supported by the new Structural Funds regulations that focus on the provision of community-based services (Article 5 of the ERDF Regulation and Article 8 of the ESF Regulation). However, while the ESF Regulation states that ESF “should not support any action that contributes to segregation or to social exclusion”,<sup>120</sup> the same prohibition on investing Structural Funds in institutional infrastructure is not included in the ERDF Regulation. It is therefore important that the EC makes clear that Structural Funds (in particular ESF and ERDF, but also other Funds) cannot be used for this purpose, for example by issuing guidance on what services are not eligible for Structural Funds. Such guidance will need to be disseminated across the different parts of the EC, as well as to Member States, so that it is understood and adhered to by all those involved in the planning, implementation and monitoring of Structural Funds. Unless this happens, there is a risk that Structural Funds will continue to be used to maintain institutional care settings.
- *The principle of non-discrimination and the investment of Structural Funds in institutions:* ENIL–ECCL consider that investing Structural Funds into institutional care is contrary to the CRPD and amounts to unlawful discrimination under EU law.<sup>121</sup> Although the Commission’s action to assess the implementation of Article 16 (non-discrimination) in relation to the planning and management of Structural Funds is welcome, that report<sup>122</sup> (referred to at **paragraph 94**) did not cover the concern that Structural Funds were being used to build new

institutions and/or renovate existing institutions and therefore made no recommendations on this point. It only looked at non-discrimination in relation to gender.

**3.3 KEY ISSUE: If such failures are to be avoided in the future, the significant negative consequences of past failures to ensure that Structural Funds support the development of community-based and inclusive services must be acknowledged**

**EU report:**

- **Paragraph 100:** mentions the DECLOC study from 2007, stating that it “provided evidence in support of transition from institutional care to community-based alternatives, as they can provide better results for users, their families and staff while the costs are comparable when based on comparable quality standards.” The same study “found that institutional care for disabled people in Europe fell short of acceptable standards and recommended wider use of community-based services”.

**ENIL–ECCL comment:**

- *Human rights abuses in institutions and concerns about Structural Funds perpetuating abuse:* Although the EU report notes that the DECLOC report had “found that institutional care for disabled people in Europe fell short of acceptable standards and recommended wider use of community based services”, (**paragraph 100**) no comment is made on this observation. While recognising that it is the responsibility of Member States to inspect their institutional care settings, where Structural Funds are used to maintain such places, ENIL–ECCL consider that it is the EC’s responsibility to ensure that EU funds do not perpetuate human rights violations.
  - This is highly relevant considering the numerous reports that have highlighted the significant human rights abuses that occur on a frequent basis within institutions,<sup>123</sup> including the use of cage beds.<sup>124</sup> While many such reports focus on the large institutions in countries within Central and Eastern Europe, in which the living conditions are extremely poor, human rights violations within institutions are not unique to this part of the EU.<sup>125</sup>
  - A 2014 Al Jazeera investigation into the situation of people with disabilities in Romanian institutions noted that Structural Funds had been invested in two of the institutions in which residents were subject to human rights abuses.<sup>126</sup>
- *A missed opportunity to develop community-based services:* Using Structural Funds to maintain institutional care means that funding is being diverted away from developing community-based services which would enable people with disabilities to live and participate in the community.<sup>127</sup>
  - It is estimated<sup>128</sup> that between 2007 and 2013 a total of at least 150 million Euros were invested into the renovation or building of new institutions for disabled people in the countries of Bulgaria, Hungary, Latvia, Lithuania, Romania and the Slovak Republic.
  - Additional information provided to ENIL–ECCL suggests that Structural Funds have also been invested in institutional care in the Czech Republic, Estonia and Poland.<sup>129</sup>
- *Services replicate institutional cultures:* ENIL–ECCL’s partners in Hungary and Bulgaria highlight the problem that services referred to as “community-based” or “independent living” are being supported, when in fact they remain institutional in character.<sup>130</sup> This may be due to a number of factors, such as the number of residents living in one place, the fact that residents are not able to choose where, or with whom, they live, and the fact that the staff are not properly trained to work in the new services.
  - There is also an overreliance on what are often referred to as “small group homes”. For example, in Bulgaria, an ongoing deinstitutionalisation project for children consists of building 149 small group homes for 12 children each,<sup>131</sup> with plans to build additional group homes for adults with disabilities in the future. Although group homes generally have better living conditions than institutions, the attitude of the staff is not necessarily different, with residents required to “submit a written request in order to go out, specifying the reason and the time they will return” and not being allowed out without a carer.<sup>132</sup>

- ENIL–ECCL consider that a better approach would be to support projects that make mainstream housing accessible to people with disabilities (such as investing in social housing, adaptation of existing flats and purchasing existing flats or homes in the community).
- *Insufficient emphasis on social inclusion:* While some community-based services have been funded, mainly through ESF, there are concerns as to what extent these new services facilitate the genuine social inclusion of people with disabilities. For example:
  - In Bulgaria, Structural Funds have supported personal assistance services with the objective of providing employment for “unemployed relatives who are engaged in the care of the disabled member of the family”. Thus, although having the positive objective of reducing the number of people in institutions, “personal assistance” is used as an employment measure for family members of persons with disabilities, rather than seeking to facilitate independent living.<sup>133</sup>
  - In Romania, 43.7 million EUR of Structural Funds were invested in an employment project that aimed to increase the employment of people with disabilities through training. However, despite a significant investment, the project resulted in the employment of 116 people.<sup>134</sup> In ENIL–ECCL’s view, this not only suggests a failure to assess the needs of people with disabilities, but also shows that such measures must be a part of an overall national effort to include persons with disabilities in society, in order to work.

### 3.4 KEY ISSUE: Concerted action required to avoid future misuse of Structural Funds

#### EU report:

- **Paragraph 96:** refers to the *ex ante conditionalities* that have been introduced in the new Structural Fund regulations. These are described as “pre-conditions to ensure that institutional and strategic policy arrangements are in place for effective investment”.
- **Paragraphs 97 and 98:** highlight the importance of supporting the “transition from institutional care to community-based care”, in connection with ESF and ERDF.
- **Paragraph 97:** states that at least 20% of ESF funding will target social inclusion.
- **Paragraph 99:** recognises the important role of NGOs, DPOs and service providers, “in monitoring investments, raising awareness of the situation of persons with disabilities in residential settings, and providing guidance for compliance with the principles of the CRPD for an effective transition to community-based living”.

#### ENIL–ECCL comment:

- *Positive changes in the Structural Funds regulations but outstanding concerns:* The new provisions in the regulations, together with the emphasis on using Structural Funds to support the “transition from institutional to community-based care”, as well as social inclusion, accessibility and non-discrimination, are very positive. They have the potential for ensuring that Structural Funds are effectively used to facilitate independent living of people with disabilities in the EU. However, ENIL–ECCL are concerned that there is no information on how the EC will assess Member States’ compliance with these requirements. The key points of concern are set out below.
- *Identifying measures for the shift from institutional to community-based care:* The EC Position Papers on the development of Partnership Agreements and programmes for 2014–2020 identify the development of community-based alternatives and/or the promotion of independent living as a funding priority for Bulgaria, Croatia, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Romania, Slovenia and the Slovak Republic.<sup>135</sup> In line with the thematic *ex ante* conditionality, this means that these Member States should have in place a strategy which includes “measures for the shift from institutional to community based care” as a condition for using Structural Funds.<sup>136</sup> However, it is unclear how the EC will assess whether the measures identified by the Member States are adequate. Experience shows that, while Member States may have de-institutionalisation strategies in place, they do not necessarily fully support the right to independent living.<sup>137</sup> This can inadvertently lead to EC accepting the Member States’ strategies, regardless of their quality, and the Structural Funds being invested into services which replicate an institutional culture.

- *Assessing capacity to comply with the CRPD*: The general ex ante conditionality on disability requires the existence of “administrative capacity for the implementation and application of [the CRPD]”. The criteria for fulfilment refer to the involvement of “bodies in charge of protection of rights of persons with disabilities or representative organisations of people with disabilities and other relevant stakeholders” throughout the process of programmes funded by Structural Funds, training of staff on disability law and policy and practical application of the CRPD and monitoring compliance with Article 9. It is not clear how the Member States’ compliance with these conditions is going to be assessed.
- *Action needed to avoid inappropriate use of Structural Funds*: the following points will need to be addressed by the EC to ensure that in the future Structural Funds are used to promote, rather than hinder, independent living.
  - *Clear strategies for transition to independent living* will be required. The EEG Guidelines state that governments should prepare a strategy that sets out the overall framework for guiding the necessary reforms in three key areas, namely the closure of institutions, the development of community-based services (including prevention of institutionalisation) and inclusive mainstream services.<sup>138</sup> Such strategies should be agreed with all relevant Ministries, including Finance, and should be based on a country-wide needs assessment, with clear definitions, in particular describing community-based services and how this differs from institutional care.
  - There is a need for *clear and precise definitions*, in order to ensure that services developed by projects supported by Structural Funds comply with Article 19. One of the reasons for the continued investment in institutional-like settings appears to be the lack of understanding of what is meant by the terms “institution” and “community-based services”.<sup>139</sup> For example, in the Czech Republic, some of the renovations of existing institutions were regarded as being part of the deinstitutionalisation process, even though the only changes made were to improve the physical environment.<sup>140</sup> In Romania, the CoE Commissioner for Human Rights noted that purported changes to long-stay residential care settings for both children and adults have been cosmetic.<sup>141</sup> For example, having visited a “Centre for Education”, he noted that although the name suggested that this was a mainstream school “for children with and without disabilities”, it was in fact “a residential institution accommodating more than 50 infants, children and young adults with disabilities”.<sup>142</sup>
  - Ensure *co-ordination between different EU funds*: reports suggest that due to a lack of co-ordination of different EU funds, the drive to improve the accessibility of buildings has led to Structural Funds, through Operational Programmes on energy efficiency, being invested to improve the accessibility of institutions. For example, in Hungary, two institutions (one with 80 residents and one with 102 residents) received funds for this purpose.<sup>143</sup> While accessibility as such is a positive goal, making institutions accessible results in a waste of resources, which could have been invested in the development of community-based services, and delays the closure of the institution. This also highlights the need for an emphasis on social inclusion in the Member States’ strategies.
- *Putting partnership principle into practice*: the EU report’s statement (**paragraph 99**) that the Commission recognises the importance of working with people with disabilities and other stakeholders to ensure the transition from institutional care to community-based services is very positive. Such engagement is provided for in the European Code of Conduct on Partnership (adopted in 2014), in relation to the programming, implementation, monitoring and evaluation of Structural Funds.<sup>144</sup> However, Member States are likely to require clear guidance on how to put this principle into practice. ENIL–ECCL have found that to date there has been a lack of engagement with NGOs in relation to the preparation of the partnership agreements and operational programmes by the managing authorities in the Member States.<sup>145</sup>

### 3.5 KEY ISSUE: Clear monitoring mechanisms required to ensure effective use of Structural Funds to promote the right to independent living

#### EU report:

- **Paragraph 93**: states that the Commission “has undertaken to promote the use of EU Structural Funds to assist Member States in the transition from institutional to community-based services and to raise awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people”.

- **Paragraph 95:** states that “managing authorities must ensure that all products, goods, services and infrastructures” intended for the general public, that are funded by Structural Funds, must be accessible to all citizens.
- **Paragraph 99:** states that, while the Commission has responsibility for ensuring that Member States have appropriate plans in place for applying Structural Funds, it is not responsible for how Member States implement these plans. It explains:
 

“According to the principle of shared management to which the Funds are subject, the Commission has the responsibility to ensure that the Member States’ operational programmes comply with EU law, including EU legislation and the CRPD, and their strategies are in line with EU strategies and policies, including the Disability Strategy. Implementation, on the other hand, lies with the Member States.”
- **Paragraph 99:** also states “The Commission is committed to suspending or withdrawing payments in the event of this principle being breached.”

#### ENIL–ECCL Comment:

- *Clarity on EU’s responsibilities needed:* The commitment of the Commission to utilise Structural Funds in the promotion of the transition to community-based services, together with the positive changes introduced by the new regulations on the use of Structural Funds, is very welcome.
  - However, ENIL–ECCL is concerned by the EU report’s statement that responsibility for implementation lies with the Member States. The likely result of this limitation of responsibilities is that the Commission will not be able to monitor the use of Structural Funds effectively. For example, Structural Funds could be used to fund services that are located on the outskirts of town, with poor transport links; or to provide housing that is not accessible to people with disabilities. These are crucial issues of direct relevance to whether Structural Funds are supporting projects that meet the objective of promoting independent living.
  - Given that the funds are being provided by the EU, it is argued that the EU has a responsibility not just during the programming phase of Structural Funds use, but also for monitoring the implementation of the specific projects. This is necessary **to ensure that Structural Funds are not being invested in projects that conflict with the EU’s obligations under the CRPD.**<sup>146</sup> This view is supported by the European Ombudsman, who opened an investigation into the issue in May 2014, noting that: “It is key for the credibility of the European Union that, wherever EU money is spent, fundamental rights are respected. In many cases, these funds are supposed to help the most vulnerable members of society. But if, for example, there are complaints that EU money is used to “institutionalise” persons with disabilities instead of helping to integrate them, the Commission clearly needs to ensure the matter is investigated and corrective action taken if needed.”<sup>147</sup>
- *Clear commitment to act to prevent inappropriate use of EU funds:* In the past, the Commission was reluctant to take action even where concerns were raised that significant amounts of European funds were invested in institutional care (the renovation of existing institutions and building new long stay facilities). Therefore, the statement in **paragraph 99** of EU report that the Commission will use its powers to suspend or withdraw payments in the future, to ensure that funds are used in compliance with the CRPD, is very welcome. However:
  - If the Commission is to be in a position to use this power to suspend or withdraw payments, an effective monitoring mechanism (covering all EU funded projects) for ensuring that Structural Funds are used in accordance with the CRPD, is required. However, no details are provided on how the necessary monitoring will be undertaken in 2014–2020. ENIL–ECCL found that in the previous programming period, monitoring committees in the Member States were unable to prevent Structural Funds being invested into institutional care.<sup>148</sup>
  - In relation to accessibility of mainstream services (**paragraph 95**), it is not clear how compliance with these provisions will be monitored, nor who would assess for compliance. As of yet, there are no accessibility standards at the EU level, and Member States’ standards vary. If this is to be monitored by civil society groups, additional funding will be required. Furthermore, it is not clear what would happen if projects supported by Structural Funds are not accessible.
- *Lack of clarity on the EU’s monitoring framework:* ENIL–ECCL is concerned about the planned move of the Unit for the Rights of Persons with Disabilities, which coordinates the implementation and monitoring of the CRPD in

the EC, from DG Justice to DG Employment, Social Affairs, Skills and Labour Mobility.<sup>149</sup> While this may help put more emphasis on the employment of people with disabilities, ENIL–ECCL considers that such move is likely to lead to other CRPD rights being overlooked, including the right to independent living. It is unclear what role the First Vice-President of the EC, responsible for “upholding the Charter of Fundamental Rights and the Rule of Law in all of the Commission’s activities” will play in the implementation and monitoring of the CRPD at EU level.

#### Questions regarding the use of Structural Funds:

- Question 7:** *Where the need for “measures for the shift from institutional to community-based care” is identified as a funding priority by the EU, what action does the EU take to ensure that the Member State allocates a sufficient amount of Structural Funds for this purpose?*
- Question 8:** *How will the EU ensure that all projects funded by Structural Funds accord with the CRPD, including the requirement under Article 19 that all people with disabilities have a right to “choose where and with whom they live”?*
- Question 9:** *What action will the EU take if a Member State uses Structural Funds to support programmes that do not promote the right to independent living under Article 19, or otherwise do not comply with the EU or Member State’s obligations under the CRPD?*
- Question 10:** *What monitoring mechanisms within the EU are in place to ensure the effective use of Structural Funds to promote the right to independent living and how does this involve people with disabilities and their representative organisations?*

## 4. Promoting personal assistance as an essential element of independent living

ENIL and the wider Independent Living movement consider personal assistance “a tool which allows for independent living”<sup>150</sup>. This view is supported by ANED, which considers it one of the core elements of independent living.<sup>151</sup>

Moreover, personal assistance is referred to specifically in Article 19. Under Article 19(b), State Parties are required to ensure that people with disabilities have access to “community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”.

ENIL considers that personal assistance is “a necessary support service in the enablement of disabled people to live a life as fully included and participating citizens in their communities” and “is instrumental in the empowerment and inclusion of disabled people”. Personal assistance, as set out in Article 19, should be distinguished from other types of services, such as care provided by nurses and other medical professionals, social workers, charities or the church. For personal assistance to facilitate independent living, it is important that:

- disabled people are able to employ and train their assistants (if necessary, with support);
- disabled people have control over the tasks performed by the assistants;
- disabled people have access to as much personal assistance as they need;
- that the service is sufficiently funded (through direct payments or personal budgets), enabling them to hire personal assistants from the open labour market; and
- that peer support is available and adequately funded, in order to encourage disabled people to take up personal assistance and other independent living services.

Personal assistance should not be limited to supporting people with disabilities with their basic needs, at home, but should support their lifestyle choices. For example, it should allow them to have a family, to work, study, travel, socialise and to be otherwise active in their local communities. As such, personal assistance is key to disabled people's enjoyment of other CRPD rights.

ENIL argues that personal assistance should be available to all people with disabilities, including children and older people. Centres for Independent Living and other user-led organisations can play an important role in ensuring that people with disabilities (and their families, if relevant) are able to manage their personal assistance. However, to date, too little attention has been given to the importance of ensuring that personal assistance schemes are available to all people with disabilities living in the EU.

**The following key issues are considered below:**

4.1	Lack of attention given to promoting personal assistance schemes
4.2	Lack of portability of personal assistance schemes

#### 4.1 KEY ISSUE: Lack of attention given to promoting personal assistance schemes

##### EU report:

- **Paragraph 103:** states that “EU law does not directly address the issue of personal assistance schemes, which are a matter of national competence.”

##### ENIL–ECCL comment:

- *EU's role in promoting personal assistance schemes:* The EU's stance on personal assistance schemes is disappointing. It fails to take into account the EU's role in promoting the use of personal assistance schemes through Structural Funds investments. In addition, the EU's Disability Strategy places great emphasis on the importance of developing personal assistance schemes. Under the heading “Participation”, the strategy states that EU action will support national activities to:

“achieve the transition from institutional to community-based care, including use of Structural Funds and the Rural Development Fund for training human resources and adapting social infrastructure, *developing personal assistance funding schemes*, promoting sound working conditions for professional carers and support for families and informal carers;” [emphasis added]

- The summary of the EC's work in the area of “Participation” specifically refers to personal assistance, stating that the EU action will support national activities to: “achieve full participation of people with disabilities in society, by: ....providing quality community-based services, including access to personal assistance.” As ENIL's survey referred to above demonstrates, little progress has been made in this area in the Member States.
- The EC staff working document, which accompanies the EU Disability Strategy, includes in its list of actions (under the heading “Enhance Member States' efforts towards the transition from institutional care to community-based care”): “Promote the exchange of good practice among Member States in the Disability High Level Group on personal assistance funding schemes”. However, no mention of this work is included in the EU report. Similarly, the Disability High Level Group annual reports on the implementation of the UN CRPD fail to provide information about access to personal assistance.
- *Recognising that personal assistance schemes are an essential part of the range of community based services to be developed:* As noted above, regulations for both the ESF and the ERDF emphasise the importance of developing community-based services. The preamble (recital 16) of the ERDF regulation states that community-based services “should cover all forms of in-home, family-based, residential and other community services which support the right of all persons to live in the community, with an equality of choices, and which seek to prevent isolation or segregation from the community”.

- Personal assistance schemes are a crucial element of the range of services that will be required. This is made clear by Article 19(b) of the CRPD, which makes specific reference to personal assistance, and the EEG’s Common European Guidelines, which refer to personal assistance as “one of the most important services for independent living for children and adults with disabilities”.<sup>152</sup> Therefore, when negotiating programmes for 2014–2020 with the Member States, the EC should promote personal assistance schemes as a measure to be supported by Structural Funds.

## 4.2 KEY ISSUE: Lack of portability of personal assistance schemes

### EU report:

- **Paragraph 103:** refers to Regulation (EC) No 883/2004, which “provides for the coordination of social security schemes and, in certain specific circumstances, for the entitlement to have a social security benefit ‘exported’ to another Member State”.
- **Paragraph 103:** then states that a “benefit relating to independent living such as personal assistance would need to be regarded as a sickness benefit for it to be exportable under EU law. In all other cases, while there is nothing to prevent exportability, there is no obligation under EU law concerning the exportability of such benefits”. The report cited in support of this statement is *Disability Benefits and Entitlements in European Countries: Mutual Recognition and Exportability of Benefits – A synthesis of evidence provided by ANED country reports and additional sources* which was produced by the Academic Network of European Disability Experts (ANED) in 2010. This report (referred to as “the Disability Benefits report”) and its recommendations are discussed below.

### ENIL–ECCL comment:

- *Lack of portability undermines EU citizenship rights:* The problems with the portability of benefits are recognised in the EU Disability Strategy. Under the heading “Participation”, it is noted that there are “many obstacles preventing people with disabilities from fully exercising their fundamental rights – including their Union citizenship rights – and limiting their participation”, and that one of the rights affected is “the right to free movement”. The EU report notes that one of the obstacles is that people with disabilities “can lose access to national benefits” when moving to another EU country. ENIL–ECCL considers that these are important issues that should be addressed by the EU.
- *No information provided on work under the EU Disability Strategy connected to personal assistance:* The Commission staff working document, which accompanies the EU Disability Strategy, includes in its list of actions under the heading “Address problems related to intra-EU mobility” the following two areas of action, neither of which is referred to in the EU report in relation to Article 19. They are to:
  - “Promote dialogue among Member States in the Disability High Level Group on the portability of rights such as the right to personal assistance.” (2010)
  - “Identify obstacles encountered by persons with disabilities in the exercise of rights as EU citizens, in particular the right to free movement and residence”. (During 2010–2015)
- *No information on the recommendations of ANED’s Disability Benefits report:* Although the authors of the ANED report concluded that “it seems that an independent living-related benefit, such as personal assistance, needs to be regarded as a sickness benefit for it to be exportable under EU law”, they also noted that this “seems to be out of tune with regard to developments relating to independent living”.<sup>153</sup>
  - ENIL–ECCL consider that framing personal assistance schemes as sickness benefits is contrary to the CRPD and should therefore be revised to ensure compliance with the CRPD.
  - The EU report makes no mention of the Disability Benefit report recommendations on actions that could be taken to address the barriers to the free movement of people with disabilities, relating to “mutual recognition and exportability of disability-related benefits”. These include: the collection of information about all the disability-related benefits at EU level; coordinated action among the Member States within the framework

of EU law, to allow for temporary export of all disability-related benefits for those wishing to exercise their right to free movement, or to make it possible for people with disabilities to apply for disability-benefits in the host Member State before taking up residence; and action to be taken by the Commission to encourage voluntary agreements between the Member States, or to propose legislation on the matter.<sup>154</sup> It is clear that the European Commission has an important role to play in finding workable solutions to support the free movement of people with disabilities in the EU.

- *Failing to recognise the link between Europe 2020 targets and personal assistance:* The EU report fails to mention other policy initiatives, such as the Social Investment Package and the European Semester, both of which seek to help Member States reach Europe 2020 targets (which include increasing access to employment and education, and reducing poverty and social exclusion in the EU, see Annex I). ENIL–ECCL considers this a missed opportunity by the EC to promote personal assistance, as a way of increasing employment rates among people with disabilities, increasing the number of young people in education and fighting poverty. For example, the EC could include the relevant recommendations to the Member States in the Country-specific Recommendations adopted under the European Semester.<sup>155</sup>

#### Questions on promoting personal assistance as an essential element of independent living:

**Question 11:** *What action will the EU take to ensure that personal assistance schemes are sufficiently supported by the Structural Funds, along with other community-based services?*

**Question 12:** *What action will the EU take to ensure that people with disabilities have access to essential independent living services, including personal assistance, when taking up residence in another EU Member State?*

**Question 13:** *How does the EU plan to use existing policy initiatives, such as those related to reaching Europe 2020 targets, to promote access to personal assistance for people with disabilities?*

## Conclusion

For the reasons explored in this report, ENIL–ECCL are concerned that the EU report gives insufficient attention to the problems and challenges faced by people with disabilities living in the EU, in relation to the right to independent living (Article 19). It fails to provide a realistic picture of the current situation of people with disabilities, with the corresponding problem that there is little discussion on how the continuing widespread and weighty barriers to achieving the goals set out in the Disability Strategy might be addressed. In particular, while the action by the European Commission to highlight, in both policy and legislation, the need for Member States to ensure the shift from institutional care to community-based services is very welcome, more effective action is required to ensure that people with disabilities can exercise their right to independent living in accordance with Article 19.

ENIL–ECCL hopes that the range of comments and questions it has posed in this report will be of assistance to the CRPD Committee in assessing the extent to which the EU has complied with its obligations under the CRPD, in particular Article 19, and to consider what further action the EU should take to address any areas in which it falls short in meeting its obligations.

# Annex I: European Union initiatives with the potential to promote Independent Living

- **European Disability Strategy 2010–2020:** The European Commission (“EC”) has identified the provision of “quality community-based services, including personal assistance as one of the goals of the Strategy”. The EC has committed to “promote the transition from institutional to community-based care by: using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people”. Moreover, it agreed to support the national activities in this area, including the development of personal assistance schemes.<sup>156</sup>
- **Europe 2020 Strategy** (particularly its flagship initiative the European platform against poverty and social exclusion): The EU’s strategy for a smart, sustainable and inclusive growth contains a number of objectives which can support the implementation of Article 19. These include: reducing poverty, extending employment opportunities, promoting lifelong learning, promoting the active inclusion of the most vulnerable groups, providing decent housing for everyone and overcoming all forms of discrimination.<sup>157</sup> The European Semester – a yearly cycle of economic policy coordination – set up by the EC to help Member States reach the Europe 2020 targets has the potential to help evaluate progress in this respect (by covering access to independent living in the Country Specific Recommendations).<sup>158</sup>
- **Social Investment Package:** This policy framework contains a number of recommendations related to independent living. For example, the Commission Communication on the European Social Fund (ESF) states that both ESF and the European Regional Development Fund (ERDF) can contribute to “desegregation of educational facilities, the shift to community based care and integrated housing policies.”<sup>159</sup> The Recommendation on children asks that Structural Funds are used to support deinstitutionalisation, and requires that Member States “stop the expansion of institutional care for children without parental care”.<sup>160</sup>
- **European Structural and Investment Funds Regulations 2014–2020:** The new Structural Funds Regulations, specifically those governing the use of the ESF and the ERDF contain a number of provisions which have the potential to support the development of community-based alternatives to institutional care in the Member States. They are included under the objective of “Promoting social inclusion, combating poverty and any discrimination”. For example, one of the ERDF priorities is “investing into health and social infrastructure which contributes to ... transition from institutional to community-based services” (Article 5, ERDF Regulation). The Regulations also introduce *ex-ante* conditionalities, which require Member States to have a national strategy for poverty reduction in place, which “depending on the identified needs, includes measures for the shift from institutional to community-based care”. In addition, the Regulations include a general *ex ante* conditionality on disability, which requires the existence of “administrative capacity for the implementation and application of [the CRPD]”. The criteria for fulfilment concern the involvement of “bodies in charge of protection of rights of persons with disabilities or representative organisations of people with disabilities and other relevant stakeholders” throughout the process of programmes funded by Structural Funds, training of staff on disability law and policy and practical application of the CRPD and monitoring compliance with Article 9.
- **Commission Position Papers on the use of Structural Funds:** In the framework of preparation of Partnership Agreements and Operational Programmes for the use of Structural Funds in 2014–2020, the European Commission has issued Position Papers with the proposed priorities for investment<sup>161</sup>. In respect of 12 Member States (Bulgaria, Czech Republic, Estonia, Greece, Hungary, Lithuania, Latvia, Poland, Romania, Slovenia, Slovakia and Croatia), deinstitutionalisation (in relation to one or more groups, such as children, people with disabilities, people with mental health problems, older people or homeless people) was identified as one of the investment priorities.

- **Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009):** The Ad Hoc Expert Group was founded in 2009 at the initiative of the then Commissioner for Employment, Vladimir Spidla. Its report, which was endorsed by the EC, set out a number of recommendations to the EC and the Member States on how to facilitate the process of deinstitutionalisation in the EU. The follow-up initiative to the Ad Hoc Expert Group – the European Expert Group on the Transition from Institutional to Community-based Care (EEG) – published the Common European Guidelines on the Transition from Institutional to Community-based Care and the Toolkit on the Use of EU Funds for the Transition from Institutional to Community-based Care in 2012 (revised in 2014). These two guides were presented by EEG members to the Commission officials during a training session in 2012, and were also distributed to EC staff in DG Employment and DG Regional policy. ENIL–ECCL understands that, in addition, internal guidance on the transition from institutional care to community-based services was developed by DG Employment, Social Affairs and Inclusion and DG Regional Policy, and transmitted to the relevant officials. Finally, the EC has supported a series of seminars, organised by members of the EEG, during 2013 and 2014 on the use of Structural Funds for deinstitutionalisation (in Latvia, Estonia, Romania, Hungary, Croatia, Poland, Bulgaria, Czech Republic, Slovakia, Slovenia and Lithuania).
- **EU Fundamental Rights Agency reports:** three relevant reports were published on a) independent living of persons with intellectual disabilities and mental health problems, b) involuntary placement and treatment of persons with mental health problems, and c) legal capacity of persons with intellectual disabilities and mental health problems.<sup>162</sup>
- **Progress reports on candidate and potential candidate countries:** The European Commission has covered the situation of children and adults with disabilities in institutional care, as well as availability of community-based services in a number of Progress Reports (on Albania, Bosnia and Herzegovina, Croatia, FYR Macedonia, Kosovo, Montenegro, Serbia and Turkey).
- **European Ombudsman initiative on the use of Structural Funds:** In May 2014, the European Ombudsman opened an investigation, on her own initiative, in relation to the use of Structural Funds, following reports about these funds being used to renovate or build institutions for people with disabilities. She has asked the EC a detailed set out questions on how it ensures that Member State respect fundamental rights in projects funded by the EU, and what sanctions it can apply. The EC was asked to respond by 30 September 2014.<sup>163</sup>
- **Other actions:** In addition to the above initiatives, the financial support of the EC to organisations of disabled people, including ENIL, and the provision of funding for relevant studies, such as the DECLOC report (as mentioned in the EU’s CRPD report) should also be acknowledged as positive steps in the much needed work to promote independent living for people with disabilities in the EU.

# Annex II: Determining the EU's obligations under the CRPD<sup>164</sup>

The CRPD is a 'mixed agreement', which means that it "covers fields that fall in part within the competence of the EU, in part within that of the Member States and in part within the shared competence of the EU and its Member States".<sup>165</sup> It is therefore necessary to ascertain which fields fall within the EU's exclusive competence and in which fields the EU and Member States share competence. This distinction is important, because it affects the extent of the EU's responsibility to ensure compliance with the CRPD. Where the EU has exclusive competence, it is responsible for meeting the obligations under the CRPD. Where the EU and Member States share competence, both the EU and the Member States may take action, so long as the EU has not exercised its competence in that area.<sup>166</sup> In other areas, such as education and vocational training, the EU can support and supplement action by Member States.<sup>167</sup>

Despite its significance, the scope of the EU's competency in relation to the obligations to be fulfilled under the CRPD is unclear. Under Article 44 of the CRPD, the EU was required to set out the areas in which the EU Member States "have transferred competence with respect to matters governed by this Convention". The EU purported to do so in its Council Decision concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities ("the Council Decision").<sup>168</sup> This is referred to in **paragraph 4** of the EU CRPD report, which states that Annex II to the Council Decision "illustrates the extent of the Union competence with respect to matters governed by the CRPD". However, Annex II does not distinguish between those areas that fall within the exclusive competence of the EU and those where the EU shares competence with Member States. The Council Decision also notes that the "scope and the exercise of Community competence are, by their nature, subject to continuous development".<sup>169</sup>

Professor Lisa Waddington encapsulates the problem caused by this lack of clarity on the extent of the EU's competency when she comments "it is these fields of shared competence where uncertainty exists as to how to proceed, and at which level – EU or Member State – action should be taken".<sup>170</sup> It appears that the declaration concerning the competence of the EU and the Member States represents the EC subjective view, as it was not subject to any external review or control.<sup>171</sup>

The Council Decision lists the areas of shared competence and those of exclusive competence:

- **Areas of shared competence:** "action to combat discrimination on the ground of disability, free movement of goods, persons, services and capital agriculture, transport by rail, road, sea and air transport, taxation, internal market, equal pay for male and female workers, trans-European network policy and statistics".
- **Areas of exclusive competence:** "the compatibility of State aid with the common market and the Common Custom Tariff" as well as the European Union's own public administration. In addition, the EU has "exclusive competence where the Convention affects existing – or presumably new – EU provisions that establish 'common rules', from which Member States cannot deviate".<sup>172</sup> However, there is no indication in the list of legal instruments in the appendix to Annex II of the Council Decision as to which of the instruments, if any, are considered to have established "common rules" and therefore fall within the EU's exclusive competence.

The note preceding the list of legal instruments in Annex II of the Council Decision warns that the extent of the EU's competence "must be assessed by reference to the precise provisions of each measure and in particular, the extent to which these provisions establish common rules that are affected by the provisions of the Convention". As Professor Waddington notes:

"...the reader must decide for him or herself what these instruments reveal about the extent of the Community competence, since no further commentary or insight is given. Moreover, no attempt is made to identify which instruments establish the all important common rules which trigger EU exclusive competence."<sup>173</sup>

# Annex III: Glossary

## ENIL's key definitions on Independent Living

**These definitions are intended for use in the development of guidelines, policy and legislation at the European Union level, Member State level and local level. Their aim is to give decision makers clear guidance for the design and implementation of disability policy. They have been developed to prevent the manipulation and the misuse of our language for the development of policies that are counter-productive to Independent Living.**

The concept of Independent Living (IL)<sup>174</sup> is much older than the UN Convention on the Rights of Persons with Disabilities ('CRPD'). It has played a key part in the drafting of the CRPD, especially Article 19, but is also underpinning other articles, none of which can be realised without IL. Article 19 sets out the right to choose where, with whom and how to live one's life. This allows for self-determination upon which IL is based. There is a continuous debate on *independence vs. interdependence*; ENIL considers that all human beings are interdependent and that the concept of IL does not contravene this. IL does not mean being independent from other persons, but having the freedom of choice and control over one's own life and lifestyle.

### Independent Living (IL):

IL is the daily demonstration of human rights-based disability policies. IL is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in our daily life. IL requires that the built environment and transport are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that IL is for all disabled persons, regardless of the level of their support needs.

### Personal Assistance (PA):

PA is a tool which allows for IL. PA is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. PA should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model which is most suitable for our needs. PA allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.

### Deinstitutionalization (DI):

DI is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to IL. Effective DI occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his/her life (if necessary, with support). Essential to the process of DI is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. DI is also about preventing institutionalization in the future; ensuring that children are able to grow up with their families and alongside neighbours and friends in the community, instead of being segregated in institutional care.

### Community-based Services (CBS):

The development of CBS requires both a political and a social approach, and consists of policy measures for making all public services, such as housing, education, transportation, health care and other services and support, available and accessible to disabled people in mainstream settings. Disabled people must be able to access mainstream services

and opportunities and live as equal citizens. CBS should be in place to eliminate the need for special and segregated services, such as residential institutions, special schools, long-term hospitals for health care, the need for special transport because mainstream transport is inaccessible and so on. Group homes are not IL and, if already provided, must exist alongside other genuine, adequately funded IL options.

### **Institution:**

ECCL defines an 'institution' as any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.

The Ad Hoc Expert Group Report on the Transition from Institutional to Community-based care defines 'institutional care' as any residential care where:

- users are isolated from the broader community and/or compelled to live together;
- these users do not have sufficient control over their lives and over decisions which affect them;
- the requirements of the organisation itself tend to take precedence over the users' individualised needs.

# Annex IV: Resources

## General reports

European Expert Group on the Transition from Institutional to Community-based Care, 2014, *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care: Revised edition*. Available at: <http://deinstitutionalisationguide.eu>

Mental Disability Advocacy Centre, 2014, *Cage beds and coercion in Czech psychiatric institutions*. Available at: [http://www.mdac.info/sites/mdac.info/files/cagebed\\_web\\_en\\_20140624\\_0.pdf](http://www.mdac.info/sites/mdac.info/files/cagebed_web_en_20140624_0.pdf)

European Network on Independent Living – European Coalition for Community Living, 2013, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition to Community Living*. Available at: <http://www.enil.eu/recommended-readings-2/ENIL-ECCL-briefing-on-structural-funds-investments-for-people-with-disabilities/>

European Network on Independent Living, 2013, *Personal Assistance Services in Europe*. Available at: <http://www.enil.eu/wp-content/uploads/2012/06/European-Survey-on-Personal-Assistance-Final.pdf>

European Union Agency for Fundamental Rights, 2013, *Legal capacity of persons with intellectual disabilities and persons with mental health problems*. Available at: <http://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf>

Open Society Foundations Petition to the European Parliament, 2013. Available at: <http://www.opensocietyfoundations.org/sites/default/files/petition-eu-parliament-20121018.pdf>

European Expert Group on the Transition from Institutional to Community-based Care, 2012, *Common European Guidelines on the Transition from Institutional to Community-based Care*. Available at: <http://www.deinstitutionalisationguide.eu>

European Expert Group on the Transition from Institutional to Community-based Care, 2012, *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care*. Available at: <http://deinstitutionalisationguide.eu>

Mental Health Europe and the Open Society Foundations, 2012, *Mapping Exclusion – Institutional and community-based services in the mental health field in Europe*. Available at: [http://www.mhe-sme.org/fileadmin/Position\\_papers/Mapping\\_Exclusion\\_-\\_ind.pdf](http://www.mhe-sme.org/fileadmin/Position_papers/Mapping_Exclusion_-_ind.pdf)

European Foundation Centre, 2012, *Assessing the impact of European governments' austerity plans on the rights of people with disabilities, European report*. Available at: [http://www.enil.eu/wp-content/uploads/2012/12/Austerity-European-Report\\_FINAL.pdf](http://www.enil.eu/wp-content/uploads/2012/12/Austerity-European-Report_FINAL.pdf)

Office of the High Commissioner for Human Rights (OHCHR), 2012, *Getting a Life – Living Independently and Being Included in the Community*. Available at: [http://www.europe.ohchr.org/documents/Publications/getting\\_a\\_life.pdf](http://www.europe.ohchr.org/documents/Publications/getting_a_life.pdf)

Open Society Foundations (OSF), 2012, *The European Union and the Right to Community Living – Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities*. Available at: <http://www.opensocietyfoundations.org/sites/default/files/europe-community-living-20120507.pdf>

European Union Agency for Fundamental Rights, 2012, *Choice and control: the right to independent living. Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*. Available at: [http://fra.europa.eu/sites/default/files/fra\\_uploads/2129-FRA-2012-choice-and-control\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2129-FRA-2012-choice-and-control_EN.pdf)

European Coalition for Community Living (ECCL), 2010, *Wasted Time, Wasted Money, Wasted Lives... A Wasted Opportunity? – A Focus Report on how the current use of Structural Funds perpetuates the social exclusion of disabled people in Central and Eastern Europe by failing to support the transition from institutional care to community-based services*. Available at: <http://www.community-living.info/documents/ECCL-StructuralFundsReport-final-WEB.pdf>

Townsley, R. et al, 2010, *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report*, ANED. Available at: <http://www.disability-europe.net/content/aned/media/ANED-Task%205%20Independent%20Living%20Synthesis%20Report%2014.01.10.pdf>

Ad Hoc Expert Group, 2009, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*. Available at: [ec.europa.eu/social/BlobServlet?docId=3992&langId=en](http://ec.europa.eu/social/BlobServlet?docId=3992&langId=en)

Mansell, Jim et al. 2007, *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Available at: [http://www.kent.ac.uk/tizard/research/DECL\\_network/documents/DECLOC\\_Volume\\_2\\_Report\\_for\\_Web.pdf](http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf)

## Reports by the Council of Europe Commissioner for Human Rights

Council of Europe Commissioner for Human Rights, 2012, *The right of people with disabilities to live independently and be included in the community*, CommDH/IssuePaper(2012)3. Available at: <https://wcd.coe.int/ViewDoc.jsp?id=1917847>

Austria: <https://wcd.coe.int/ViewDoc.jsp?id=1970297>

Czech Republic: <https://wcd.coe.int/ViewDoc.jsp?id=2030637>

Denmark: <https://wcd.coe.int/ViewDoc.jsp?id=2145355>

Estonia: <https://wcd.coe.int/ViewDoc.jsp?id=2075361&Site=COE&BackColorInternet=B9BDEE&BackColorIntranet=FFCD4F&BackColorLogged=FFC679>

Portugal: <https://wcd.coe.int/ViewDoc.jsp?id=1959473&Site=&BackColorInternet=B9BDEE&BackColorIntranet=FFCD4F&BackColorLogged=FFC679>

Romania: <https://wcd.coe.int/ViewDoc.jsp?id=2208933&Site=COE>

Slovak Republic: <https://wcd.coe.int/ViewDoc.jsp?id=1885987>

Spain: <https://wcd.coe.int/ViewDoc.jsp?id=2106465&Site=COE&BackColorInternet=B9BDEE&BackColorIntranet=FFCD4F&BackColorLogged=FFC679>

## Shadow reports on the implementation of the CRPD

The Shadow reports are available on the website of the UN OHCHR – Sessions for CRPD – Convention on the Rights of Persons with Disabilities.

Austria: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fAUT%2f10%2f20808&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fAUT%2f10%2f20808&Lang=en)

Belgium: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fCSS%2fBEL%2f18084&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fCSS%2fBEL%2f18084&Lang=en) and [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fCSS%2fBEL%2f18152&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fCSS%2fBEL%2f18152&Lang=en)

Czech Republic: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fCZE%2f15594&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fCZE%2f15594&Lang=en)

Denmark: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fICO%2fDNK%2f16287&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fICO%2fDNK%2f16287&Lang=en)

Germany: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fDEU%2f16323&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fDEU%2f16323&Lang=en) and [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fDEU%2f16592&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=INT%2fCRPD%2fNGO%2fDEU%2f16592&Lang=en)

- Hungary: [http://mdac.info/sites/mdac.info/files/english\\_crpd\\_alternative\\_report.pdf](http://mdac.info/sites/mdac.info/files/english_crpd_alternative_report.pdf)
- Spain: [http://www2.ohchr.org/SPdocs/CRPD/5thsession/CERMI\\_Spain\\_5thSession\\_en.doc](http://www2.ohchr.org/SPdocs/CRPD/5thsession/CERMI_Spain_5thSession_en.doc)
- Sweden: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2f10%2f20823&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fNGO%2f10%2f20823&Lang=en)

## Concluding observations of the Committee on the Rights of Persons with Disabilities

The Concluding observations are available on the website of the UN OHCHR – Sessions for CRPD – Convention on the Rights of Persons with Disabilities.

- Austria: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUT%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUT%2fCO%2f1&Lang=en)
- Belgium: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBEL%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBEL%2fCO%2f1&Lang=en) (in French)
- Denmark: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDNK%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDNK%2fCO%2f1&Lang=en)
- Hungary: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en)
- Spain: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2fCO%2f1&Lang=en)

## Concluding observations of the Committee on the Rights of the Child

The Concluding observations are available on the website of the UN OHCHR Committee on the Rights of the Child.

Concluding observations on Hungary, Finland, Italy, Cyprus, Greece, Austria, Malta, Slovenia, Germany and Portugal:  
[http://tbinternet.ohchr.org/\\_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRC](http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRC)

# Endnotes

1. See Commission Staff Working Document, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*, June 2014.
2. See the Glossary (Annex III) for ENIL's definition of independent living.
3. See Commission Staff Working Document, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*, June 2014. See: [http://ec.europa.eu/justice/discrimination/files/swd\\_2014\\_182\\_en.pdf](http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf).
4. *Ibid*, paragraph 107.
5. Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J., (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report*. Canterbury: Tizard Centre, University of Kent (referred to as “the DECLOC report”). See: [http://www.kent.ac.uk/tizard/research/DECL\\_network/documents/DECLOC\\_Volume\\_2\\_Report\\_for\\_Web.pdf](http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf). Although this figure dates from 2007, there have been no further major studies aimed at establishing the number of people with disabilities living in institutions in the EU since then.
6. United Nations Office of the High Commissioner for Human Rights, *Getting a Life – Living Independently and Being Included in the Community*, 2012, page 11. See: [http://www.europe.ohchr.org/documents/Publications/getting\\_a\\_life.pdf](http://www.europe.ohchr.org/documents/Publications/getting_a_life.pdf).
7. See the Glossary (Annex III) for full definitions of these terms.
8. See also the Common European Guidelines on the Transition from Institutional to Community-based Care, 2012, page 25, available at: <http://deinstitutionalisationguide.eu> and the Glossary (Annex III).
9. See, for example, Article 26 of the Charter of Fundamental Rights of the EU and Article 15 of the Revised European Social Charter.
10. Quinn, G. & Doyle, S. (2012a). *Taking the UN Convention on the Rights of Persons with Disabilities Seriously: The Past and Future of the EU Structural Funds as a Tool to Achieve Community Living. The Equal Rights Review, Vol. 9*, page 69 – 94. See: [http://www.equalrightstrust.org/ertdocumentbank/err9\\_quinn\\_doyle.pdf](http://www.equalrightstrust.org/ertdocumentbank/err9_quinn_doyle.pdf).
11. Council of Europe Commissioner for Human Rights, *The right of people with disabilities to live independently and be included in the community*, CommDH/IssuePaper(2012)3, 2012, page 11. See: <https://wcd.coe.int/ViewDoc.jsp?id=1917847>.
12. CommDH/Speech(2014)9, Strasbourg, 2 October 2014. See: [wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2610517&SecMode=1&DocId=2188914&Usage=2](http://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2610517&SecMode=1&DocId=2188914&Usage=2)
13. See: [wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2503663&SecMode=1&DocId=2130702&Usage=2](http://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2503663&SecMode=1&DocId=2130702&Usage=2)
14. United Nations Office of the High Commissioner for Human Rights, *Getting a Life – Living Independently and Being Included in the Community*, 2012, page 12.
15. This is discussed below.
16. ENIL uses the term ‘disabled people’ in line with the social model of disability. According to the social model, people are disabled by the barriers in society, rather than by the nature of their impairment.
17. Accordingly, Croatia was not specifically included in this study, as it only joined the EU in July 2013, although it is referred to if included in a relevant report.
18. European Foundation Centre (EFC), *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities VC/2008/1214 – Final Report*, 2010, page 33. See: [http://www.efc.be/programmes\\_services/resources/Documents/UN\\_Convention\\_Summary\\_EN.pdf](http://www.efc.be/programmes_services/resources/Documents/UN_Convention_Summary_EN.pdf).
19. Council Decision (EC) 2010/48 of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities OJ L 23/35, Annex II (OJ L 23/55). See: [http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L\\_.2010.023.01.0035.01.ENG](http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv:OJ.L_.2010.023.01.0035.01.ENG).
20. European Foundation Centre (EFC), *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities VC/2008/1214 – Final Report*, 2010.
21. *Ibid*, page 9.
22. Opinion of the European Economic and Social Committee on the Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC (own-initiative opinion), SOC/464, Brussels, 12 December 2012, paragraphs 1.2–1.4.
23. European Parliament Resolution of 27 February 2014 on the situation of fundamental rights in the European Union (2012), paragraph 51. See: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT%20TA%20P7-TA-2014-0173%200%20DOC%20XML%20V0//EN>.
24. See, for example, ENIL–ECCL *Briefing on Structural Funds Investments for People with Disabilities* from 2013, concerning Bulgaria, Hungary, Latvia, Lithuania, Romania and Slovakia; available at: <http://www.enil.eu/recommended-readings-2/ENIL-ECCL-briefing-on-structural-funds-investments-for-people-with-disabilities/>.
25. See Open Society Foundations (OSF), *The European Union and the Right to Community Living – Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities*, 2012, available at: <http://www.opensocietyfoundations.org/sites/default/files/europe-community-living-20120507.pdf> and United Nations Office of the High Commissioner for Human Rights, *Getting a Life – Living Independently and Being Included in the Community*, 2012.
26. Opinion of the European Economic and Social Committee on the Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC (own-initiative opinion), SOC/464, Brussels, 12 December 2012, paragraph 2.2.

27. European Foundation Centre (EFC), *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities VC/2008/1214 – Final Report*, 2010, page 10.
28. European Parliament Resolution of 27 February 2014 on the situation of fundamental rights in the European Union (2012), paragraph 50.
29. See [www.wakeupcall.eu/about-us/](http://www.wakeupcall.eu/about-us/).
30. See Common European Guidelines on the Transition from Institutional to Community-based Care, 2012.
31. European Foundation Centre (EFC), *Assessing the impact of European governments' austerity plans on the rights of people with disabilities, European Report*, 2012, page 29. See: [http://www.enil.eu/wp-content/uploads/2012/12/Austerity-European-Report\\_FINAL.pdf](http://www.enil.eu/wp-content/uploads/2012/12/Austerity-European-Report_FINAL.pdf).
32. Mental Health Europe and the Open Society Foundations, *Mapping Exclusion – Institutional and community-based services in the mental health field in Europe*, 2012, page 16. See: [http://www.mhe-sme.org/fileadmin/Position\\_papers/Mapping\\_Exclusion\\_-\\_ind.pdf](http://www.mhe-sme.org/fileadmin/Position_papers/Mapping_Exclusion_-_ind.pdf).
33. The DECLOC Report, page 29.
34. *Ibid*, page 25.
35. *Ibid*, page 11, see also pages 94–95.
36. *Ibid*, page 95.
37. Eurostat is the statistical office of the European Union. Its task is to provide the EU with statistics at European level that enable comparisons between countries and regions. See: <http://epp.eurostat.ec.europa.eu/portal/page/portal/eurostat/home>.
38. Mental Health Europe and the Mental Health Initiative of the Open Society Foundations, *Mapping Exclusion – Institutional and community-based services in the mental health field in Europe*, 2012, page 13.
39. O'Brien, C. (2014) More back-slapping than soul-searching: The European Commission's reflections on the UN Convention on the Rights of Persons with Disabilities. *EU Law Analysis*. Retrieved October, 2014, from <http://eulawanalysis.blogspot.co.uk/2014/06/more-back-slapping-than-soul-searching.html>
40. Opinion of the European Economic and Social Committee on the Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC (own-initiative report), SOC/464, Brussels, 12 December 2012, paragraph 4.7.
41. See: European Parliament, Report on mobility and inclusion of people with disabilities and the European Disability Strategy 2010–2020, 2010/2272(INI), 6 July 2011; available at: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+REPORT+A7-2011-0263+0+DOC+XML+V0//EN>
42. See, for example, parliamentary question by Adam Kosa MEP and Romana Jordan MEP and the answer by Commissioner Reading, 26 September 2013; available at: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-%2f%2fEP%2f%2fTEXT%2bWQ%2bE-2013-010955%2b0%2bDOC%2bXML%2bV0%2f%2fEN&language=EN>.
43. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Portugal from 7–9 May 2012, 10 July 2012, paragraph 27. See: <https://wcd.coe.int/ViewDoc.jsp?id=1959473&Site=&BackColorInternet=B9BDEE&BackColorIntranet=FFCD4F&BackColorLogged=FFC679>.
44. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Spain from 3–7 June 2013, 9 October 2013, paragraphs 50–81. See: <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2389885&SecMode=1&DocId=2077824&Usage=2>.
45. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Romania from 31 March–4 April 2014, 8 July 2014, paragraph 79. See: <https://wcd.coe.int/ViewDoc.jsp?id=2208933&Site=COE>.
46. European Foundation Centre, *Assessing the Impact of European Governments' Austerity Plans on the Rights of People with Disabilities, Key Findings*, October 2012, page 97.
47. *Ibid*, page 54.
48. European Union Agency for Fundamental Rights (FRA), *Choice and control: the right to independent living. Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*, 2012. See: [http://fra.europa.eu/sites/default/files/fra\\_uploads/2129-FRA-2012-choice-and-control\\_EN.pdf](http://fra.europa.eu/sites/default/files/fra_uploads/2129-FRA-2012-choice-and-control_EN.pdf).
49. See, for example, Annex 2 (Selection of reports about institutionalisation of children and adults in countries accessing Structural Funds and IPA) of the *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based care*, 2012.
50. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Romania from 31 March–4 April 2014, 8 July 2014, paragraph 15.
51. See, for example, Mental Health Europe and the Mental Health Initiative of the Open Society Foundations, *Mapping Exclusion – Institutional and community-based services in the mental health field in Europe*, 2012, page 21.
52. Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session (2–13 September 2013), 30 September 2013, paragraphs 36–38. See: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUT%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUT%2fCO%2f1&Lang=en).
53. See Shadow reports for Belgium (2011), Denmark (2013) and Germany (2013) in Annex IV.
54. See the Initial report for Italy in Annex IV.
55. See ANED DOTCOM (the Disability Online Tool for the Commission) entry for Luxembourg, available at: <http://www.disability-europe.net/content/luxembourg-d1-choice-living-arrangements>.
56. Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Spain, adopted by the Committee at its sixth session (19–23 September 2011), 19 October 2011, paragraph 39. See: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2fCO%2f1&Lang=en).
57. Background note on French persons with disabilities in Belgian institutions for the CRPD Committee, prepared by OHCHR – Regional office for Europe, August 2014.

58. European Union Agency for Fundamental Rights (FRA), *Choice and control: the right to independent living. Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*, 2012, page 11.
59. European Union Fundamental Rights Agency (FRA), *Legal capacity of persons with intellectual disabilities and persons with mental health problems*, 2013. See: <http://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf>.
60. *Ibid*, pages 45–47.
61. See the Shadow report for Austria (2013) in Annex IV.
62. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to the Czech Republic, from 12–15 November 2012, 21 February 2013, paragraph 101. See: <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2324044&SecMode=1&DocId=2037440&Usage=2>.
63. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Denmark, from 19–21 November 2013, 24 March 2014, paragraph 122. See: <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2487451&SecMode=1&DocId=2121972&Usage=2>.
64. Information provided to ENIL–ECCL by partner organisation from Latvia.
65. Information provided to ENIL–ECCL by partner organisation from Lithuania.
66. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Romania from 31 March–4 April 2014, 8 July 2014, paragraph 45.
67. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Slovakia, from 26–27 September 2011, 20 December 2011, paragraph 100. See: <https://wcd.coe.int/ViewDoc.jsp?id=1885987&Site=COE&BackColorInternet=B9BDEE&BackColorIntranet=FFCD4F&BackColorLogged=FFC679>.
68. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Spain from 3–7 June 2013, 9 October 2013, page 2 (Summary).
69. Information provided to ENIL–ECCL by partner organisation from Bulgaria and Latvia.
70. At the end of 2012, 51.6% of the 6,1 thousand people in institutional care were people with mental health problems and 31,5% people with intellectual disabilities. State-owned institutions accommodate up to 500 residents.
71. According to paragraph 88 of the report, as of 2011, almost 60,000 persons with psycho-social disabilities in the Czech Republic live in institutions.
72. See the Council of Europe Commissioner for Human Rights reports on Denmark (paragraph 131) and Spain (paragraph 86).
73. Mental Health Europe and the Open Society Foundations, *Mapping Exclusion – Institutional and community-based services in the mental health field in Europe*, 2012.
74. See the Council of Europe Commissioner for Human Rights reports on the Czech Republic, Romania and Estonia.
75. Committee on the Rights of Persons with Disabilities, concluding observations on the initial period report of Hungary, adopted by the Committee at its eighth session (17–28 September 2012), 22 October 2012. See: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en).
76. See the Concluding observations of the Committee on the Rights of the Child on Austria, Greece, Lithuania and Portugal in Annex IV.
77. Background note on French persons with disabilities in Belgian institutions for the CRPD Committee, prepared by OHCHR – Regional office for Europe, August 2014.
78. New institutions are still being planned and built, while community-based services remain inadequate. See the Shadow report on Austria (2013) in Annex IV.
79. See the Shadow reports on Belgium (2011) and Denmark (2013) in Annex IV.
80. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Estonia from 25–27 March 2013, 20 June 2013. See: <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2308567&SecMode=1&DocId=2023896&Usage=2>.
81. Committee on the Rights of Persons with Disabilities, concluding observations on the initial period report of Hungary, adopted by the Committee at its eighth session (17–28 September 2012), 22 October 2012, paragraph 33.
82. See the Initial report on Italy in Annex IV.
83. Information provided by ENIL–ECCL partner organisation in Lithuania.
84. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Romania from 31 March–4 April 2014, 8 July 2014, paragraphs 26–27.
85. See the Shadow report on Spain (2010), the CRPD Committee Concluding observations (2011) and the Council of Europe Human Rights Commissioner’s Report on Spain (2013, paragraph 56).
86. See paragraph 26 of the Council of Europe Commissioner for Human Rights Report on Romania, referring to a report by the Institute for Public Policy, “Monitoring report on Romania’s readiness to enforce the UN Convention on the Rights of Persons with Disabilities”, December 2013 (page 14); available at: <http://www.ipp.ro/eng/pagini/monitoring-report-on-romania-s-readiness.php>.
87. Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Denmark, 3 October 2014, paragraph 42. See: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fDNK%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fDNK%2fCO%2f1&Lang=en).
88. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Denmark, from 19–21 November 2013, 24 March 2014, paragraph 111.
89. See: [wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2503663&SecMode=1&DocId=2130702&Usage=2](https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2503663&SecMode=1&DocId=2130702&Usage=2).
90. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Austria from 4–6 June 2012, 11 September 2012. See: <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2139565&SecMode=1&DocId=1924052&Usage=2>.

91. See the Shadow reports on Austria (2013) and Belgium (2011) in Annex IV.
92. Information provided by ENIL–ECCL partner organisation in Estonia.
93. See ANED DOTCOM entry for Poland, available at: [http://www.disability-europe.net/dotcom?term%5B%5D=213&term%5B%5D=143&term%5B%5D=164&term%5B%5D=165&term%5B%5D=166&term%5B%5D=167&term%5B%5D=168&term%5B%5D=169&term%5B%5D=170&term%5B%5D=171&view\\_type=matrix](http://www.disability-europe.net/dotcom?term%5B%5D=213&term%5B%5D=143&term%5B%5D=164&term%5B%5D=165&term%5B%5D=166&term%5B%5D=167&term%5B%5D=168&term%5B%5D=169&term%5B%5D=170&term%5B%5D=171&view_type=matrix).
94. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Romania from 31 March–4 April 2014, 8 July 2014.
95. In May 2014, an interinstitutional monitoring group was established to monitor the implementation of the Transition Plan. Information provided by ENIL–ECCL partner organisation in Lithuania.
96. See ANED DOTCOM entry for Cyprus, available at: [http://www.disability-europe.net/dotcom?term%5B%5D=217&term%5B%5D=148&term%5B%5D=149&term%5B%5D=150&term%5B%5D=158&term%5B%5D=164&term%5B%5D=165&view\\_type=detail\\_list](http://www.disability-europe.net/dotcom?term%5B%5D=217&term%5B%5D=148&term%5B%5D=149&term%5B%5D=150&term%5B%5D=158&term%5B%5D=164&term%5B%5D=165&view_type=detail_list).
97. Information provided by ENIL–ECCL partner organisation in the Czech Republic.
98. Committee on the Rights of Persons with Disabilities, concluding observations on the initial period report of Hungary, adopted by the Committee at its eighth session (17–28 September 2012), 22 October 2012.
99. Information provided by ENIL–ECCL partner organisation in Bulgaria.
100. See the Shadow reports on Denmark (2013) and Spain (2010) in Annex IV.
101. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Romania from 31 March – 4 April 2014, 8 July 2014.
102. See paragraph 110 of the report.
103. See page 2 (Summary) of the report.
104. See paragraphs 57–66 of the report.
105. Information provided by ENIL–ECCL partner organisation in Bulgaria.
106. See the Committee on the Rights of the Child Concluding observations for Austria (2012), Cyprus (2012), Finland (2011), Germany (2014), Greece (2012), Italy (2011), Malta (2013), Portugal (2014) and Slovenia (2013) – links to these reports are provided in Annex IV.
107. European Network on Independent Living, *Personal Assistance Services in Europe*, 2013. See: <http://www.enil.eu/wp-content/uploads/2012/06/European-Survey-on-Personal-Assistance-Final.pdf>.
108. See the DECLOC Report (page 3) and the Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, available at: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes>
109. European Parliament Resolution of 14 January 2009 on the situation of fundamental rights in the European Union 2004-2008, 14 January 2009, paragraph 82. See: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT%20TA%20P6-TA-2009-0019%200%20DOC%20XML%20V0//EN>
110. EEG, Revised edition of the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care, 2014, page 12. See: [www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu).
111. See, for example, ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving Transition from Institutional Care to Community Living*, November 2013.
112. See EEG, Common European Guidelines on the Transition from Institutional to Community-based Care, 2012.
113. European Union, *The control system for Cohesion Policy, How it works in the 2007–2013 budget period*, October 2009, page 5. See: [http://ec.europa.eu/regional\\_policy/sources/docgener/presenta/audit2009/audit2009\\_en.pdf](http://ec.europa.eu/regional_policy/sources/docgener/presenta/audit2009/audit2009_en.pdf).
114. See the European Commission Position papers on the development of Partnership agreements and programmes in 2014–2020, for Bulgaria, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Romania, Slovenia, Slovakia and Croatia.
115. Links to the reports and documents referred to below can be found in Annex IV (Resources).
116. For further information, see page 69 of the Revised edition of the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care, 2014.
117. Until October 2014, the seminars were held in Latvia, Estonia, Romania, Hungary, Croatia, Poland, Bulgaria, the Czech Republic, Slovakia, Slovenia and Lithuania.
118. Available at: [www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu).
119. Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, page 21.
120. Regulation (EU) No 1304/2013 of the European Parliament and of the Council of 17 December 2013 on the European Social Fund and repealing Council Regulation (EC) No 1081/2006, Preamble, Recital 19; available at: <http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32013R1304&from=EN>.
121. See, for example, the Open Society Foundations (OSF), *The European Union and the Right to Community Living – Structural Funds and the European Union’s Obligations under the Convention on the Rights of Persons with Disabilities*, 2012.
122. Public Policy and Management Institute, *Study on the Translation of Article 16 of the Regulation (EC) No 1083/2006 on the promotion of gender equality, non-discrimination and accessibility for disabled persons, into Cohesion policy programmes 2007-2013 co-financed by the ERDF and the Cohesion Fund, Final report*, 15 September 2009. See: [http://ec.europa.eu/regional\\_policy/sources/docgener/evaluation/pdf/eval2007/art16\\_finalrep\\_en.pdf](http://ec.europa.eu/regional_policy/sources/docgener/evaluation/pdf/eval2007/art16_finalrep_en.pdf).
123. See, for example, Annex 2 (Selection of reports about institutionalisation of children and adults in countries accessing Structural Funds and IPA) of the *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based care*, 2012.
124. See the Shadow report for Austria (2013 in Annex IV and Mental Disability Advocacy Centre (MDAC), *Cage beds and coercion in Czech psychiatric institutions*, 2014; available at: [http://www.mdac.info/sites/mdac.info/files/cagebed\\_web\\_en\\_20140624\\_0.pdf](http://www.mdac.info/sites/mdac.info/files/cagebed_web_en_20140624_0.pdf).

125. See, for example, *Transforming care: A national response to Winterbourne View Hospital: Department of Health Review Final Report*, December 2012; available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf).
126. See MDAC website, at: <http://mdac.info/en/content/european-commission-funding-disability-segregation-and-abuse-breaches-international-law>.
127. A similar point was made by the CRPD Committee in relation to Hungary. See the Concluding observations of the CRPD Committee on Hungary, paragraph 33.
128. This is based on the figures set out in ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, pages 11–12.
129. Personal communication.
130. ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, pages 9–10.
131. *Ibid*, page 10.
132. Information provided by ENIL–ECCL partner organisation in Bulgaria.
133. ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, page 9.
134. *Ibid*, page 14.
135. See: [http://ec.europa.eu/regional\\_policy/what/future/program/index\\_en.cfm](http://ec.europa.eu/regional_policy/what/future/program/index_en.cfm).
136. See EEG, Revised edition of the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care, 2014, page 22.
137. For example, concerns about the capacity of a de-institutionalisation strategy to support independent living have been raised by the ENIL–ECCL partners in relation to the Czech Republic and Bulgaria, and by the CRPD Committee in relation to Hungary.
138. See EEG, Common European Guidelines on the Transition from Institutional to Community-based Care, 2012.
139. ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, page 19.
140. Information provided by ENIL–ECCL partner organisation in the Czech Republic.
141. Report by Nils Muižnieks, Council of Europe Commissioner for Human Rights, following his visit to Romania from 31 March–4 April 2014, 8 July 2014, paragraph 58.
142. *Ibid*, paragraph 121.
143. ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, page 13.
144. Commission Delegated Regulation (EU) No .../.. of 7.1.2014 on the European code of conduct on partnership in the framework of the European Structural and Investment Funds; available at: [http://ec.europa.eu/regional\\_policy/what/future/pdf/preparation/da\\_code\\_conduct\\_en.pdf](http://ec.europa.eu/regional_policy/what/future/pdf/preparation/da_code_conduct_en.pdf).
145. ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, page 15–16. Problems with the lack of engagement with NGOs were also highlighted in the ECCL’s Wasted Lives Report, 2010, pages 35–36.
146. Open Society Foundations, *The European Union and the Right to Community living*, 2012, page 70. See: <http://www.opensocietyfoundations.org/sites/default/files/europe-community-living-20120507.pdf>.
147. See: <http://www.ombudsman.europa.eu/en/press/release.faces/en/54420/html.bookmark>.
148. European Coalition for Community Living, *Wasted Time, Wasted Money, Wasted Lives – A Wasted Opportunity?*, 2010.
149. This was announced on 10 September 2014 as part of the new European Commission, led by President Jean-Claude Juncker. See: [http://europa.eu/rapid/press-release\\_IP-14-984\\_en.htm](http://europa.eu/rapid/press-release_IP-14-984_en.htm)
150. See ENIL Fact sheet on Personal Assistance; available at: [http://www.enil.eu/wp-content/uploads/2014/05/FAQ\\_Personal\\_Assistance.pdf](http://www.enil.eu/wp-content/uploads/2014/05/FAQ_Personal_Assistance.pdf). The other ENIL quotes in this section are from this factsheet.
151. Townsley, R. et al, *The Implementation of Policies Supporting Independent Living for Disabled People in Europe: Synthesis Report*, ANED, 2010, page 7. See: <http://www.disability-europe.net/content/aned/media/ANED-Task%20%20Independent%20Living%20Synthesis%20Report%2014.01.10.pdf>.
152. EEG, *Common European Guidelines on the Transition from Institutional to Community-based Care*, 2012, page 88.
153. Waddington, L., *Disability benefits and entitlements in European countries: Mutual recognition and exportability of benefits, A synthesis of evidence provided by ANED country reports and additional sources report*, ANED, 2010, page 37. See: <http://www.disability-europe.net/theme/disability-benefits/reporting-free-movement-disability-benefits>.
154. *Ibid*, pages 132–143.
155. See: [http://ec.europa.eu/europe2020/making-it-happen/country-specific-recommendations/index\\_en.htm](http://ec.europa.eu/europe2020/making-it-happen/country-specific-recommendations/index_en.htm).
156. See: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:EN:PDF>.
157. EEG, *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care*, 2012, page 11.
158. See: [http://ec.europa.eu/europe2020/making-it-happen/index\\_en.htm](http://ec.europa.eu/europe2020/making-it-happen/index_en.htm).
159. COM(2013) 83 final, page 16.
160. C(2013) 778 final, point 2.2.
161. See: [http://ec.europa.eu/regional\\_policy/what/future/program/index\\_en.cfm](http://ec.europa.eu/regional_policy/what/future/program/index_en.cfm).
162. These are available at <http://fra.europa.eu/en/publications-and-resources/publications>.

163. See: <http://www.ombudsman.europa.eu/en/press/release.faces/en/54420/html.bookmark>.
164. For a detailed discussion on this issue, see Waddington, L. (2011). The European Union and the Rights of Persons with Disabilities: A Story of Exclusive and Shared Competences. *Maastricht Journal of European and Comparative Law*, 2011/4. Available at: [http://www.maastrichtjournal.eu/table\\_of\\_content.aspx?sy=2011&pn=4](http://www.maastrichtjournal.eu/table_of_content.aspx?sy=2011&pn=4).
165. European Foundation Centre (EFC), *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities VC/2008/1214 – Final Report*, 2010.
166. See EFC report *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities*, pages 33–34. It explains: “once the EU moves to legislate in a certain field, Member States cannot enact autonomously new legislation within that field. In the exercise of these competences, both the principles of subsidiarity and proportionality have to be respected”. It should be noted that those Member States that have only signed the CRPD would, given the EU accession to the CRPD, be required to comply with the CRPD so far as the provisions impact upon EU law.
167. See Article 6 of the Treaty of the Functioning of the European Union (TFEU).
168. Council Decision (EC) 2010/48 of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities OJ L 23/35, Annex II (OJ L 23/55). See also the Code of Conduct between the Council, the Member States and the Commission setting out internal arrangements for the implementation by and representation of the European Union relating to the United Nations Convention on the Rights of Persons with Disabilities (2010/C 340/08).
169. Annex II, L 23/55; the sentence continues “...and the Community will complete or amend this Declaration, if necessary, in accordance with Article 44(1) of the Convention”.
170. Waddington, L. (2011). The European Union and the Rights of Persons with Disabilities: A Story of Exclusive and Shared Competences. *Maastricht Journal of European and Comparative Law*, 2011/4, page 438. The lack of clarity on this issue is highlighted by other commentators; see, for example: De Burca, G. (2010). The EU in the negotiation of the UN Disability Convention. *European Law Review*, 35, No. 2, 2010 (available at: [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1525611](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1525611)) and Reiss, J. (2014). Innovative Governance in a Federal Europe: Implementing the Convention on the Rights of Persons with Disabilities. *European Law Journal*, Vol. 20, No. 1, January 2014, 107, 114.
171. *Ibid*, page 441. Referring to paragraph 2, Annex II of the Council Decision which states that the EU “has exclusive competence to enter into this Convention in respect of those matters only to the extent that provisions of the Convention or legal instruments adopted in implementation thereof affect common rules previously established by the European Community”.
172. *Ibid*, page 445.
173. *Ibid*, page 443.
174. Independent Living derives from the Independent Living movement that started in the late 1960s in Berkeley, California as a grassroots movement.





## 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 and is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform.

## About the European Coalition for Community Living

The European Coalition for Community Living (ECCL) is an initiative working towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation. ECCL's vision is of a society in which people with disabilities live as equal citizens, with full respect for their human rights. They must have real choices regarding where and with whom to live, choices in their daily lives and real opportunities to be independent and to actively participate in their communities. Since January 2008, ECCL has been a part of the European Network on Independent Living (ENIL).

ENIL–ECCL is a member of the European Expert Group on the Transition from Institutional to Community-based Care.

## Contact us

### Ines Bulic

Coordinator of the European Coalition for Community Living  
European Network on Independent Living  
E-mail: [coordinator@community-living.info](mailto:coordinator@community-living.info)

### European Network on Independent Living

Ground Floor, Chase House  
City Junction Business Park  
Northern Cross, Malahide Road  
Dublin 17, Ireland

Website: [www.enil.eu](http://www.enil.eu)

**The ENIL–ECCL Shadow report on the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union “Realising the Right to Independent Living: Is the European Union Competent to Meet the Challenges?” seeks to provide the Committee on the Rights of Persons with Disabilities with information that will be of assistance when assessing the extent to which the EU has complied with its obligations under Article 19 (Living independently and being included in the community). The report focuses on two specific areas: the use of European Structural and Investment Funds to promote independent living and the promotion of personal assistance as an essential element of independent living.**

“Unfortunately, Europe still has a long way to go even to eradicate the most obvious violations of this right; that is, the segregation of persons with disabilities in large institutions. The human rights violations such institutions engender are well documented, including in the case-law of the European Court of Human Rights and the reports of the Council of Europe anti-torture Committee (CPT), yet they continue to blight the European landscape. There are still European countries refurbishing existing institutions or even building new ones – sometimes, shamefully, with EU structural funds.”

—Mr Nils Muižnieks,  
Council of Europe Commissioner for Human Rights

“It is key for the credibility of the European Union that, wherever EU money is spent, fundamental rights are respected. In many cases, these funds are supposed to help the most vulnerable members of society. But if, for example, there are complaints that EU money is used to “institutionalise” persons with disabilities instead of helping to integrate them, the Commission clearly needs to ensure the matter is investigated and corrective action taken if needed.”

—Ms Emily O’Reilly, European Ombudsman