



# Working Together to Close the Gap Between **RIGHTS** and **REALITY**

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A report on the action needed to ensure that European Structural and Investment Funds promote, not hinder, the transition from institutional care to community living

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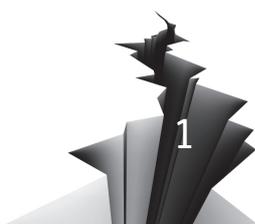
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# Executive Summary

This report focuses on the continued and pressing need for action to be taken to enable people with disabilities to live and participate in the community (“the right to community living”) and the crucial role of European Structural and Investment Funds (ESIFs) in achieving this objective.

In addition to highlighting the importance of ESIFs in the work to realise community living for people with disabilities, the report proposes a series of questions to assist in the evaluation of Member States’ Operational Programmes (the documents that set out the broad framework of the activities to be funded by ESIFs). The purpose of these questions is to assist in identifying areas in which there is a risk that ESIFs will hinder, rather than promote, the right to community living and thus enable prompt and effective action to be taken to address these concerns, thereby avoiding a repeat of the problems with the use of ESIFs that arose in the past. Of particular concern is to ensure that ESIFs are not used to fund projects that maintain systems of institutionalised care, or otherwise fund projects that perpetuate the social exclusion of people with disabilities.

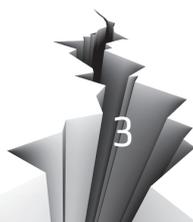
Accordingly, this report is intended to be of use to all those involved in this area of work, in particular those responsible for the planning, implementation, monitoring and evaluation of projects funded by ESIFs as part of the “measures for the shift from institutional to community based care”.

## The need for action to promote Community Living

That there is a need for action is emphasised by the Committee on the Rights of Persons with Disabilities (CRPD Committee) when considering the steps the EU should take to ensure its compliance with Article 19 (Living independently and being included in the community) of the Convention on the Rights of Persons with Disabilities (CRPD).<sup>1</sup> The CRPD Committee raised concerns about the use of ESIFs, stating that persons with disabilities, “especially

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1. Article 19 provides that all persons with disabilities, regardless of the type or degree of the impairment or the level of support necessary have the right to “live in the community, with choices equal to others”.



persons with intellectual and/or psychosocial disabilities still live in institutions rather than in local communities”. It noted that ESIFs continue to be “used for maintenance of residential institutions rather than for development of support services for persons with disabilities in local communities”. The CRPD Committee recommended that the EU:

*“...develop an approach to guide and foster deinstitutionalisation, to strengthen the monitoring of the use of ESI Funds – to ensure they are being used strictly for the development of support services for persons with disabilities in local communities and not the re-development or expansion of institutions. It further recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.”<sup>2</sup>*

This recommendation reflects the concern that despite the policies of the EU and Member States that emphasise the importance of promoting the social inclusion of people with disabilities, in many countries institutional care remains the predominant form of care and progress towards alternatives to institutionalisation has been slow. This is especially true for Central and Eastern Europe and the Baltic countries (which became EU members in 2004), which have a strong legacy of institutional care and very few community-based services in place.

## Identifying key areas of action to achieve Community Living

ESIFs can help to address the lack of community-based services and the institutionalisation of people with disabilities if invested in initiatives that seek to develop community-based alternatives to institutionalisation and promote the social inclusion of people with disabilities. Accordingly, the report notes that there are five key areas that must be addressed if Member States are to achieve the transition from their current systems of institutional care to the provision of services and supports that enable community living. These key areas are based on the common themes arising from reports and guidance concerning the right to community living. They also reflect EU law and policy and the commitments made by States when ratifying the CRPD. Nonetheless, ENIL–ECCL have identified the following concerns in each of these five key points for community living:

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2. Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1 (Advance Unedited Version) 4 September 2015, paras 50–51. The CRPD Committee’s Concluding observations are available on the website of the UN OHCHR – Sessions for CRPD – Convention on the Rights of Persons with Disabilities available at: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5) (accessed 02/03/2016) (CRPD Concluding Observations).

**1. Strategic Vision for the Transition from Institutional Care to Community Living**

**CONCERN:** There is a lack of strategic vision. Despite the crucial importance of developing strategies for the transition from institutional care to community living, not all Member States have such strategies in place.

**2. Prohibition of investments in institutional care**

**CONCERN:** Proposed measures indicate planned investments in institutional care rather than seeking to eliminate institutional care.

**3. Assessment of the situation**

**CONCERN:** There is little analysis by Member States of the situation of people with disabilities, and therefore unclear whether there is an understanding of the gap between the vision of community living and reality.

**4. Range of community-based services that promote social inclusion**

**CONCERN:** There is a lack of clarity on the planned range of services, with insufficient attention given to promoting social inclusion.

**5. Participation of civil society – putting the partnership principle into practice**

**CONCERN:** Concerted action will be required to encourage the participation of civil society.

Given such concerns, the following questions have been developed to assist in identifying potential problems with the planning and implementation of the activities proposed by Member States' Operational Programmes (OPs). The questions seek to highlight the core issues that must be addressed to ensure that the measures for the transition from institutional care to community based services support the right to community living. For ease of reference, the questions are ordered under the same headings as the five key action points and areas of concern discussed above.

## Action needed to ensure ESIFs promote, not hinder, the realisation of the right to Community Living: proposed questions to assist in identifying potential problems

### 1. Strategic Vision for the Transition from Institutional Care to Community Living

**Are the measures for transition from institutional to community-based care underpinned by a strategy for the closure of institutions and development of alternative community-based services that support community living?**

- Q.1 Is there a strategy for the closure of institutions and promotion of community living in place?
- Q.2 What are the key elements of the deinstitutionalisation strategy?
- Q.3 Does the Operational Programme recognise the differing needs and interests of the different groups of people resident in institutional care?
- Q.4 To what extent does the Operational Programme cover measures for the *transition from institutional care to community-based services*?

### 2. Prohibition of investments in institutional care

**Are there any concerns that the proposed activities include investments in institutional care?**

- Q.5 Is there any indication that the Member State intends to maintain residential institutions as part of their system of care?
- Q.6 Are “intermediate” facilities proposed for individuals who are currently resident in institutions?
- Q.7 Is there any indication that investments in institutions may be made under other investment priorities, for example supporting energy efficiency?

### 3. Assessment of the situation – Identifying the gap between the vision and reality

**Do the reasons for the investment priorities and proposed activities reflect the need to eliminate the use of institutional care and take action to address the current barriers to community living?**

- Q.8 What information is provided about people with disabilities, children and other groups resident in institutional care?
- Q.9 What reasons are given for introducing the measures for transition from institutional care to community-based services?

#### 4. Range of community-based services that promote social inclusion – clarity of purpose to promote community living

**Do the proposed actions support community living, in particular promote social inclusion and avoid the replication of institutional care?**

- Q.10 Are there any concerns that the proposed services are likely to replicate institutional care?
- Q.11 Is there clarity on what services are to be provided?
- Q.12 Do the services support social inclusion?
- Q.13 How is progress towards achieving the transition from institutional care to community-based services that support community living measured?

#### 5. Participation of civil society – putting the partnership principle into practice

**To what extent are people with disabilities and other stakeholders involved in the planning and implementation of strategies for the transition from institutional care to community-based services?<sup>3</sup>**

- Q.14 Information about user involvement: Is it clear how the proposed action will meaningfully involve users of services and families, where relevant, in the design of the service funded, in line with the partnership principle?
- Q.15 Monitoring and evaluation: Is it clear how users of services, and their representative organisations and families, where relevant, will be meaningfully involved in monitoring and evaluation of the services funded?

## Conclusion

Given the crucial role of ESIFs in developing community-based alternatives to institutional care that promote community living, it is important that Member States and the European Commission work together to realise the vision for community living. This requires a shared understanding of what needs to be achieved, why this is necessary and what needs to be done to realise this vision. While the specific challenges to be addressed and necessary reforms (such as health and social care structures, legal and financial regulations) will vary between Member States, they will all need to establish clear strategies and action plans for the shift away from institutional care to the provision of community-based services that promote the social inclusion of people with disabilities. The European Commission can assist

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3. Questions 14 and 15 are based on the checklist for Managing Authorities and Monitoring Committees on the selection of projects in *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based care*, 2012 (the EEG Toolkit) pages 44–45.



Member States in undertaking this work, by providing leadership and guidance on how ESIFs can be most effectively utilised to promote the social inclusion of people with disabilities.

It is hoped that this report and its suggested questions will be of assistance to the European Commission when undertaking its monitoring and evaluation of the implementation of Member States' Operational Programmes – so as to ensure that the activities funded by ESIFs are directed towards realising community living. It is vital that in this EU programming period, Member States, the European Commission and civil society work together to ensure that ESIFs promote, not hinder, the work to realise the right to community living: to close the gap between rights and reality.

# 1. Introduction

*The Committee recommends that the European Union develop an approach to guide and foster deinstitutionalisation, to strengthen the monitoring of the use of ESI Funds – to ensure they are being used strictly for the development of support services for persons with disabilities in local communities and not the re-development or expansion of institutions. It further recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.<sup>4</sup> (Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of the European Union, September 2015)*

This report focuses on the continued and pressing need for action to be taken to enable people with disabilities to live and participate in the community and how European Structural and Investment Funds (ESIFs) can be used to achieve this objective. That there is a need for action is emphasised by the above recommendation of the Committee on the Rights of Persons with Disabilities (CRPD Committee), on the steps that the EU should take to ensure its compliance with Article 19 (Living independently and being included in the community) of the Convention on the Rights of Persons with Disabilities (CRPD).

In addition to explaining why ESIFs have such an important role in achieving the goal of enabling people with disabilities to live and participate in the community, this report is concerned with identifying areas in which there is a risk that ESIFs will hinder, rather than promote, the right to community living under Article 19 CRPD. It therefore **sets out a series of questions to assist in the evaluation of Member States' Operational Programmes** (referred to as "OPs", these are documents that set out the broad framework of the activities to be funded by ESIFs). The questions focus on five key areas (the adoption of a strategic vision, prohibition of investments in institutional care, proposed measures to be based on a country/regional assessment of the situation, the development of a range of community-

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4. Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1 (Advance Unedited Version) 4 September 2015, paras 50–51. The CRPD Committee's Concluding observations are available on the website of the UN OHCHR – Sessions for CRPD – Convention on the Rights of Persons with Disabilities available at: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5) (accessed 02/03/2016) (CRPD Concluding Observations).

based services that promote social inclusion and facilitating the participation of civil society). Each of these five areas must be addressed if Member States are to achieve the transition from their current systems of institutional care to the provision of services and supports that enable community living. Therefore, the purpose of the questions is to assist in the identification of potential problems with the use of ESIFs so that prompt and effective action can be taken to address these concerns and by doing so, avoid a repeat of the problems with the use of ESIFs that arose in the past. Of particular concern is to ensure that ESIFs are not used to fund projects that maintain systems of institutionalised care, or otherwise fund projects that perpetuate the social exclusion of people with disabilities.

Accordingly, this report is intended to be of use to all those involved in this area of work, in particular those responsible for the planning, implementation, monitoring and evaluation of projects funded by ESIFs as part of the “measures for the shift from institutional to community based care”. This includes desk officers at the European Commission, especially those who are new to the issue of deinstitutionalisation, as well as members of the Managing Authorities and Monitoring Committees. In addition, it is hoped that this report will be of use to civil society groups, including organisations of people with disabilities, in particular those organisations who have not previously worked on matters to do with EU funding, but are interested in doing so for the current programming period (2014–2020).

## ESIFs: crucial role in promoting community living and eliminating institutional care

The development of community-based alternatives to the current and widespread institutionalisation of people with disabilities in many parts of the European Union (EU) is of crucial importance. Although policies of the EU and Member States highlight the need for action to ensure the social inclusion of people with disabilities, progress towards alternatives to institutionalisation has been slow and 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), which have a strong legacy of institutional care and very few community-based services in place.

ESIFs can help to address the lack of community-based services and the institutionalisation of people with disabilities. They offer a significant resource to support a range of initiatives that can facilitate the development of community-based alternatives to institutionalisation and other services and supports that promote the social inclusion of people with disabilities. In other words, ESIFs have a crucial role in promoting “community living” for all people with disabilities.

## ESIFs, community living and the Convention on the Rights of Persons with Disabilities

The imperative to promote community living and the corresponding need to develop community-based alternatives to institutional care is underpinned by the CRPD. The EU and all of the Member States from Central and Eastern Europe and the Baltic countries have ratified this international human rights treaty and have therefore committed to ensuring that people with disabilities can exercise the rights set out under the CRPD. This includes the rights under Article 19 CRPD (living independently and being included in the community) – see the box below – which provides that all persons with disabilities, regardless of the type or degree of the impairment or the level of support necessary have the right to “live in the community, with choices equal to others”. It articulates a clear vision for the future – that people with disabilities can live in the community as equal citizens. It also makes clear that all people with disabilities have a right to do so.

Accordingly, this report refers to Article 19 as “the right to community living” or “the right to independent living” (these terms are used interchangeably).

### 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.

That the EU has a crucial role in the work to promote the right to community living was made clear by the CRPD Committee, the body responsible for monitoring States' compliance with the CRPD. In its concluding observations on the EU's progress in implementing the

CRPD, the CRPD Committee raised concerns about the use of ESIFs, stating that persons with disabilities, “especially persons with intellectual and/or psychosocial disabilities still live in institutions rather than in local communities”. It noted that ESIFs continue to be “used for maintenance of residential institutions rather than for development of support services for persons with disabilities in local communities”. As noted at the beginning of this report, the CRPD Committee made the following recommendation:

*The Committee recommends that the European Union develop an approach to guide and foster deinstitutionalisation, to strengthen the monitoring of the use of ESI Funds – to ensure they are being used strictly for the development of support services for persons with disabilities in local communities and not the re-development or expansion of institutions. It further recommends that the European Union suspend, withdraw and recover payments if the obligation to respect fundamental rights is breached.<sup>5</sup>*

Concerns about the use of ESIFs have also been raised by the EU Ombudsman, who noted in her own-initiative inquiry, that the EU “should not allow itself to finance, with EU money, actions which are not in line with the highest values of the Union”.<sup>6</sup> The EU Ombudsman’s decision set out a number of “guidelines for improvement”, which although directed to compliance with the EU Charter of Fundamental Rights, are also applicable to the CRPD.<sup>7</sup> For example, the EU Ombudsman recommends that when assessing the success of programmes and actions financed by ESIFs, the EU should include “consideration of how they have contributed to the promotion of respect for the fundamental rights enshrined in the Charter”. In addition, she recommends that the EU apply “strictly and consistently its sanctioning prerogatives, when applicable *ex ante* conditionalities (preconditions) are not complied with within the deadlines” (the relevance of *ex ante* conditionalities are discussed below).

ENIL–ECCL hope that this report will assist the EU in its work to respond to the concerns raised by the CRPD Committee and the EU Ombudsman. The objective that all must work towards is to ensure that ESIFs provide effective support to achieving the transition from institutional care to community living.

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5. Concluding observations on the initial report of the European Union, CRPD/C/EU/CO/1 (Advance Unedited Version) 4 September 2015, paras 50–51. (CRPD Concluding Observations n.1).
  6. *Decision of the European Ombudsman closing her own-initiative inquiry OI/8/2014/AN concerning the European Commission*, (European Ombudsman (2015) available at: <http://www.ombudsman.europa.eu/et/cases/decision.faces/en/59836/html.bookmark> (accessed 02/03/16).
  7. Given that the CRPD has been ratified by the EU and the majority of EU Member States (all Member States are signatories to the CRPD).

## Overview of the report

The information provided in this report draws upon a range of publications that have highlighted concerns about the use of ESIFs (see Annex A), as well as reports issued by the CRPD Committee.<sup>8</sup> In addition, ENIL–ECCL’s general observations on the Operational Programmes (OPs) concerning the European Social Fund (ESF) and European Regional Development Fund (ERDF) of Bulgaria, Estonia, Hungary, Latvia, Lithuania and Slovakia for the period 2014–2020, are included in chapter 4. Such observations are included to illustrate areas that are likely to require further investigation to ensure that ESIFs support activities that promote the development of inclusive community-based services, rather than the continuation of institutional care.<sup>9</sup> The areas considered are as follows:

- **Vision: The Right to Community Living (chapter 2)** – considers the meaning and scope of Article 19 CRPD and why the institutionalisation of people with disabilities is contrary to the CRPD.
- **Realising the Vision of Community Living (chapter 3)** – considers the importance of ESIFs in the deinstitutionalisation process and the realisation of the goal of community living.
- **Operational Programmes and Onward: Action Needed to Ensure that ESIFs Promote, not Hinder, the Realisation of the Right to Community Living (chapter 4)** – considers the potential problems that may lead to ESIFs being invested in institutional care or in services that do not support community living and suggests a series of questions which may help to identify and address these concerns.
- **Conclusion (chapter 5)**

While the discussions below focus on issues concerning people with disabilities, many of the issues raised will also be relevant to other groups at risk of institutionalisation, such as children, older people and homeless people.

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8. CRPD Concluding observations n.1

9. Comments on the OPs are of a general nature only, in order to provide examples of the concerns raised, and where relevant highlight positive examples.

## Explanation of definitions

A recurring difficulty in the use of ESIFs to promote the transition from institutional care to community living is that the key terms are unclear or misunderstood. For this reason an explanation of some of the core terms used in this report is set out below:

- The terms “community living” and “independent living” are used to encapsulate the vision articulated in Article 19 CRPD: **that people with disabilities are able to live in their local communities as equal citizens with the support that they need to participate in every-day life.** This will include, for example, living in their own homes or with their families, going to work, going to school and taking part in community activities. It also means that people with disabilities have the same choice, control and freedom as other citizens.<sup>10</sup> Annex B provides further information on ENIL’s key definitions on Independent Living.
- The terms “institution” and “institutional care” refer 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>11</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” or “family-type 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,<sup>12</sup> or they remain subject to a rigid daily regime designed around the convenience of staff, rather than their needs, wishes and aspirations.
- The term “deinstitutionalisation” includes both the closure of institutions and the development of community-based services (see description below) that promote social inclusion and prevent institutionalisation. It should be noted that this term is sometimes (incorrectly) understood as referring only to the closure of institutions.

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10. The term ‘community living’ and its contrast with life in residential institutions is discussed in chapter 2, 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>

11. See also the Common European Guidelines on the Transition from Institutional to Community-based Care, 2012, page 25, available at: <http://deinstitutionalisationguide.eu>

12. See for example the CRPD Committee’s concluding observations for Denmark; the Committee stating that it was “concerned about the recent surveys indicating the limited possibility for persons with disabilities to freely choose where to live” (CRPD/C/DNK/CO/1 para. 42) CRPD Concluding observations n.1.

However, as discussed below, to be compliant with the right to community living under Article 19 CRPD, as well as EU law and policy, strategies for “deinstitutionalisation” must encompass the development of community-based alternatives, which promote independent living, including support services and accessible mainstream services. Annex B provides a more detailed definition of this term.

- The term “community-based services” includes support services for disabled people as well as mainstream services that should be accessible to everyone. See Annex B for a more detailed definition of this term.



## 2. Vision: The Right to Community Living

*Article 19 CRPD makes clear that all people with disabilities have the right to live and participate in the community as equal citizens. In contrast, in many parts of the European Union, people with disabilities are living in institutions, excluding them from society and placing them at risk of other serious human rights violations. The CRPD therefore requires EU Member States in which the institutionalisation of people with disabilities is prevalent to take concrete action to ensure the shift from institutional care to the provision of a range of community-based services that promote community living.*<sup>13</sup>

As noted above, Article 19 CRPD provides a clear vision for the future – that people with disabilities can live in the community as equal citizens. It also sets out what action States should take in order to realise this vision of community living. This chapter explains why, in countries where the institutionalisation of people with disabilities is still prevalent, the measures taken by governments to realise the rights under Article 19 must include the development of community-based services that promote social inclusion, provide alternatives to institutional care and prevent institutionalisation.

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13. For detailed discussions on Article 19 and its relevance to the institutionalisation see: 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, (authors Camilla Parker and Luke Clements) available at: [www.opensocietyfoundations.org/reports/european-union-and-right-community-living](http://www.opensocietyfoundations.org/reports/european-union-and-right-community-living) and United Nations Office of the High Commissioner for Human Rights, *Getting a Life – Living Independently and Being Included in the Community*, 2012 (authors Gerard Quinn and Suzanne Doyle) (Getting a Life). 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, <https://wcd.coe.int/ViewDoc.jsp?id=1917847> Open Society Foundations *Community, not Confinement The Role of the European Union in Promoting and Protecting the Right of People with Disabilities to Live in the Community* (author Dr. Israel Butler) (2015) (Community not Confinement) available at [www.opensocietyfoundations.org/reports/community-not-confinement](http://www.opensocietyfoundations.org/reports/community-not-confinement)

## The Importance of Article 19 CRPD

Article 19 is of key importance because it sets out what steps States are required to take to ensure that people with disabilities are able to live in the community as equal citizens.

Although it has links to other human rights, such as Article 26 of the EU Charter of Fundamental Freedoms ('Integration of people with disabilities'), Article 19 CRPD stands out because it is the first time that an explicit right to live independently is set out in a human rights treaty. It requires States to take concerted action to ensure that people with disabilities are able to exercise their right to community living. States must recognise the right of people with disabilities 'to live in the community, with choices equal to others' and take steps to facilitate their 'full enjoyment of this right' and 'their full inclusion and participation in the community'.

In particular States are required to take action in three main areas, by ensuring that people with disabilities have:

- A choice on where and with whom to live, on an equal basis with others "and are not obliged to live in particular living arrangements",
- Access to a range of community support services, and
- Equal access to mainstream services, which are responsive to their needs.

Article 19, together with the themes of inclusion and participation, which are integral to the CRPD, makes clear that States should take action to ensure that people with disabilities receive the support they need to participate in society as equal citizens. Thus, to be compliant with the CRPD, the purpose of community-based services must be to provide the support that people with disabilities need to achieve their aspirations and engage in community life. Indeed, the right to live independently and be included in the community has been described as 'the key portal to living a fuller life', being 'much celebrated since it is the one that delivers on "choice" where it matters most to people – where to live and with whom'.<sup>14</sup>

Accordingly, while 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 CRPD. Crucially, residential care services must form part of a range of options that support community living – residential care should never be the only option.

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14. Quinn, G. & Doyle, S. (2012). *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, pages 69–94. See: [http://www.equalrightstrust.org/ertdocumentbank/err9\\_quinn\\_doyle.pdf](http://www.equalrightstrust.org/ertdocumentbank/err9_quinn_doyle.pdf)

## Article 19 and the Institutionalisation of People with Disabilities

The vision of community living is in stark contrast to the situation of people with disabilities who in parts of the EU, are placed in large, often remote institutions, and have very little contact with the outside world.

Article 19 CRPD requires that people with disabilities are able to choose where and with whom they live. In addition, it requires States to ensure that people with disabilities 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”, as well as equal access to all community services and facilities that are intended for the general population. Placing people with disabilities in institutions, solely on the basis of their disabilities, so that they are prevented from engaging with family or friends or being involved in community life, is in itself a violation of their rights under Article 19 CRPD. This is clear when comparing the vision of community living articulated by Article 19 CRPD to institutional life.

Indeed, the EU’s definition of an “institution”, set out in the *European Commission’s Guidance on Ex ante Conditionalities for the European Structural and Investment Funds (PART II)* illustrates how institutions are in direct conflict with the concept of community living:

*‘An institution is any residential care where:*

- *residents are isolated from the broader community and/or compelled to live together;*
- *residents 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 residents’ individualised needs.’<sup>15</sup>*

Over the past decade, numerous reports have highlighted the severe and wide-ranging human rights abuses that form part of daily life in such institutional settings, such as physical or other abuse perpetrated against residents.<sup>16</sup> Moreover, as the Council of Europe Commissioner for Human Rights, Nils Muižnieks, observes, the very fact of institutionalisation engenders far-reaching and invasive human rights violations:

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15. 13 February 2014, page 259. Available at: [http://ec.europa.eu/regional\\_policy/en/information/legislation/guidance/](http://ec.europa.eu/regional_policy/en/information/legislation/guidance/)

16. See, for example, Annex 3 (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 (the EEG Toolkit). See: [www.deinstitutionalisationguide.eu](http://www.deinstitutionalisationguide.eu)

*'The problem is not only the suffering and inhuman and degrading treatment that persons with disabilities are often subjected to in these institutions, far from the public eye. These are also places where people suffer simply by virtue of having been deprived of any control over their life choices, regardless of the relative comfort of their living arrangements in some cases.*

*I have witnessed first-hand the toxic effects of institutions on their inmates: how they cultivate a feeling of helplessness; how the institution erodes one's confidence in one's ability to make choices; how it deprives people of life experiences and skills needed to build up autonomy and identity.*

*Many who could otherwise function in the community without a great deal of support have become unable or afraid to leave these institutions, because they have known nothing else.'*<sup>17</sup>

Irrespective of any physical or other abuse perpetrated against residents, the segregation of people with disabilities in institutions is a human rights violation. Although Article 19 CRPD does not prohibit institutional care expressly, its continued use is in direct conflict with the rights guaranteed under this right. Indeed, the CRPD Committee considers that "placing in institutions is contrary to Article 19 of the Convention, and leaves persons with disabilities vulnerable to violence and abuse".<sup>18</sup> The CRPD Committee has raised concerns about the high (and in some cases, increasing<sup>19</sup>) numbers of individuals in institutional care,<sup>20</sup> in particular children<sup>21</sup> (and has called for an end to the institutionalisation of children under 3 years of age<sup>22</sup>). In relation to four EU Member States (Belgium, Czech Republic, Denmark and Hungary) the Committee has also raised concern about resources being allocated to institutional care.<sup>23</sup>

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17. *Deinstitutionalisation in the work of the Council of Europe Commissioner for Human Rights* Address by Nils Muižnieks Council of Europe Commissioner for Human Rights: <https://wcd.coe.int/ViewDoc.jsp?id=2242191&Site=CM>

18. Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session (2–13 September 2013) CRPD/C/AUT/CO/1 para 36 (Austria).

19. Austria, Costa Rica, Denmark, Korea) (CRPD Concluding observations n.1).

20. Azerbaijan, China, Germany (CRPD Concluding observations n.1).

21. Azerbaijan, Belgium, China, Costa Rica, Croatia, Czech Republic, Dominican Republic, El Salvador, Mauritius, Ukraine (CRPD Concluding observations n.1).

22. Czech Republic (para 40) (CRPD Concluding observations n.1).

23. (CRPD Concluding observations n.1) .

## Causes of institutionalisation

A common reason for the prevalence of institutionalisation is the lack of community-based services. The paucity of such services also contributes to people with disabilities who are not institutionalised leading “disconnected and lonely lives”.<sup>24</sup> This is why it is of crucial importance that States take action to develop a range of community-based services, which provide an alternative to institutional care, prevent institutionalisation and promote the social inclusion of people with disabilities. The development of community-based services that address the widespread social exclusion of people with disabilities is therefore a significant and necessary step towards realising the rights set out under Article 19 – in other words, to achieve the vision of community living.

The need for such measures is reinforced by Article 4 CRPD which requires States “to take measures to the maximum of its available resources...with a view to achieving full realization of these rights”. This concept of “progressive realisation” recognises that States may not be able to achieve compliance with all rights under the CRPD immediately, but emphasises that doing nothing is not an option. While its purpose and scope has a far wider reach, the rights articulated in Article 19 CRPD require that where the institutionalisation of people with disabilities is still prevalent, States must prioritise the necessary action to remedy the situation.

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24. Getting a Life above (n.11), page 12.



### 3. Realising the Vision of Community Living

- *The key elements towards realising the vision of community living are*
  - a) the adoption of a strategic vision for the transition from institutional care to community living with an effective implementation plan (timeframe and benchmarks/measurable indicators), which covers all groups of people with disabilities;*
  - b) the prohibition of investments that maintain and/or extend institutional care;*
  - c) proposed measures to be based on a country/region based assessment of the situation;*
  - d) a range of community-based services that promote social inclusion and*
  - e) the participation of civil society.*
- *ESIFs have a crucial role in supporting the work to realise the vision of community living.*

#### Community Living, Closure of Institutions and Article 19 CRPD

The CRPD Committee has made clear that in countries where institutionalisation is prevalent, it expects States to take concrete action to develop community-based alternatives and support community living,<sup>25</sup> with the allocation of sufficient resources for independent living in the community.<sup>26</sup> It has highlighted the need for institutional care to be phased

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25. Austria above (n.1), Australia Argentina, Azerbaijan, Belgium Brazil, China, Cook Islands Costa Rica, Denmark Dominican Republic, El Salvador, Gabon, Kenya Korea Mexico, Mongolia, New Zealand, Paraguay, Peru, Qatar, Spain, Sweden Turkmenistan, Ukraine (CRPD Concluding observations n.1).

26. Azerbaijan, Cook Islands, Czech Republic, Germany, Hungary, Kenya, Korea, Spain (CRPD Concluding observations n.1).

out, as well as commenting on the need for deinstitutionalisation plans to be in place and implemented, with clear timeframes and measurable indicators/benchmarks.<sup>27</sup> The Open Society Foundation report, *Community, not Confinement: The Role of the European Union in Promoting and Protecting the Right of People with Disabilities to Live in the Community* summarises the CRPD's comments on the action that EU Member States must take to implement Article 19, as follows:

*...parties must: create a deinstitutionalisation plan (covering all residential institutions including small institutions and foster homes) with a clear timeline (that does not fix the endpoint of deinstitutionalisation excessively far in the future), concrete benchmarks and effective monitoring; formulate and implement a process through which services are made accessible to persons with disabilities (including through the allocation of sufficient resources to support services in local communities); adopt a legal framework that entitles persons with disabilities to adequately funded personal assistance services and guarantees them choice over where and with whom they live.*<sup>28</sup>

The CRPD Committee's recommendations on the action that governments should take to address the institutionalisation of people with disabilities are similar to the measures suggested by civil society organisations, as well as the European Commission. Such measures are considered below (see *Guidance on Transition from Institutional to Community-based Care and the use of ESIFs*).<sup>29</sup>

## Community Living, Closure of Institutions and the European Union

A study supported by the European Commission and published in 2007 (*Deinstitutionalisation and community living – outcomes and costs: report of a European Study – the DECLOC report*) estimated that 1.2 million people with disabilities across the EU were living in institutions. It also noted that “institutional care for disabled people in Europe fell short of

27. See CRPD Committee's concluding observations for Argentina, Australia, Austria, Azerbaijan Brazil, China, Czech Republic Costa Rica, Denmark Dominican Republic, Ecuador, El Salvador, Kenya ('with a timeframe and) Mauritius, Mexico Korea (develop effective strategies) Paraguay Mongolia, Turkmenistan Ukraine (CRPD Concluding observations n.1).

28. *Community not Confinement*, above (n.10) pages 50–51.

29. The European Agency for Fundamental Rights has developed a set of indicators 'to enable the assessment of the fulfilment of Article 19 of the CRPD'. This can be obtained at: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living>

acceptable standards”.<sup>30</sup> As part of the work to strengthen “the vision of new possibilities in the community” the DECLOC report recommended that governments should “Adopt policies in favour of inclusion” and recommended the following three specific areas of work:

- Set out the goal that all disabled people should be included in society and that the help they receive should be based on the principles of respect for all individuals, choice and control over how they live their lives, full participation in society and support to maximise independence.
- Commit to stop building new institutions or new buildings in existing institutions, and to spending the majority of available funds to develop services in the community.
- Specify the overall timetable and plan for transition from institutions to services in the community.

That there is a need for action to address this widespread institutionalisation and social exclusion of people with disabilities is highlighted by the European Commission. Emphasising the link between respect for human rights and the imperative of achieving the shift from a system of institutional care to the provision of community-based services and other support to promote the social inclusion of people with disabilities, the European Commission states:

*‘The shared European values of human dignity, equality and the respect for human rights should guide us as our societies develop structures of social care and support fit for the 21st century. The implementation of adequate reforms of care systems needs to take place in Member States. Following the provisions of the UN Convention on the Rights of Persons with Disabilities (UN CPRD), the UN Convention on the Rights of the Child and the European Convention on Human Rights, Member States and the European Union should implement measures reinforcing the transition from institutional to community-based services. Among the key articles of the UN CPRD relevant for deinstitutionalisation, article 19 lays down the right to an independent living.’<sup>31</sup>*

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30. 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)

31. [http://ec.europa.eu/regional\\_policy/en/policy/themes/social-inclusion/desinstit/](http://ec.europa.eu/regional_policy/en/policy/themes/social-inclusion/desinstit/)

## Community Living, Closure of Institutions and the use of ESIFs

The European Commission stated in the *European Disability Strategy 2010–2020, A Renewed Commitment to a Barrier Free Europe* (“the Disability Strategy”), that it would use ESIFs to promote the “transition from institutional to community-based care” and to raise awareness of the situation of people with disabilities living in residential institutions. It reiterated this commitment in its report to the CRPD Committee.<sup>32</sup>

### *ESIFs role in promoting community living*

ESIFs have an important role in addressing the prevalence of institutionalisation of people with disabilities in many parts of the EU. With the EU’s ratification of the CRPD, ESIF investments must accord with the CRPD and as noted above, compliance with Article 19 CRPD requires the development of community-based services that obviate the need for such institutions. This means that ESIFs cannot be invested in institutional care.<sup>33</sup> Instead, they can be used to:

- Plan and implement the transition from institutional care to a system of community-based services and supports that enable people with disabilities to live and participate in their communities as equal citizens.
- Support the development of new services, including services that prevent institutionalisation and the provision of technical support for reforming legislative and financial frameworks to underpin and support community-based services that promote community living.<sup>34</sup>
- Such projects can include investments in health and social care infrastructure and financing employment initiatives, such as the provision of training of staff working in community-based services or supporting personal assistance schemes.

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32. 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, para 93.

33. This point is discussed in the reports referred to in (n.10) above.

34. See 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>

## ESIFs and Ex ante conditionalities

Largely thanks to the European Commission, the provisions governing the use of ESIFs for the period 2014–2020 include significant and positive reforms, such as a greater emphasis on social inclusion, accessibility, non-discrimination and the introduction of an *ex ante* conditionality on compliance with the CRPD.<sup>35</sup>

Significantly, an *ex ante* conditionality for both the ESF and the ERDF has been introduced for activities under the thematic objective of “Promoting social inclusion, combating poverty and any discrimination”, requiring that “a national strategic policy framework for poverty reduction” is in place. In addition, in cases where such needs are identified, the Member State must include “measures for the shift from institutional to community based care”.<sup>36</sup> The European Commission’s position papers on the development of Member States’ Partnership Agreements identified the need for such measures in twelve Member States, namely: Bulgaria, Croatia, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Romania, Slovenia and Slovakia.<sup>37</sup> Accordingly, this *ex ante* conditionality applies to all of the Member States of CEE and the Baltic countries. **In other words, a prerequisite for their use of ESIFs is that they have in place measures for the shift from institutional to community-based care.**

Guidance on *ex ante* conditionalities issued by the European Commission<sup>38</sup> refers to Member States for which “the shift to community-based care has not yet been completed”, stating that “the *ex ante* conditionality requires that their strategic policy frameworks on poverty reduction include measures to support that shift to community-based services”. The criteria for fulfilment of this condition are that such measures are in place as well as measures “for enabling access to mainstream services in their community (education and training, employment, housing, health, transport, leisure activities) to everyone, regardless the nature of their impairment”. This guidance defines “Measures for the transition from institutional to community based care” as follows:

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35. Regulation (eu) no 1303/2013 of the European Parliament and of the Council of 17 December 2013 laying down common provisions on the European Regional Development Fund, the European Social Fund, the Cohesion Fund, the European Agricultural Fund for Rural Development and the European Maritime and Fisheries Fund and laying down general provisions on the European Regional Development Fund, the European Social Fund, the Cohesion Fund and the European Maritime and Fisheries Fund and repealing Council Regulation (EC) No 1083/2006 (the CPR).
  36. The CPR (n.32), Annex XI Ex Ante Conditionalities, Part I Thematic Ex Ante Conditionalities.
  37. EEG Toolkit above (n.13), page 22.
  38. Guidance on Ex ante Conditionalities for the European Structural and Investment Funds PART II [http://ec.europa.eu/regional\\_policy/sources/docgener/informat/2014/eac\\_guidance\\_esif\\_part2\\_en.pdf](http://ec.europa.eu/regional_policy/sources/docgener/informat/2014/eac_guidance_esif_part2_en.pdf)

*'These measures include the development of services based in the community enabling people to live independently and preventing the need of institutionalisation. In the case of children in alternative care, the provision of family-based or family-like care which include family support should be in place.'*

Further guidance from the European Commission, *Draft Thematic Guidance Fiche for Desk Officers: Transition from Institutional to Community-based Care (Deinstitutionalisation)* ('the Thematic guidance') is discussed below.

## Guidance on ESIFs and the Transition from Institutional to Community-based Care

The European Expert Group on the Transition from Institutional to Community-based Care ("the EEG") and the European Commission have published guidance intended to assist those working to develop community-based alternatives to institutional care and show how ESIFs can be used to achieve this objective.

### *EEG guidance: Guidelines and Toolkit*

The EEG produced the following two publications, with input from a range of individuals and organisations, including the European Commission, which provide guidance on the work required to achieve the transition to from institutional care to community living:

- *Common European Guidelines on the Transition from Institutional to Community-based Care (2012)* ('the EEG guidelines')<sup>39</sup> set out practical advice on how to plan and implement the shift from institutional care to the provision of a range of community-based services that support social inclusion. For example, the guidelines state that services "should enable individual users and families to participate in the community on an equal basis with others". They provides guidance on undertaking an assessment of needs of the population and the available services in the country (chapter 2) and developing a deinstitutionalisation strategy and action plans (chapter 3).
- *Toolkit on the Use of European Funds for the Transition from Institutional to Community-based Care (2012, Revised 2014)* ('the EEG Toolkit') provides guidance on how ESIFs can be used to facilitate the development of community-based alternatives to institutional care. For example, it provides guidance on what should be contained in Partnership

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39. 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*. (EEG Guidelines) Available at: <http://www.deinstitutionalisationguide.eu>

Agreements and Operational Programmes (chapter 2) and the implementation of Operational Programmes so that the projects supported take forward the deinstitutionalisation strategy and action plans for the transition from institutional care to community-based services (chapter 3). Thus, it notes that ESF OPs should include actions such as undertaking individual needs assessments for each person involved in the transition plan and drawing up ‘individual care/support and preparation plans for each child or adult involved in the plans’ and the ERDF could include improving the existing infrastructures for community-based support.<sup>40</sup>

### *EEG guidance: emphasis on a comprehensive strategy for community living*

The EEG Guidelines highlight the importance of developing a strategy for deinstitutionalisation, which it describes as “a political document which provides an overall framework for guiding the reforms in social care and other systems towards the closure of institutions; the development of community-based services; and inclusive mainstream services”. Depending on the country context, the strategy could be developed at a national or regional level. It will ensure that the reform is implemented in a coordinated, holistic and systematic way’.<sup>41</sup> The EEG Toolkit emphasises that ‘it is crucial’ that the actions envisaged by the Member State to promote social inclusion and combat poverty and discrimination ‘support the implementation of a comprehensive national or regional **deinstitutionalisation strategy** and that **actions supported by the ESF and the ERDF are duly integrated and coordinated**’.<sup>42</sup>

### *EEG guidance: emphasis on the importance of the CRPD*

The EEG guidelines highlight the importance of the CRPD to the work to achieve the transition from institutional care to community-based services that support community living. Given its importance to the right to community living, each chapter refers to relevant obligations under the CRPD. The guidelines note that the obligations under Article 19 CRPD cannot be met “if countries continue to place individuals in institutional care”. Furthermore, they suggest that countries and the EU should use the guidelines “as a tool to implement the CRPD”.<sup>43</sup>

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40. EEG Toolkit above (n.13), pages 35–36.

41. EEG Guidelines above (n.36), 64.

42. EEG Toolkit above (n.13), 35.

43. EEG Guidelines above (n.36), 17.

## European Commission guidance

The European Commission's *Draft Thematic Guidance Fiche for Desk Officers: Transition from Institutional to Community-based Care (Deinstitutionalisation)* ('the Thematic guidance')<sup>44</sup> provides a brief guide on what measures could be supported by ESIFs to support relevant policy objectives such as promoting the social inclusion of people with disabilities and achieving the transition from institutional to community-based care. It refers to both the EEG reports, and makes similar points to those highlighted in them, in particular:

- **Strategic vision:** the Thematic guidance suggests that the proposed measures should be “part of a strategic vision on how the transition from institutional to community based care will be implemented in line with the criteria under the proposed ex-ante conditionality for active inclusion”. The thematic guidance states that the proposed measures could include measures in three areas:
  - for preventing the need for institutionalisation,
  - to develop services based in the community, enabling people to live independently, and
  - enabling access to mainstream services, such as employment and housing, ‘to everyone, regardless of the nature of their impairment’.
- **Analysis of the situation and assessed needs required:** the Thematic guidance states that the proposed measures, which can include preventing the need for institutionalisation, developing services to enable people to live independently and to make mainstream services accessible, should be based on such an analysis. The analysis should cover matters such as the needs of population at risk of institutionalisation, resources (e.g. financial) and causes of institutionalisation. (The EEG Toolkit states that the ‘strategic vision...should be based on an assessment of the needs of the population and the available services in the country’.<sup>45</sup>)
- **Focus on promoting social inclusion:** The Thematic guidance states that:
  - the proposed measures ‘should provide evidence on the real needs they envisage to address and a justification of the objectives’
  - the ‘description should inform on how the action will facilitate the social inclusion of the target group’
  - assurance should be provided that any group of individuals will not be excluded from the support because of the type of their impairment (e.g. because of the complexity of their support needs).

44. Version 2 – 27/01/2014.

45. See EEG Toolkit above (n.13), 2.9.

- **Prohibiting the use of ESIFs to invest in institutional care:** the EEG Toolkit states that ESIFs “cannot be used to build or renovate long-stay residential institutions, regardless of size”. The Thematic guidance makes the same point, stating that such activities are excluded. It adds:

*Note that the size of the institution cannot be used in isolation as a criterion to judge whether the supported infrastructure can be considered as community-based service or simply a scaled-down institution. The starting point should be whether it provides a setting allowing for the possibility for independent living, inclusion in the community (including physical proximity of the location) and high-quality care. However, it is clear that the larger the infrastructure the more likely it is that these criteria will not be fulfilled.*

That ESIFs cannot be used to maintain institutional care was also made clear in the EU's report to the CRPD Committee on its progress in implementing the CRPD ('the EU's CRPD report')<sup>46</sup> which states that the 'ERDF should as a basic principle not be used for building new residential institutions or the renovation and modernisation of existing ones'. It added:

*'Targeted investments in existing institutions can be justified 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 [emphasis added].'*<sup>47</sup>

ENIL–ECCL welcome this clarification. Given that the wording in the relevant part of the Thematic guidance is not as clear cut (so may therefore be open to a different interpretation), it is suggested that the guidance is revised to reflect the statement contained in the EU CRPD report.

**Planning measures in different areas:** the Thematic guidance gives examples of measures that can be funded by the ESIFs, which demonstrate the importance of having a holistic approach when developing the measures and ensuring that these are coordinated. For example, it notes that ESF can fund the re-training of staff “especially where there is a shift of model (training institutional care staff to work in new community based services)” and ERDF investments into social housing “which will be available to those leaving institutional care or at risk of being institutionalised”.

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46. 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 (The EU's CRPD report). 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)

47. The EU's CRPD report (n.43) para. 98.

## Taking Action to Achieve Community Living: Key Points

The following common themes can be identified from the comments made by the CRPD Committee on Article 19, the EEG guidelines and the European Commission's Thematic guidance on the need to close institutions and develop inclusive community-based alternatives:

- i. *Adoption of a **strategic vision for the transition from institutional care to community living**.* In addition to the points set out in ii. – vi. below, such strategies should include:
  - clear goals, based on the general principles of the CRPD, including freedom to make one's own choices, independence and full and effective participation in the community;
  - clear timeframe, including a target date for the closure of the institution(s) and a target date for prohibiting admissions to long-stay institutions;
  - a co-ordinated approach to planning and implementing the action plans for the range of areas that need to be addressed (e.g. social care, health, housing and education);
  - recognition of the need to develop clear standards for all community-based services and that such standards need to be developed in close collaboration with representative organisations of people with disabilities and their families; and
  - monitoring and evaluation framework with measurable indicators (including means for evaluating individuals' quality of life).
- ii. *Prohibition of investments that maintain and/or extend **institutional care***
- iii. *Proposed measures based on a country/region based **assessment of the situation***
- iv. *Develop a **range of community-based services that promote social inclusion**: community-based services to focus on the three main areas (enabling people with disabilities to live in the community, preventing the need for institutionalisation, and facilitating people with disabilities' access to mainstream services). The promotion of social inclusion should be a key objective when developing the range of services (this being a core element of community living)*
- v. *Facilitate the **participation of civil society** (in particular people with disabilities and other users of services, as well as non-governmental organisations providing community-based alternatives to institutional care): in the planning and implementation of strategies and action plans for the transition from institutional care to community living.*

The next chapter highlights problems that might arise in relation to these five action points and proposes questions designed to identify such concerns.

## 4. Operational Programmes and Onward: Action Needed to Ensure that ESIFs Promote, Not Hinder, the Realisation of the Right to Community Living

- *ESIFs must be used to positive effect in the current finance period 2014–2020: they can assist Member States in meeting their obligations under Article 19 CRPD by facilitating the necessary reforms in the provision of health and social care and access to mainstream services.*
- *Action must be taken to ensure that ESIFs do not support activities that reinforce the system of institutionalisation.*
- *A range of questions are suggested to assist in assessing whether Member States:*
  - a) have a vision for community living;*
  - b) are prohibiting investments in institutional care and intend to eliminate institutional care;*
  - c) seek to address the identified barriers to community living;*
  - d) propose activities that are based on an assessment of the situation, support community living and avoid the replication of institutional care; and*
  - e) are putting the partnership principle into practice by seeking to involve people with disabilities and other stakeholders in the planning and implementation of strategies for the transition from institutional care to community living.*

A significant concern arising from the previous EU financing period (2007–2013) is that the potential of ESIFs to support the development of community-based services as alternatives to institutional care and promote the social inclusion of people with disabilities, was not realised sufficiently. Even more worryingly, in some cases, ESIFs financed the continuation of institutional care, a concern that has been raised by ENIL-ECCL and other organisations since 2007.<sup>48</sup> For example, it is estimated that during the previous EU financing period (2007–2013) 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.<sup>49</sup> The Council of Europe’s Commissioner for Human Rights expressed his concern about the inadequate implementation of the rights under the CRPD, in particular Article 19, as follows:

*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>50</sup>*

Given the past failure of ESIFs to facilitate community living and prevent institutionalisation, it is imperative that they are used to positive effect in the current finance period 2014–2020 by facilitating the necessary reforms in the provision of health and social care and access to mainstream services, and **do not** support activities that reinforce the system of institutionalisation. Of key importance, therefore, is to ensure that the activities proposed by Member States’ Operational Programmes accord with the five points identified above (*Taking Action to Achieve Community Living: Key Points*), namely:

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48. These are included in the list of resources at Annex A.
49. See ENIL–ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, (ENIL–ECCL Briefing 2013), pages 11–12: <http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf>
50. Keynote Speech by Nils Muižnieks Council of Europe Commissioner for Human Rights International Symposium “Human Rights and Disability” Vienna, Austria, 10–11 April 2014 <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2503663&SecMode=1&DocId=2130702&Usage=2>

- i. Adoption of a **strategic vision** for the transition from institutional care to community living.
- ii. **Prohibition of investments** that maintain and/or extend **institutional care**
- iii. Proposed measures based on a country/region based **assessment of the situation**
- iv. Development of a **range of community-based services that promote social inclusion**
- v. Facilitating **participation** of civil society

## Concerns about Operational Programmes for 2014–2020

ENIL–ECCL is concerned that the key points for community living outlined above, which reflect both the commitments made by States when ratifying the CRPD and EU law and policy, have yet to be addressed by all Member States.

ENIL–ECCL’s general observations on the ESF and ERDF funded OPs of Bulgaria, Estonia, Hungary, Latvia, Lithuania and Slovakia for the period 2014–2020 highlight significant problems, which if not addressed will undermine the potential of ESIFs to facilitate the shift from institutional care to community living.<sup>51</sup> Indeed, further investigation will be required to ensure that ESIFs are not invested in institutional care.

The areas of concern are as follows:

- i. ***Strategic Vision for the Transition from Institutional Care to Community Living*: there is a lack of strategic vision.** Despite the crucial importance of developing strategies for the transition from institutional care to community living, not all Member States have such strategies in place. In most of the OPs considered, the measures for the transition from institutional care to community-based services are not framed within the context of a strategic vision for community living.
- ii. ***Prohibition of investments in institutional care*: proposed measures indicate planned investments in institutional care rather than seeking to eliminate institutional care.** The description of planned activities in some OPs indicate the intention to invest in institutions, whether through the repair or reconstruction of existing institutions or the development of smaller institutional settings, for example facilities for up to 25 people.

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51. The purpose of the comments on the Operational Programmes are to highlight areas that need to be addressed to ensure that ESIFs are used to promote community living and not to maintain institutional care. Accordingly, they are of general application and the examples used do not identify the relevant Member State(s).

- iii. **Assessment of the situation:** there is little analysis of the situation of people with disabilities, and therefore unclear whether there is an understanding of the gap between the vision of community living and reality. Most of the OPs considered provide limited information on the situation of people with disabilities and other groups, such as children and older people, who are living in institutions, or are at risk of being institutionalised. This is a significant concern given that a fundamental element of developing strategies for community living is to ascertain the gap between the vision for community living and the actual situation in the country, so that the strategies and action plans can seek to address the problems identified.
- iv. **Range of community-based services that promote social inclusion:** there is a lack of clarity on the planned range of services, with insufficient attention given to promoting social inclusion. The OPs considered provide little detail on the type and range of community-based services to be developed and how these are intended to promote social inclusion. Despite the declarations of some OPs that they aim to achieve social inclusion, their approach and the measures do not support this statement. It is particularly disappointing that few OPs refer to the development of personal assistance schemes, even though personal assistance is referred to specifically in Article 19 CRPD in the description of the range of services to be developed by States ‘to support living and inclusion in the community, and to prevent isolation or segregation from the community’. Another significant concern is that measures for social housing to be made available to people with disabilities, to develop housing that is physically accessible to people with disabilities, or to develop home adaptation schemes, which are key for community living, are rarely included.
- v. **Participation of civil society – putting the partnership principle into practice:** Action will be required to encourage the participation of civil society. Although this aspect is not generally addressed in the OPs considered, it will be a significant consideration for the on-going assessment of the planning and implementation of the activities funded by ESIFs. In particular, Member States should ensure the involvement of people with disabilities (and their families, where relevant) in the planning and implementation of strategies for the transition from institutional care to community-based services that support community living.

## Proposed questions to assist in identifying potential problems with the use of ESIFs when developing calls for proposals

In the light of the above observations, ENIL–ECCL have developed a series of questions, which are intended to assist in identifying potential problems with the planning and implementation of the activities proposed by the OPs. They seek to highlight the core issues that must be addressed to ensure that the measures for the transition from institutional care to community-based services support the right to community living. For ease of reference, the questions are ordered under the same headings as the key action points for achieving community living and areas of concern discussed above:

### a) Strategic Vision for the Transition from Institutional Care to Community Living

Are the measures for transition from institutional care to community-based services underpinned by a strategy for the closure of institutions and development of alternative community-based services that support community living?

### b) Prohibition of investments in institutional care

Are there any concerns that the proposed activities include investments in institutional care?

### c) Assessment of the situation – Identifying the gap between the vision and reality

Do the reasons for the investment priorities and proposed activities reflect the need to eliminate the use of institutional care and take action to address the current barriers to community living?

### d) Developing a range of community-based services that promote social inclusion – clarity of purpose to promote community living

Do the proposed actions support community living, in particular promote social inclusion and avoid the replication of institutional care?

### e) Facilitating participation of civil society – putting the partnership principle into practice

To what extent are people with disabilities and other stakeholders involved in the planning and implementation of strategies for the transition from institutional to community-based services? To what extent are people with disabilities involved in the relevant monitoring committees? To what extent is information available about ESIFs in accessible formats?

Even though the Partnership Agreements have been agreed and the OPs adopted, the questions set out below are likely to be of relevant at future stages of the planning and implementation of the activities set out in the OPs. For example they could assist:

- Desk officers of the European Commission when reviewing OPs, annual reports and progress reports
- Managing Authorities when drawing up the calls for proposals and the criteria for selecting the operations to be funded
- Members of monitoring committees when reviewing the implementation of the OP and the progress towards achieving its objectives
- Those attending annual review meetings e.g. service user representatives
- Civil society organisations seeking to review the progress of projects funded by ESIFs

### f) Strategic Vision for the Transition from Institutional Care to Community Living

Are the measures for transition from institutional care to community living underpinned by a strategy for the closure of institutions and development of alternative community-based services that support community living?

- *The development and implementation of strategies for the transition from institutional care to community-based services (further referred to as “deinstitutionalisation strategies”) for all people with disabilities will be a crucial element to ensure Member States’ compliance with Article 19. Of particular importance is that such strategies should set out a clear and agreed vision for what needs to be achieved.*
- *Member States’ Operational Programmes (OPs) should be based upon, and take forward, the goals and objective of such strategies.*

As noted above, the requirement to have in place a strategy for the closure of institutions and the development of community-based alternatives that support community living

stems from the CRPD and EU law and policy. The CRPD Committee requires that governments of countries in which institutional care exists adopt such a strategy that promotes community living and includes a timetable and benchmarks for progress. The provisions governing the use of ESIFs require that those Member States for which such a need has been identified, will not be eligible for ESIFs unless they include measures for the “transition from institutional to community-based care”. The Thematic guide suggests that the proposed measures should be “part of a strategic vision on the transition from institutional to community based care” and that this should be in line with the criteria under the ex-ante conditionality for active inclusion.

Accordingly, the strategic vision is key as it sets out the Member State’s overall goal. Such strategies, while including the closure of institutions, should seek to promote community living. They should set out how people with disabilities and others currently placed in institutions, are to be able to live and participate in the community as equal citizens. For this reason, the references below use the term “deinstitutionalisation strategy” but will also refer to strategies “for the transition from institutional care to community living”. Whichever term is used, the strategy should encompass action to ensure that people with disabilities can exercise their right to community living. **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.**

Without the clarity of purpose there is a danger that ESIFs will not be used to their full potential in facilitating the shift from institutional care to community living. More worryingly, if invested in services and infrastructure that reinforce the institutionalisation of people with disabilities, ESIFs may hinder the implementation of positive reforms.

Achieving the shift from institutional care to community-based services is a complex process, requiring careful planning in consultation with a range of stakeholders, including people with disabilities. Its full implementation may take a number of years and be undertaken in stages, through a series of action plans that cover different aspects of the work envisaged by the strategy for the transition from institutional care to community living. This may mean that the activities that Member States propose in OPs as measures for the transition from institutional to community-based care may form only a part of the activities envisaged by the deinstitutionalisation strategy. However, it is essential that such activities are seen as being integral to the implementation of the overall strategy.

Thus, it is suggested that when describing the activities the Member State proposes shall be funded by ESIF, **the OPs should demonstrate that the relevant priorities, specific objectives and proposed activities have been developed in the context of the wider deinstitutionalisation strategy (or that part of the work proposed is to support**

**the development of such a strategy**). The EEG Toolkit recommends that either the deinstitutionalisation strategy is in place and mentioned as a reference framework for the planned actions – or if one is not in place, ‘its development is planned as a priority operation to be funded by the Technical Assistance of the OP’.<sup>52</sup>

## STRATEGIC VISION FOR THE TRANSITION FROM INSTITUTIONAL CARE TO COMMUNITY LIVING: POINTS TO CONSIDER

### Q.1 Is there a strategy for the closure of institutions and promotion of community living in place?

- **Ascertaining whether such a deinstitutionalisation strategy is in place is a crucial question when considering OPs that relate to the objective of ‘promoting social inclusion, combating poverty and any discrimination’.**
- As noted by ENIL–ECCL in its briefing of April 2015, not all Member States have adopted and/or are developing strategies for the closure of institutions and promotion of community living.<sup>53</sup> This is a significant concern given that the measures that Member States propose to take – which should therefore be detailed in their OPs – should be linked to, and take forward, the Member State’s wider ‘strategic vision’, namely its deinstitutionalisation strategy. The Open Society Foundation argues:

*Where EU law requires member states to create a poverty reduction strategic framework that includes a component on deinstitutionalisation, this obligation must be interpreted in line with Article 19 of the CRPD. Where a member state fails to fulfil this requirement by failing to develop a deinstitutionalisation plan with a clear timeline and concrete benchmarks, the Commission may suspend payments under the ESIFs.<sup>54</sup>*

- Some Member States have adopted, and are in the process of implementing a deinstitutionalisation strategy for one group of people, for example children, but have made less progress in either developing or implementing a strategy in relation to other groups. Given that measures taken by Member States should be within the framework of a deinstitutionalisation strategy that covers all user groups, such a situation merits further investigation:

52. EEG Toolkit, above (n.13), pages 40–41.

53. ENIL–ECCL *Briefing on the use of European Structural and Investment Funds to support the transition from institutional care to community living for people with disabilities* April 2015. (ENIL-ECCL Briefing 2015) Available at: <http://community-living.info/2015/09/14/briefing-on-the-use-of-structural-funds-to-support-the-transition-from-institutional-care-to-community-living/> 2–5.

54. Community not Confinement above (n.10), 55.

- While recognising that governments may not be able to implement their deinstitutionalisation strategies simultaneously for all groups living in institutions, the EEG guidelines make clear that the strategy should cover all user groups. Action plans developed for the group of people given priority “should be decided on the basis of the assessment of the situation and in consultation with all stakeholders”.<sup>55</sup>
- Article 19 CRPD requires governments to take concrete and purposeful action to ensure that all people with disabilities are able to exercise their right to community living. In Member States where institutional care is still prevalent, compliance with Article 19 will entail the preparation, adoption and implementation of a deinstitutionalisation strategy that covers all people with disabilities.

### Q.2 What are the key elements of the deinstitutionalisation strategy?

- As noted above, the EEG guidelines and the CRPD Committee highlight the need to develop action plans to implement the strategy, which should include a timeframe and mechanisms for monitoring progress.
- While it is positive that some OPs of Member States make specific reference to the EEG’s guidelines when referring to the planning of their deinstitutionalisation strategies, not all do so. This indicates the need to raise awareness of both the EEG guidelines and the EEG Toolkit.
- Despite the importance of the CRPD in developing deinstitutionalisation strategies, as highlighted by the EEG Guidelines, few Member States refer to the CRPD. However, by way of a positive example, one Member State comments that its deinstitutionalisation strategy was developed in the light of the CRPD.
- A question of particular importance when considering Member States’ OPs is to ascertain whether (as advised by the EEG guidelines) the deinstitutionalisation strategy is based on an assessment of the needs of the population and the available services in the country.<sup>56</sup>

### Q.3 Does the Operational Programme recognise the differing needs and interests of the different groups of people resident in institutional care?

- Some OPs refer to people with disabilities and “elderly people” as if they are a homogenous group. This highlights the need to ensure that the measures being proposed are not based on assumptions, such as “the elderly” and “the disabled”

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55. EEG Guidelines above (n.36), 72.

56. EEG Guidelines, above (n.36), Chapter 2.

will be in need of long-term health and/or social care; rather, that the proposed measures are in response to the assessed need. The EEG guidelines provide advice on the type of information that should be obtained about residents in institutions, including the reasons for their placement and “disability/illness/degree of frailty”.<sup>57</sup>

- It is also unclear in some OPs whether the term “people with disabilities” covers people with intellectual disabilities and people with mental health problems. This will need to be clarified, particularly given the high proportion of people with mental health problems and/or intellectual disabilities resident in institutions.<sup>58</sup>
- **The CRPD Committee has made clear that it considers that all people with disabilities should be included in States’ deinstitutionalisation plans.**<sup>59</sup>

#### Q.4 To what extent does the Operational Programme cover measures for the transition from institutional care to community-based services?

- Member States have taken very different approaches to meeting the requirement to include measures for the “transition from institutional to community-based care”. Whereas some have identified this as a specific objective, others do not refer to this requirement specifically when outlining their activities; identifying more nuanced objectives such as reducing the numbers of people in institutions or reducing the size of the residential care institutions.
- In some OPs it is not always clear whether the long term plan is to replace institutional care with community-based services altogether, or simply to reduce the number of people placed in institutional care and/or modernise institutional facilities. This is why it is necessary to consider the OP alongside the Member State’s deinstitutionalisation strategy.
- It will be important to clarify what is meant by the various terms used so as to ensure that the activities described in the OPs will not support institutional care. Terms such as “large capacity facilities for long-term stays”, “protected homes” and “rehabilitation centres” suggest that the services are likely to be institutional in nature rather than services that are community-based and seek to promote social inclusion.
- The information provided in some OPs suggests that the relevant Member State intends to continue to provide institutional care for certain groups of people; for example, referring to “specialised institutional care services to persons who cannot

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57. EEG Guidelines, above (n.36), 58.

58. DECLOC report, above (n.27).

59. Croatia and Czech Rep (CRPD Concluding observations n.1).

take care of themselves”. The Thematic guide states that “[a]ssurance should be provided that any group of individuals will not be excluded from the support because of the type of their impairment (e.g. because of the complexity of their support needs)”.

## g) Prohibition of investments in institutional care

**Are there any concerns that the proposed activities include investments in institutional care?**

- *A commitment to close institutions together with clear plans for the development of community-based alternatives that support community living is required so that institutions become redundant.*
- *The investment of ESIFs in institutional care is not permitted.*

In the past, investments in institutional care were made for a number of reasons, not just due to a lack of vision for community living (for example, due to a concern about the poor living conditions in institutions). In other cases, such investments were due to a lack of co-ordination between funds, with institutions receiving funds to meet targets unrelated to reform in health and social care, such as improving accessibility or energy efficiency.<sup>60</sup> Such investments perpetuate the institutionalisation of people with disabilities, children and older people. Not only does it delay the closure of the institution given that often “authorities are reluctant to close a service in which a great deal of money has been invested”<sup>61</sup> but also takes up financial and other resources that could have been applied to developing community-based alternatives.

**Investments in institutional care are not acceptable in the current financing period.** The European Commission has stated that as a general principle ESIFs should “not be used for building new residential institutions or the renovation and modernisation of existing ones”. ESIFs can only be used to renovate residential care institutions in exceptional circumstances AND “**only as transitional measures within the context of a de-institutionalisation strategy**”:

*Targeted investments in existing institutions can be justified in exceptional circumstances 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 [emphasis added]**.*

60. For examples of such investments, see ENIL–ECCL Briefing 2013, above (n.46), 12 –13.

61. *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, 2008, p.14.

Given this commitment, it is important to establish that the activities proposed under an OP do not contravene this principle.

ENIL–ECCL’s briefing of April 2015, which was based upon information provided by partner organisations from Bulgaria, Czech Republic, Hungary, Romania and Slovakia<sup>62</sup> highlighted the concern that in some Member States there was a lack of a clear commitment to close all long-stay residential institutions for people with disabilities. For example:

- In the Czech Republic, information suggests that there has been a significant increase of places in the so-called ‘homes with a special regime’ and the majority of funding spent on ‘care’ for people with disabilities is still directed towards institutional care.
- In Hungary, the government still intends to allow investments to be made in institutions for up to 25 people.

**ENIL–ECCL is of the view that funding such institutions would be in violation of Article 19 of the CRPD and the European Commission should not permit ESIFs to support projects for this purpose.**<sup>63</sup> This would be contrary to the EU’s obligations as a State Party to the CRPD as well as the EU policy of not allowing investments into the building or renovation of long-stay residential institutions in 2014–2020.<sup>64</sup>

The EEG guidelines provide information and guidance on the planning and preparation for the closure of institutions, noting that this will involve plans for the transition of the residents to community-based alternatives “based on their individual needs and preferences” and plans for the redeployment and training of staff.<sup>65</sup>

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62. ENIL–ECCL Briefing 2015 above (n.46) The following organisations kindly provided information for the ENIL–ECCL Briefing 2015: the Hungarian Civil Liberties Union (TASZ), the Institute for Public Policy (IPP, Romania), SOCIA (Slovakia), the Centre for Independent Living Sofia (Bulgaria) and JDI – Jednota pro deinstitucionalizaci (the Czech Republic).

63. Community not Confinement above (n.10), 54 states that Member State’s Partnership Agreements (PAs) and Operational Programmes (OPs): ‘should not contain commitments to support projects that would perpetuate institutionalisation – ideally the PAs and the OPs should include express prohibition on measures of this nature’.

64. EU Report to CRPD, above (n.43).

65. EEG Guidelines, above (n.36), see page 73 “Key Guidance 6: Plans for the Closure of Institutions” and the various chapters noted therein.

## PROHIBITION OF INVESTMENTS IN INSTITUTIONAL CARE: POINTS TO CONSIDER

**Q.5 Is there any indication that the Member State intends to maintain residential institutions as part of their system of care?**

- **As noted above, ESIFs must not be invested to maintain institutional care – such a use of ESIFs is contrary to the CRPD and EU law.**
- In some OPs, the descriptions of the type of services to be developed suggest that they may include residential institutions; for example, “family-like services”, “high quality service places”, “large capacity facilities for long-term stays” and “rehabilitation centres”.
- Terms such “family-type residential centres”, “residential care homes”, “specialised institutional care services to persons who cannot take care of themselves”, “resident social services” may well be institutional care settings and therefore their construction or renovation should not be funded by ESIFs.
- Other terms such as “centres for rehabilitation” may in fact be describing a traditional institution. It will be necessary to ascertain what is meant by these terms.

**Q.6 Are “intermediate” facilities proposed for individuals who are currently resident in institutions?**

- Some Member States suggest that intermediary facilities will be needed for residents, for example because they are unable to look after themselves. This would require further investigation, including how such decisions are made (decisions about the services to be provided to individuals should be based on individual assessment of needs) and whether this is to be reviewed at regular intervals. This is to ensure that such “intermediate” placements do not become permanent. In addition, it is important to ensure that any such intermediary facilities are based in the community and not within the perimeter of institutions.

**Q.7 Is there any indication that investments in institutions may be made under other investment priorities, for example supporting energy efficiency?**

- ENIL–ECCL has previously raised concerns that in the past financing period ESIFs were invested in institutions to meet targets unrelated to reforms in health or social care, such as improving energy efficiency.<sup>66</sup> Given that in some OPs for the period 2014–2020, Member States highlight energy efficiency as being a priority area, action should be taken to make clear that residential institutions are not eligible for such projects.

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66. ENIL–ECCL Briefing 2013, above (n.46).

## h) Assessment of the situation – Identifying the gap between the vision and reality

**Do the reasons for the investment priorities and proposed activities reflect the need to eliminate the use of institutional care and take action to address the current barriers to community living?**

- *The reasons given for taking action to shift from institutional care to community-based alternatives are important. It provides an indication of whether the Member State has an understanding of the current situation, such as how many people are living in institutions and the reasons for their institutionalisation, as well as the barriers to independent living, for example the lack of available and/or accessible community-based services.*

Member States are required to give reasons for their choice of thematic objectives and corresponding investment priorities.<sup>67</sup> Such reasons should draw upon the country-wide assessment of the needs of the population – as outlined in chapter 2 of the EEG guidelines. This is necessary to ensure that the activities in the OP are directed towards addressing the needs of the population that are not met by existing services and to ensure that the services that are provided promote the social inclusion of people with disabilities, and other groups in institutional care or those at risk of being institutionalised. Accordingly, Question 3 above (Does the Operational Programme recognise the differing needs and interests of the different groups of people resident in institutional care) is relevant to the issues considered under this action point as well.

The EEG Toolkit notes that “the transition from institutional to community-based care/ services has been identified as a key action under the thematic objective ‘promoting social inclusion, combating poverty and any discrimination’ for both the ESF and the ERDF”.<sup>68</sup> It suggests how the ESF and the ERDF can assist in progressing the necessary deinstitutionalisation measures:

- ESF: such measures should be part of the ‘ESF investment priority “enhancing access to affordable, sustainable and high quality services” (Article 3(1)(b))’; also, the reasons why the development of community-based alternatives to institutional care has been chosen should be given, “drawing on the identification of needs and the necessary investments to meet those needs”. **An ESF OP should:**
  - “look at the situation of those groups in society experiencing (or at risk of) poverty and social exclusion, especially those in institutional care or at risk of being institutionalised”

67. CPR (n.32), Article 96(2).

68. EEG Toolkit above (n.13), see pages 34–35.

- include information such as the types of services provided, information on who is receiving such services, data on those in need of care and/or support who are living in the community, details of those who are living in residential care, information on access to mainstream services and resources allocated to institutional care and to community-based services.
- ERDF: deinstitutionalisation should be part of the “ERDF investment priority ‘investing in health and social care infrastructure’ (Article 5(9))” with a further link to “investing in educational structure” in relation to children. **An ERDF OP:**
  - “should provide an assessment of the existing social, education and health infrastructure relevant to the process of transition from institutional to community-based services”, which should include information such as the number, size and location of long-stay residential institutions, the number, size and location of supported living units and details of other housing options, including where they are located. (The term ‘long-stay institutions’ includes ‘social care institutions, infant homes, orphanages, psychiatric hospitals and homeless shelters where there is no possibility of move-on/alternative to long-stay’.)

The importance of collecting data about the people living in institutions was highlighted by the DECLOC report<sup>69</sup> and the EU Agency for Fundamental Rights (FRA).<sup>70</sup> The lack of data on the situation of people with disabilities generally, and those living in institutions has been highlighted in a number of reports.<sup>71</sup> Article 31 CRPD requires States Parties to “collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention”.

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69. The DECLOC report above (n.27) 94.

70. See EU FRA’s Human rights indicators on Article 19 at <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>

71. See for example ENIL–ECCL, *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, 18–20. Available at: <http://www.enil.eu/news/is-the-european-union-competent-to-ensure-access-to-independent-living/>

## ASSESSMENT OF THE SITUATION – IDENTIFYING THE GAP BETWEEN THE VISION AND REALITY: POINTS TO CONSIDER

### Q.8 What information is provided about people with disabilities, children and other groups resident in institutional care?

- Despite the crucial importance of collecting data on the current situation of people with disabilities and other groups at risk of institutionalisation, such as children, the information provided in OPs is limited. It is not clear whether and what type of information is available and whether it includes both quantitative and qualitative analysis of reasons for institutionalisation and barriers to community living. It is also not clear whether disabled people have been consulted in the process.
- While such information may be detailed in other documents, such as the Member State's deinstitutionalisation strategy, it will be important to ensure that this – and other information relevant to the assessment of the country situation – is available and the measures proposed in the OP are based on these findings.
- In the absence of such information it is difficult to assess whether there is a good understanding of the problems and whether the measures are adequate.

### Q.9 What reasons are given for introducing the measures for transition from institutional care to community-based services?

- Some OPs refer to the lack of community-based services and the predominance of traditional large residential institutions.
- Albeit general concerns about the social exclusion of people with disabilities are highlighted, few OPs make the specific link between institutionalisation and social exclusion or the human rights violations inherent in institutionalisation of individuals. Notably, one OP acknowledges these concerns, referring to the poor quality of life in institutions as compared to good community-based services and noting that “institutional care often means lifelong social exclusion and segregation”. Another OP refers to the poor living conditions and the exclusion from “learning, employment, cultural” opportunities.

### i) Range of community-based services that promote social inclusion – clarity of purpose to promote community living

**Do the proposed actions support community living, in particular promote social inclusion and avoid the replication of institutional care?**

- *People with disabilities will require a range of services in the community to be available to them. This will include specific services and supports, such as personal assistance schemes and access to mainstream services such as housing.*

An issue of particular concern to ENIL-ECCL is that services referred to as being “community-based” and/or purporting to promote independent living may, in reality, be institutional in character. This can happen for a number of reasons, such as the number of residents living in one place, who have not been given the choice of where and with whom they wish to live. It may also be due to the lack of staff who have the right training and motivation to support residents in living independently (for example, helping residents in undertaking domestic chores and to shop and cook for themselves).<sup>72</sup>

The concern that the approach taken by governments could result in the continued institutionalisation of people with disabilities, albeit in settings where the physical conditions are better than in the large residential institutions, was raised in ENIL-ECCL’s April 2015 briefing. For example, the briefing noted that in Bulgaria it is planned to replace large residential institutions with small group homes (SGHs), with no indication whether other (mainstream) housing options will be developed as well.<sup>73</sup> Similarly, in Romania, the planned investments are directed towards family-type homes and protected houses, rather than making mainstream housing available to people with disabilities (by, for example, purchasing existing apartments or houses in the community). The over-reliance on ‘small group homes’, ‘family-type homes’ and ‘protected housing’ is likely to lead to the continued segregation of people with disabilities from the community. Such facilities should be used (if at all) in exceptional circumstances only, alongside mainstream housing options (such as regular apartments of different sizes and already existing houses in the community).

The EEG Guidelines include detailed guidance on the range of services to be provided in the community as alternatives to institutionalisation.<sup>74</sup> Such services “should enable individual users and families to participate in the community on an equal basis with others”; seek to prevent institutionalisation and also support individuals moving back into the community. The Guidelines emphasise that the services to be provided will depend on local need, providing examples of the range of community-based services that could be developed. These include personal assistance (whereby the service user employs and trains assistants and chooses when, how and what kind of assistance to receive), housing adaptations, technical aids (such as speech recognition software), crisis interventions and emergency services, home help and short breaks. The EEG Toolkit set out examples of the range of services and other actions that ESIFs can fund to facilitate the transition from institutional care to community-based services and supports:

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72. See discussion in ENIL-ECCL Briefing 2013 above (n.46), pages 9–10.

73. This is similar to the previous programming period, when large residential institutions for children were replaced mainly with SGHs (accommodating up to 12 children).

74. EEG Guidelines, above (n.36), Chapter 5 provides further details.

- ESF: the development of a range of community-based services, such as the services outlined in the EEG Guidelines; individual needs assessments of each individual involved in the transition (this will be of crucial importance as this will highlight the person's needs, how they wish to live their life and the support they should receive<sup>75</sup>), drawing up local plans on the transition to community-based services, improving access to mainstream services, improving the quality and increasing the capacity of existing community-based services, staff training and activities to facilitate user involvement.
- ERDF: the actions include the development and adaptation of social, health and education infrastructures for the provision of community-based services, improving the quality and capacity of existing infrastructures for community-based services, development of accessible housing for people with disabilities in the community, investment in social housing (to be available to those leaving institutional care or at risk of being institutionalised) and home adaptations.<sup>76</sup>

The EEG toolkit provides a list of “output and result indicators” for the measures taken to support the transition to community-based services under both the ESF and ERDF.<sup>77</sup> These include:

- ESF: the number of individual assessments carried out, the number of individual care/support plans developed and implemented and the number of staff trained and deployed to community or mainstream services, increased range of services in the community.
- ERDF: number of independent living units in the community, reduction in the number of institutional places, number of long-stay institutions closed down and increased percentage of individuals with support needs accessing social housing and mainstream services.

The EEG Toolkit also highlights the importance of developing a framework for assessing the quality of services and the quality of life of those who are using such services. Chapter 9 of the EEG Guidelines provides information on monitoring and evaluating the quality of services provided. A core aspect of such standards must be to ensure respect for the human rights of all individuals receiving such services.<sup>78</sup>

In addition, it will be important to consider how to develop action plans that promote a holistic and co-ordinated approach. For example, the development of support services

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75. See chapter 7 of the EEG Guidelines (above, (n.36)) for further details.

76. EEG Toolkit above (n.13), pages 35–37.

77. EEG Toolkit above (n.13), pages 37–39.

78. See EEG Guidelines, above (n.36), 146–147.

in the community and the improvement of access to mainstream services need to be accompanied by the provision of training to staff so that they are competent to respond to the needs of people with disabilities using such services.

## RANGE OF COMMUNITY-BASED SERVICES THAT PROMOTE SOCIAL INCLUSION – CLARITY OF PURPOSE TO PROMOTE COMMUNITY LIVING: POINTS TO CONSIDER

### Q.10 Are there any concerns that the proposed services are likely to replicate institutional care?

- Terms such as “group homes”, “family homes”, “homes for young people”, “high quality service places” and “protected houses” may refer to facilities that are smaller than the traditional large residential institutions but the number of residents and care regime provided may replicate the institutional culture that is prevalent in the larger institutions.
  - Such facilities might result in the provision of institutional care in a smaller setting unless action is taken to ensure that the residents are able to engage in community life and the regime in the home does not replicate the institutional culture of the larger institutions.
  - The Thematic guidance states:
 

*Note that the size of the institution cannot be used in isolation as a criterion to judge whether the supported infrastructure can be considered as community-based service or simply a scaled-down institution. The starting point should be whether it provides a setting allowing for the possibility for independent living, inclusion in the community (including physical proximity of the location) and high-quality care. However, it is clear that the larger the infrastructure the more likely it is that these criteria will not be fulfilled.*
- The Thematic guidance refers to a range of activities that the ESF and ERDF can fund. These could be compared to the activities proposed in the OPs. They could also be referred to the Managing Authorities when drawing up the criteria for selecting the operations to be funded. The suggested activities in the Thematic guidance include:
  - For ESF: “drawing up an action plan on the transition to community-based services which would include individual care support and preparation for each service user involved” and “development of an integrated network of community-based services such as: personal assistance, home care, family counselling, day care, job search assistance, nursing, foster care, etc.”
  - For ERDF: development and adaption of social, health and education infrastructures for the provision of community-based services.

**Q.11 Is there clarity on what services are to be provided?**

- Terms such as “people in need of long term care” and “models of long-term care for people incapable of self-care” are too vague to be able to ascertain whether they are in reality community-based services or a replication of institutional care. It will be important to clarify the meaning of these terms, to ascertain how many people will be living in such facilities and whether the residents are able to choose whether they wish to live there, and with whom they want to live.
- While the terms “community-based services”, “services for social inclusion”, “independent living” and references to the need to “improve the quality of life” are positive, it will be important to ensure that the services actually provided are geared towards meeting these positive objectives.

**Q.12 Do the services support social inclusion?**

- While the provision of community-based health and social care is important, other services to enable people to live and participate in the community are essential, for example, access to mainstream housing. For example, ERDF can support projects that undertake necessary adaptations to the family homes of people with disabilities. The reviewed OPs do not include measures to make accessible homes of people with disabilities and only a few plan activities to make accessible and affordable housing available to people with disabilities.
- While reference to “services for social inclusion” appears positive, it will be necessary to know what services this term covers to be able to ascertain whether they are in fact promoting social inclusion.
- ENIL–ECCL considers that personal assistance schemes should be promoted given that they are such an important means of realising independent living for people with disabilities.

**Q.13 How is progress towards achieving the transition from institutional care to community-based services that support community living measured?**

- It is difficult to ascertain how some of the proposed indicators suggested in the OPs will demonstrate real progress towards achieving the transition from institutional care to community-based services. For example, few OPs include the closure of institutions as a target. At the same time, meeting targets for reducing the numbers of people with disabilities placed in institutions does not necessarily mean that the alternative services are of a better quality or enhance individuals’ opportunity to participate in community life.

- Ensuring that the community-based alternatives to institutional care support community living is even more problematic. For example, while an objective that people with disabilities have “improved access to services” is laudable, it is not clear how this is measured. Furthermore, this assumes that the services received are of a good quality.
- It is for this reason that the development of a framework to assess the quality of community-based services is so important. One OP highlights this, stating that a “systematic evaluation of progress and efficiency of transition from institutional to community-based care” is needed.
- It will also be necessary to consider how the situation of those who continue to live in institutions is monitored so as to ensure that the standards of care are good and the human rights of the residents are respected.

#### j) Participation of civil society – putting the partnership principle into practice

**To what extent are people with disabilities and other stakeholders involved in the planning and implementation of strategies for the transition from institutional care to community-based services?**

The European Code of Conduct on Partnership, adopted in 2014, makes clear that organisations of people with disabilities and other civil society groups are to be involved in the programming, implementation, monitoring and evaluation of ESIFs.<sup>79</sup> This will be particularly important in relation to the use of ESIFs to facilitate the shift from institutional care to community living. However, Member States are likely to require clear guidance on how to put this principle into practice.

For example, it is not known whether Managing Authorities are using, or plan to use, funds for technical assistance to build the capacity of user-led disabled persons’ organisations (DPOs) advocating for deinstitutionalisation to meaningfully participate in ESIFs implementation and monitoring. In the experience of ENIL–ECCL, which brings together mainly grassroots groups, most organisations lack the necessary expertise and influence to take part in the process.

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79. 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)

## PARTICIPATION OF CIVIL SOCIETY – PUTTING THE PARTNERSHIP PRINCIPLE INTO PRACTICE: POINTS TO CONSIDER

The two questions set out below are based on the EEG Toolkit's checklist for Managing Authorities and Monitoring Committees on the selection of projects.<sup>80</sup>

**Q.14 Information about user involvement:** Is it clear how the proposed action will meaningfully involve users of services and families, where relevant, in the design of the service funded, in line with the partnership principle?

**Q.15 Monitoring and evaluation:** Is it clear how users of services, and their representative organisations and families, where relevant, will be meaningfully involved in monitoring and evaluation of the services funded?

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80. EEG Toolkit above (n.13), pages 44–45.

## 5. Conclusion

This report has placed great emphasis on the importance of Member States developing and adopting their “vision” for community living. Given the crucial role of ESIFs in developing community-based alternatives to institutional care that promote community living, it is important that Member States and the European Commission work together to realise this vision. This requires a shared understanding of what needs to be achieved (what is meant by the terms “community living” and “independent living”), why this is necessary (recognition that everyone has the right to community living) and what needs to be done to realise this vision (what is wrong with the current system – the gap between the vision and the reality). While the specific challenges to be addressed and necessary reforms (such as health and social care structures, legal and financial regulations) will vary between Member States, they will all need to establish clear strategies and action plans for the shift away from institutional care to the provision of community-based services that promote the social inclusion of people with disabilities.

The European Commission can assist Member States in undertaking this work, by providing leadership and guidance on how ESIFs can be most effectively utilised to promote the social inclusion of people with disabilities. As noted in this report, detailed guidance has been produced to assist Member States in their work to achieve the shift from institutional care to community living, in particular the EEG Guidelines, the EEG Toolkit and the European Commission’s Thematic guide. The questions proposed in this report build on, and are intended to complement, these publications – providing an additional resource for all those working to achieve the transition from institutional care to alternative community-based and inclusive services and supports. In particular, it is hoped that the report and its suggested questions will provide assistance to the European Commission when undertaking its monitoring and evaluation of the implementation of Member States’ Operational Programmes – so as to ensure that the activities funded by ESIFs are directed towards realising community living.

It is vital that in this EU programming period, Member States, the European Commission and civil society work together to ensure that ESIFs promote, not hinder, the work to realise the right to community living: to close the gap between rights and reality.



# Annex A: Relevant Publications

Open Society Foundations *Community, not Confinement The Role of the European Union in Promoting and Protecting the Right of People with Disabilities to Live in the Community* (author Dr. Israel Butler) (October 2015) available at: [www.opensocietyfoundations.org/reports/community-not-confinement](http://www.opensocietyfoundations.org/reports/community-not-confinement)

The Committee on the Convention on the Rights of Persons with Disabilities, Concluding observations. Available at: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=5)

ENIL–ECCL List of Issues in relation to the initial report of the European Union Comments on Article 19 (Living independently and being included in the community) 2015 <http://www.enil.eu/wp-content/uploads/2015/08/List-of-Issues-ENIL-ECCLComments190715FINAL.pdf>

*Decision of the European Ombudsman closing her own-initiative inquiry OI/8/2014/AN concerning the European Commission* May 2015. Available at: <http://www.ombudsman.europa.eu/cases/decision.faces/en/59836/html.bookmark>

ENIL–ECCL *Briefing on the use of European Structural and Investment Funds to support the transition from institutional care to community living for people with disabilities* April 2015. Available at: <http://community-living.info/2015/09/14/briefing-on-the-use-of-structural-funds-to-support-the-transition-from-institutional-care-to-community-living/>

European Union Agency for Fundamental Rights *Human rights indicators on Article 19*. Available at: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>

European Commission: Draft thematic guidance fiche for desk officers, *Transition from institutional to community-based care* (de-institutionalisation – DI) Version 2, January 2014.

ENIL–ECCL, *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 Available at: <http://www.enil.eu/news/is-the-european-union-competent-to-ensure-access-to-independent-living/>

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>

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>

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>

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)

# Annex B: 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<sup>81</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 independent living. 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 independent living is based. There is a continuous debate on *independence vs. interdependence*; ENIL considers that all human beings are interdependent and that the concept of independent living does not contravene this. Independent living 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)

Independent living is the daily demonstration of human rights-based disability policies. Independent living 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 real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life. Independent living requires that the built environment, transport

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81. Independent Living derives from the Independent Living movement that started in the late 1960s in Berkeley, California as a grassroots movement.

and information 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 independent living is for all disabled persons, regardless of the gender, age and the level of their support needs.

### **Personal Assistance (PA)**

Personal Assistance is a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance 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. Personal assistance 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)**

Deinstitutionalisation is a political and a social process, which provides for the shift from institutional care and other isolating and segregating settings to independent living. Effective deinstitutionalisation 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 deinstitutionalisation is the provision of affordable and accessible housing in the community, access to public services, personal assistance, and peer support. Deinstitutionalisation is also about preventing institutionalisation in the future; ensuring that children are able to grow up with their families and alongside neighbors and friends in the community, instead of being segregated in institutional care.

### **Community-based Services (CBS)**

The development of community-based services 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. Community-based services 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 independent living and, if already provided, must exist alongside other genuine, adequately funded independent living 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.



## 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.

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All people with disabilities  
have the right to live  
in the community, with  
choices equal to others.

Article 19 of the UN Convention  
on the Rights of Persons with Disabilities

This report focuses on the continued and pressing need for action to be taken to enable people with disabilities to live and participate in the community and how European Structural and Investment Funds (ESIFs) can be used to achieve this objective.

The report sets out a series of questions to assist in the evaluation of Member States' Operational Programmes. The questions focus on five key areas: the adoption of a strategic vision, prohibition of investments in institutional care, proposed measures to be based on a country/regional assessment of the situation, the development of a range of community-based services that promote social inclusion and facilitating the participation of civil society.

The report is aimed at desk officers at the European Commission, especially those new to the issue of deinstitutionalisation, as well as Managing Authorities and Monitoring Committees in the Member States. It is also aimed at organisations of people with disabilities and other civil society groups, in particular those involved in monitoring the use of ESIFs in the current programming period (2014–2020).

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European Network on Independent  
Living – European Coalition for  
Community Living

[www.enil.eu](http://www.enil.eu)  
[www.community-living.info](http://www.community-living.info)