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European Structural and Investment Funds and People with Disabilities in the European Union

STUDY FOR THE PETI COMMITTEE

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DIRECTORATE GENERAL FOR INTERNAL POLICIES

POLICY DEPARTMENT C: CITIZENS' RIGHTS AND CONSTITUTIONAL AFFAIRS

PETITIONS

European Structural and Investment Funds and People with Disabilities in the European Union

STUDY

Abstract

This study, commissioned by the European Parliament's Policy Department for Citizens' Rights and Constitutional Affairs at the request of the PETI committee, concerns the situation of people with disabilities in the European Union (EU) and how EU funds ('European Structural and Investment Funds') can support the reforms needed to replace the outdated systems of institutional care with community-based and inclusive services. It also highlights areas that must be addressed to avoid the mistakes of the past, in particular the use of EU funds to maintain institutional care, and ensure that instead they are used to promote community living.

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CONTENTS

LIST OF ABBREVIATIONS

CEE	Central and Eastern Europe
CF	Cohesion Fund
CoE	Council of Europe
CRC	United Nations Convention on the Rights of the Child
CRPD	United Nations Convention on the Rights of Persons with Disabilities
EARDF	European Agricultural Fund for Rural Development
ECCL	European Coalition for Community Living
EDF	European Disability Forum
EEG	European Expert Group on the Transition from Institutional to Community-based Care
EESC	European Economic and Social Committee
EMFF	European Marine and Fisheries Funds
ENIL	European Network on Independent Living
ERDF	European Regional and Development Fund
ESF	European Social Fund
ESIF	European Structural and Investment Funds
EU	European Union
EU Charter	Charter of Fundamental Rights of the European Union
EU-SILC	EU Statistics on Income and Living Conditions
FRA	European Union Fundamental Rights Agency
OP	Operational Programme

LIST OF TABLES

EXECUTIVE SUMMARY

Background

This study concerns the situation of people with disabilities in the European Union (EU) and the role of EU funds, known as the European Structural and Investment Funds (ESIFs) in facilitating the transition from institutional care to community living for people with disabilities. ESIFs have the potential to play a crucial role in achieving this transition, as they can provide the financial and technical support to assist Member States in the planning and implementation of the reforms needed to replace the outdated systems of institutional care with the provision of a range of community-based services that support community living.

This study draws upon the available research and reports on the use of ESIFs in this area, including the in-depth analysis prepared for the PETI Committee prior to its Fact Finding Visit to Slovakia in September 2016, *European Structural and Investment Funds and People with Disabilities in Slovakia* ('Slovak ESIF Report').

Aim

- This study has two main aims.
  - first, is to highlight the potential role of ESIFs in achieving the transition from institutional care to community living for people with disabilities; specifically: how they can help to address the prevalence of institutionalisation within the EU by supporting the reforms that are necessary to achieve the objective of transferring from a system of institutional care to community-based services that support social inclusion.
  - second, is to consider the steps that need to be taken to ensure that ESIFs are used to promote community living, rather than to perpetuate the system of institutional care.
- With these aims in mind, this study highlights the key aspects of the current regulations governing the use of ESIFs and considers the steps that need to be taken to ensure that ESIFs are used to support the development of community-based alternatives that promote social inclusion. It does so by:
  - identifying the key problems with the use of EU funds that arose in the programming period 2007 – 2013, namely the investment into institutional care in a number of Member States; and
  - highlighting areas that will need to be addressed in order to avoid a repeat of such problems in the current financial period 2014 – 2020.
- To provide the context for the use of ESIFs, this study explains what is meant by 'community living' and shows why the institutionalisation of people with disabilities is a fundamental barrier to achieving the goal of community living and is therefore contrary to the UN Convention on the Rights of Persons with Disabilities (in particular Article 19 - Living independently and being included in the community).
- An overview is provided of the situation of people with disabilities in the EU, focusing on the prevalence of institutionalisation in many Member States and the key reasons why the transition to community living has yet to be achieved.

- In addition to providing an overview of the situation in the EU, this study provides a summary of the key issues arising from the Slovak ESIF report, together with additional information that has been obtained since that report's publication.
- A series of recommendations addressed to both the European Commission and Member States are presented at the end of this study.

1. INTRODUCTION

KEY FINDINGS

- This study focuses on the situation of people with disabilities in the European Union (EU) and the role of EU funds, known as the European Structural and Investment Funds (ESIFs), in facilitating the transition from institutional care to community living for people with disabilities.
- ESIFs can provide the financial and technical support to assist Member States in achieving this transition but in the past they have been used to maintain institutional care rather than develop community-based alternatives.
- The aim of this study is twofold: to highlight the potential role of ESIFs in supporting the reforms that are necessary to achieve community living and to consider the steps that need to be taken to ensure that ESIFs are used for this purpose, rather than to perpetuate the system of institutional care.

This study[1] concerns the situation of people with disabilities in the European Union (EU) and the role of EU funds, known as the European Structural and Investment Funds (ESIFs) in facilitating the 'transition from institutional to community-based care' for people with disabilities (the steps taken to achieve this transition from institutional care to community living are often referred to as 'the deinstitutionalisation process'[2]).

The expression 'transition from institutional to community-based care' was coined by the 2009 *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care* ('the report of the Ad Hoc Expert Group') which was drafted by a group of independent experts convened by Commissioner Vladimír Špidla 'to address the issues of institutional care reform in their complexity'.[3] It has since been adopted in various guidance[4] and regulations[5] concerning the use of ESIFs in this area. This study uses a similar expression 'transition from institutional care to community living'. This is to emphasise that the overarching goal of community-based services must be to enable people with disabilities to live and participate in the community as equal citizens (the importance of community living is discussed in Chapter 2).

ESIFs have the potential to play a crucial role in achieving the transition from institutional care to community living because they can provide the financial and technical support to assist Member States in the planning and implementation of the reforms needed to replace the outdated systems of institutional care with the provision of a range of community-based

[1] The authors would like to thank Maria Machajdikova, Miroslav Cangar, Katarina Medlova and Maros Matiasko for providing us with valuable input in relation to this study's analysis of the situation in Slovakia.
[2] An explanation of terms used in this study report is provided in Annex 1.
[3] European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, 2009* ('the report of the Ad Hoc Expert Group') 2.
[4] See for example, 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* ('the EEG Toolkit').
[5] See for example, Regulation (EU) No 1301/2013 of the European Parliament and of the Council of 17 December 2013 on the European Regional Development Fund and on specific provisions concerning the Investment for growth and jobs goal and repealing Regulation (EC) No 1080/2006, Article 5(9) 'promoting social inclusion, combating poverty and any discrimination, by: (a)…the transition from institutional to community-based services'.

services that support social inclusion. This point was highlighted by the report of the Ad Hoc Expert Group, which recommended that Member States use EU funds for this purpose, explaining that these funds can be used 'for the training (and re-training) of staff' and for the development of 'social infrastructure which will support the new community-based services'.[6] Since then, guidance has been issued to assist Member States in their work to develop community-based alternatives to institutional care, with detailed guidance on how ESIFs can be used to facilitate the necessary reforms being provided in the *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care* ('the EEG Toolkit'), published by the European Expert Group on the Transition from Institutional to Community-based Care ('the EEG').[7]

Such work is crucial given that in many parts of the EU people with disabilities continue to be institutionalised, a situation that is contrary to the EU law and policy that seek to promote the social inclusion of all EU citizens[8] and most particularly, the United Nations Convention on the Rights of Persons with Disabilities ('the CRPD'),[9] which has been ratified by the EU and all but one of the EU Member States.[10] This is especially true for Central and Eastern Europe (CEE) and the Baltic countries (which became EU members in and after 2004), given their strong legacy of institutional care and the lack of community-based alternatives.[11] However, rather than being invested in activities designed to facilitate the shift away from institutional care to a range of community-based services that support community living, serious concerns have been raised about the use of EU funds to renovate existing, or build new long-stay facilities (institutions), thereby hindering, rather than supporting the work to promote the social inclusion of people with disabilities.[12]

That EU funds have been used to maintain institutional care rather than develop community-based alternatives was the subject of a petition submitted to the European Parliament by the Open Society Mental Health Initiative, with the support of an additional thirteen civil society organisations concerned with the promotion of equal rights of people with disabilities in Europe. The petition states:

[6] Report of the Ad Hoc Expert Group (n. 1) 20.
[7] EEG Toolkit (n. 4 above).
[8] See for example: European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe COM(2010) 636 final; Europe 2020, A strategy for smart, sustainable and inclusive growth, COM(2010)2020 final; The European Platform against Poverty and Social Exclusion: A European framework for social and territorial cohesion, COM(2010) 758 final and Launching a consultation on a European Pillar of Social Rights, COM(2016)127final.
[9] For further information on this issue see, for example: Open Society Foundations, 2015, *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); Office of the High Commissioner for Human Rights (OHCHR), 2012, *Getting a Life – Living Independently and Being Included in the Community* and 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*.
[10] Ireland is the only EU Member State that has not yet ratified the CRPD. The EU ratified the CRPD in December 2010. For further information on the CRPD in the context of the role of the PETI Committee, see Directorate General for Internal Policies, (authors: Mark Priestly, Meredith Raley and Gauthier de Beco), *The Protection Role of the Committee on Petitions in the Context of the Implementation of the UN Convention on the Rights of Persons with Disabilities,* 2015.
[11] See Annex 3 (Selection of reports about institutionalisation of children and adults in countries accessing Structural Funds and IPA) of the EEG Toolkit (n. 4 above).
[12] See for example: 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* ('the Wasted Lives report'). Additional reports on this issue are listed in Annex 2 of this study.

> *We draw the urgent attention of the European Parliament to the illegal use of EU Structural Funds (principally the European Regional Development Fund) by some Central and Eastern European (CEE) Member States that have invested the funds in long-stay residential institutions which perpetuate the unjust, inappropriate and long-term social exclusion of people with disabilities.*[13]

Similar concerns have been raised by the Committee responsible for overseeing the steps taken by governments to comply with their obligations under the CRPD (the Committee on the Rights of Persons with Disabilities - 'the CRPD Committee').[14] In its *Concluding observations on the initial report of the European Union* of 2015 ('the EU Concluding Observations report'), the CRPD Committee stated that it was:

> *…concerned that across the European Union, persons with disabilities, especially persons with intellectual and/or psychosocial disabilities still live in institutions rather than in their local communities. It notes that, despite changes in regulations, the European Structural and Investment Funds continue to be used in different Member States for the maintenance of residential institutions rather than for the development of support services for persons with disabilities in local communities.*
>
> *…The Committee recommends that the European Union develop an approach to guide and foster deinstitutionalization and to strengthen the monitoring of the use of the European Structural and Investment Funds so as to ensure that they are used strictly for the development of support services for persons with disabilities in local communities and not for the redevelopment or expansion of institutions.*[15]

Drawing upon the available research and reports on the use of ESIFs in this area, including the in-depth analysis prepared for the PETI Committee prior to its Fact Finding Visit to Slovakia in September 2016, *European Structural and Investment Funds and People with Disabilities in Slovakia* (the Slovak ESIF report),[16] this study has two main aims. First, to highlight the potential role of ESIFs: specifically, how they can help to address the prevalence of institutionalisation within the EU by supporting the reforms that are necessary to achieve the objective of transferring from a system of institutional care to community-based services that support social inclusion. The second aim is to consider the steps that need to be taken to ensure that ESIFs are used for this purpose, rather than to perpetuate the system of institutional care. The study seeks to do so by identifying the key problems with the use of EU funds that arose in the past and highlighting areas that will need to be addressed in order to avoid a repeat of such problems in the current financial period.

Chapters 2 and 3 provide the context for this study. Chapter 2 explains what is meant by 'community living' and shows why the institutionalisation of people with disabilities is a fundamental barrier to achieving the goal of community living and therefore contrary to the CRPD (in particular Article 19 - Living independently and being included in the community).

[13] This petition concerns the implementation of the following EU and international standards binding on the European Union and the Member States (Petition Nr. 1459/2012).

[14] State parties to the CRPD are required to report on their progress in implementing this treaty to the CRPD Committee, to which the Committee responds in a report referred to as 'Concluding observations'.

[15] *Concluding observations on the initial report of the European Union* CRPD/C/EU/CO/1 (2015) ('the EU Concluding Observations report'), para 50 -51.

[16] Directorate General for Internal Policies, Policy Department C: Citizens' Rights and Constitutional Affairs, Petitions, (authors: Camilla Parker, Ines Bulic Cojocariu and Lilia Angelova Mladenova): *European Structural and Investment Funds and People with Disabilities in Slovakia* (2016) ('the Slovak ESIF report').

Chapter 3 provides an overview of the situation of people with disabilities in the EU, focusing on the prevalence of institutionalisation in many Member States and the main reasons why the transition to community living has yet to be achieved.

Chapter 4 focuses on ESIFs. It covers the following areas: an overview of the scope and purpose of ESIFs; their potential role in facilitating the transition from institutional care to community living; concerns raised about the inappropriate use of EU funds, namely the investment of such funds into institutional care in some of the Member States; key aspects of the current regulations governing the use of ESIFs. It identifies continuing concerns and why these need to be addressed as well as providing a summary of the key issues arising from the Slovak ESIF report, together with additional information that has been obtained since that report's publication. Chapter 5 sets out a series of recommendations addressed to both the European Commission and Member States.

2. COMMUNITY LIVING FOR PEOPLE WITH DISABILITIES

KEY FINDINGS

- The institutionalisation of people with disabilities remains a key concern in the EU.
- In addition to the human rights violations that are common within institutions, the practice of placing people with disabilities under guardianship is a huge barrier to the social inclusion of people with disabilities and therefore the right to community living.
- The segregation of people with disabilities in institutions is contrary to Article 19 of the UN Convention on the Rights of Persons with Disabilities.
- A key reason for the continued prevalence of institutionalisation is lack of services and supports in the community.

2.1. The importance of community living

The term 'community living' (also known as 'independent living')[17] is used to refer to the right of people with disabilities to live in their local communities and receive the support they need to participate in every-day life. This includes, for example, living in their own homes or with their families, attending the same schools or working in the same places as their non-disabled peers, and taking part in community activities they choose. Thomas Hammarberg, the then Council of Europe (CoE) Commissioner for Human Rights, stated in 2012 that this right 'applies to all people with disabilities' and that '[n]o matter how intensive the support needs, everyone, without exception, has the right and deserves to be included and provided with opportunities to participate in community life'. The Commissioner added:

> *Time and again it has been demonstrated that people who were deemed too 'disabled' to benefit from community inclusion thrive in an environment where they are valued, where they partake in the everyday life of their surrounding community, where their autonomy is nurtured and they are given choices. Programs from around the world have shown that all types of support needs can be answered, and are better answered, in community settings, which allow for expression of individuality and closer scrutiny to prevent abuse.*[18]

That there is such a right to community living is made clear by Article 19 (living independently and being included in the community) of the CRPD. Although this article does not create a new right, it is the first time that such a right has been articulated in an international human rights treaty.

[17] See Annex 1: Glossary.
[18] Issue Paper published by the Council of Europe, Commissioner for Human Rights, *The right of people with disabilities to live independently and be included in the community*, June 2012, p.9

2.2. Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD)

Article 19 requires governments to take action so that people with disabilities can live and participate in the community 'with choices equal to others', in particular, to ensure that people 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;
- have access to a range of community services, including personal assistance, necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; and
- have access to mainstream services and facilities, which are responsive to their needs.

Thus, a central requirement of Article 19 CRPD is that action is taken to ensure that all people with disabilities can live in the community and receive the support that they need to participate in society as equal citizens.

2.3. Institutionalisation contrary to community living

That people with disabilities continue to be placed in long-stay residential facilities ('institutions') in parts of the EU (in particular, but not exclusive to, Central and Eastern Europe), is a fundamental barrier to the realisation of the right of people with disabilities to 'live independently and being included in the community' as envisaged by Article 19 CRPD.

Not only have numerous reports highlighted the human rights violations that take place within institutions,[19] but the segregation and social exclusion of the residents of institutions (the institutions often being placed in remote and inaccessible parts of the country) is contrary to the goal of community living. As noted in Chapter 1 (Introduction), the CRPD Committee has raised serious concerns about the institutionalisation of people with disabilities. Similar concerns have been raised by the Council of Europe's Commissioner for Human Rights, Nils Muižnieks who stated in his keynote speech to the International Symposium 'Human Rights and Disability' in Vienna in April 2014 that:

> *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.*[20]

A common and significant reason for the high numbers of people being placed in institutions is because of the paucity of community-based services and supports. The lack of accessible community-based services is also likely to mean that people with disabilities who are not institutionalised 'live disconnected and lonely lives because the infrastructure of inclusion -

[19] See for example Annex 2, EEG Toolkit (n. 4 above).
[20] CommDH/Speech(2014)9, Strasbourg, 2 October 2014.

especially open and accessible services as well as personalised services - is insufficiently developed'.[21]

The continued prevalence of the institutionalisation of people with disabilities, the lack of community-based alternatives to such institutionalisation and the slow progress towards community living is discussed in the next chapter.

[21] United Nation Office of the High Commissioner for Human Rights, *Getting a Life – Living Independently and Being Included in the Community,* 2012, p 12.

3. SITUATION OF PEOPLE WITH DISABILITIES IN THE EUROPEAN UNION AND PROGRESS TOWARDS COMMUNITY LIVING

KEY FINDINGS

- Reports on the situation of people with disabilities, both generally and in relation to those living in institutions, highlight the paucity of information available.
- There are specific concerns about the situation of certain groups of people (those with mental health problems and/or intellectual disabilities and children with disabilities) and the use of guardianship.
- In those countries where institutionalisation is still prevalent, action is required to develop community-based alternatives to institutional care.
- Across the member states, the work towards the transition from institutional care to community living is extremely slow and the institutionalisation of people with disabilities remains prevalent in many countries.

3.1. Lack of information about people with disabilities living in EU

A general summary of the situation of people with disabilities is provided by the European Economic and Social Committee (EESC) in its 2012 report which states:

> *There are around 80 million persons with disabilities in Europe and, according to Eurostat figures, they are two to three times more likely to be unemployed than non-disabled people; only 20% of people with severe disabilities have a job, compared to 68% of those without disabilities. Persons with disabilities are more than 50% less likely to reach third-level education than non-disabled persons. Only 38% of persons with disabilities aged 16-34 across Europe have an earned income, compared to 64% of non-disabled people.*[22]

Although some information on people with disabilities is published at EU and national levels, concerns have been raised that such information is neither comprehensive nor consistent.

3.1.1 Inadequate information concerning people with disabilities in the EU

At the EU level, there are no standards for data collection agreed in relation to services for disabled people generally, while the data that is collected is limited in scope.[23] For example, as noted by the European Commission in the EU report to the CRPD Committee, the EU Statistics on Income and Living Conditions ('EU-SILC') survey only interviewed those aged

[22] Opinion of the European Economic and Social Committee on the Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions and the role of the EESC (own-initiative opinion), SOC/464, Brussels, 12 December 2012, para. 2.2.
[23] ENIL-ECCL, 2014, *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 (the ENIL-ECCL Shadow Report), p. 19.

16 and older, while those living in 'collective households and institutions are generally excluded'.[24] Based on EU statistics, a report of December 2013 estimated that within the EU there were 74 million persons with a moderate disability aged 16 and over living in private households (71 million in 2012) and 35 million with a severe disability (no change from 2012).[25] The European Disability Forum (EDF) has raised concerns that there is little data on overall disability prevalence available at EU level and even less that is gender disaggregated, which 'makes having a precise assessment of the situation of persons with disabilities across Europe more difficult'.[26]

In its EU Concluding Observations report, the CRPD Committee raised concerns 'at the lack of consistent and comparable data on persons with disabilities in the European Union' and recommended that the EU develop 'a comparable comprehensive data collection system with data disaggregated by gender, age, rural/urban population and impairment type'.[27]

3.1.2. Inadequate information about people with disabilities within Member States

There are also difficulties in obtaining information about people with disabilities at a national level. As noted in the Slovak ESIF report, it is difficult to provide the number of people with disabilities living in institutions in Slovakia, as statistics are based on the number of places within institutions, rather than the number of people living there and may include short-term as well as long-term stays.[28] Similar problems have been noted in relation to other Member States. For example:

- The European Foundation Centre's 2012 study noted that in the Member States information and data 'are fragmented, outdated, not recorded or not made public, which makes an accurate analysis of the country situation difficult and a cross-country comparison almost impossible'.[29]
- One of the general findings ('that coincided with findings from previous studies') of *Mapping Exclusion - Institutional and community-based services in the mental health field in Europe ('Mapping Exclusion'),* a survey (published in 2012) of mental health services across 32 European countries, including the 27 Member States was that 'data is often not readily available'. It also noted that in some countries, for example Austria, Italy and Spain the limited availability of data was because 'the health and/or social care system is decentralised'. [30]
- EDF notes that the available information from the national level is very difficult to compare because different definitions are adopted, both across countries but also by different public bodies within the same country.[31]

[24] 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, para 196. This point being highlighted in the ENIL-ECCL Shadow Report (n. 23 above) p. 19.
[25] European comparative data on Europe 2020 & People with disabilities Final report prepared by Stefanos Grammenos from Centre for European Social and Economic Policy (CESEP ASBL) on behalf of the Academic Network of European Disability Experts (ANED) December 2013, p 17.
[26] EDF, Alternative Report on the Implementation of the UN Convention on the Rights of Persons with Disabilities, 2015 (the EDF Alternative Report), p. 61.
[27] EU Concluding Observations Report (n. 14 above) paras. 72 – 73.
[28] Slovak ESIF report (n. 16 above).
[29] European Foundation Centre (EFC), *Assessing the impact of European governments' austerity plans on the rights of people with disabilities, European Report,* 2012, p. 29.
[30] Mental Health Europe and the Open Society Foundations, *Mapping Exclusion - Institutional and community-based services in the mental health field in Europe,* 2012, p. 16.
[31] EDF Alternative report (n. 26 above) p. 61.

- In relation to children with disabilities and children in alternative care the Committee on the Rights of the Child has raised concerns about the lack of availability of data in relation to a number of Member States reviewed since 2011 (for example, Finland, Italy, Cyprus, Greece, Slovenia and Germany).[32]

3.2. Prevalence of institutionalisation

It is not known how many people with disabilities live in institutional care facilities across the EU given that it is difficult to obtain up to date information on this area. However, available information suggests that the number of people with disabilities placed in institutions is rising in some parts of the EU.

3.2.1 Problems in obtaining comprehensive and accurate information

A study undertaken on behalf of the European Commission of 28 European countries, published in 2007, *Deinstitutionalisation and community living – outcomes and costs: report of a European Study* ('the DECLOC report') estimated that at least 1.2 million people with disabilities were living in institutions in the region.[33] The study reported that the review of European and international statistics showed that there were no 'existing sources providing comprehensive information about the number and characteristics of people in residential institutions in Europe'.[34]

That such problems exist in obtaining information about people living in institutions was highlighted by the Slovak ESIF report, which, albeit showing the high numbers of people with disabilities living in institutions (an estimated figure of 28,375 at the end of 2014[35]) was only able to provide indicative figures. This is because the figures provided are based on the number of places within institutions, rather than the number of people living there and may include short-term stays as well as long stays (i.e. year-round residential care).

The 2012 report *Mapping Exclusion – Institutional and community-based services in the mental health field in Europe* ('*Mapping Exclusion*'), which gathered information from 32 countries, including all the EU Member States, identified another problem. It found that official data on the number of people with mental health problems in institutional care often excluded those placed in social care homes, even though 'the number of people with mental health problems in social care homes may be as large as the number in psychiatric

[32] For the Concluding Observations of the Committee on the Rights of the Child see: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=5&TreatyID=10&TreatyID=11&DocTypeID=5

[33] 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'). The countries covered were the then 27 EU Member States and Turkey. Although this figure dates from 2007, there have been no further major studies aimed at establishing the number of people with disabilities living in institutions in the EU since then.

[34] *ibid*, page 11, see also pages 94 – 95.

[35] See Table 1 of the Slovak ESIF report (n. 16), at p. 10, which shows that of this number 450 are children with disabilities, 10. The total number of people in institutions is 39,689 persons in 861 residential institutions, including homes for older people, social care homes for adults with disabilities, specialised (medical) institutions, social care homes for children and children's homes. According to the information provided to the CRPD Committee in November 2015, there were 427 children with disabilities in 66 children's homes, with 96 children with 'mental disorders'. Despite further efforts since the publication of the Slovak ESIF report, it has not been possible to obtain more concrete information on the numbers of people with disabilities living in institutions in Slovakia.

hospitals'.[36]

3.2.2 Rise in numbers of people with disabilities in institutions is some Member States

Notwithstanding the lack of reliable data about people with disabilities noted above, there are indications that the number of people with disabilities being placed in institutional care has increased. For example, one report notes that 'Slovenia has been increasing the number of places in social care institutions',[37] while the CoE Commissioner for Human Rights noted in his 2014 country visit report, that in Romania 'the number of residential social care institutions for adult persons with disabilities has more than doubled in the past eight years, from 141 at the end of 2005 to 335 at the end of December 2013'.[38]

A similar concern has been raised in relation to some of the more developed EU Member States, such as Belgium, Denmark[39] and Luxembourg.[40] As noted in Table 1 below, the CRPD Committee has highlighted the increase in the institutionalisation of people with disabilities in relation to Austria, Germany, Italy, Portugal and Spain, as well as the CEE countries of Czech Republic and Lithuania.[41] In addition, more people with disabilities are being placed in long-stay residential settings, rather than being supported in their own homes as a result of the cuts to public services.[42]

[36] Mental Health Europe and the Open Society Foundations, *Mapping Exclusion - Institutional and community-based services in the mental health field in Europe,* 2012 (*Mapping Exclusion)* 13. Private communication provided to ENIL suggests that this is the situation for Slovakia: There are 8 psychiatric hospitals in Slovakia (with a total capacity of 2,411 beds, including a psychiatric hospital for children with a capacity of 90) but in the main, people with chronic mental health problems are placed in social care homes, rather than psychiatric institutions.
[37] See, for example, *Mapping Exclusion* (n. 36 above) p. 21.
[38] Council of Europe Commissioner for Human Rights Country visit (Romania 2014) para. 15. See Annex 4.
[39] The information in relation to Belgium and Denmark was provided by 'shadow' reports prepared by civil society organisations in relation their respective countries. It should be noted that a vast array of information is provided in such 'alternative' or 'shadow' reports given that civil society organisations set out their views on the extent to which their governments are meeting their obligations under the CRPD. These are submitted to the CRPD Committee ahead of its review of the report submitted by the State party. A list of shadow reports for Austria, Belgium, Czech Republic, Denmark and Germany is provided in Annex IV (Resources) of the ENIL-ECCL Shadow report (n. 23 above).
[40] See ANED DOTCOM (the Disability Online Tool for the Commission) entry for Luxembourg, available at: http://www.disability-europe.net/content/luxembourg-d1-choice-living-arrangements
[41] See Annex 3 for details of the CRPD's Concluding Observations.
[42] ENIL-ECCL Shadow report (n. 23). 15.

Table 1: CRPD Committee's Concerns: Institutionalisation

Member State & Date	Concerns raised in the Concluding Observations
Austria (2013)	…over the last 20 years the population of Austrians with disabilities living in institutions has increased (para 36).
Belgium (2014)	…high rate of referral to institutional care for persons with disabilities …there is insufficient information on opportunities to continue living in society and the community, since institutional care is too often seen as the only lasting solution (para 32).
Czech Republic (2015)	…urges the State party to abolish the placement of children under 3 years of age in institutionalized care as soon as possible (para 40).
Germany (2015)	…high levels of institutionalization (para 41).
Italy (2016)	… the trend to re-institutionalize persons with disabilities (para 47).
Lithuania (2016)	…Many children under 3 years of age with disabilities are still placed in residential institutions; …no guarantees that all younger persons with disabilities have realistic options of choosing not to live in residential facilities for the elderly (para 39).
Portugal (2016)	…forcing some people to live in institutions for persons with disabilities or for older persons (para 38).
Slovakia (2016)	…high number of institutionalized persons with disabilities, in particular women with disabilities (para 55).
Spain (2011)	…those living in residential institutions are reported to have no alternative to institutionalization (para 39).

Source: (UN Committee of the Rights of People with Disabilities (the CRPD Committee)[43])

3.2.3. People with mental health problems and people with intellectual disabilities

The finding by the DECLOC report of 2007 that people with mental health problems and people with intellectual disabilities form the majority of people living in institutions is echoed by more recent reports. ENIL-ECCL report that information from Bulgaria, Latvia and Lithuania[44] highlight the particular vulnerability of these two groups of people to institutionalisation. Furthermore, following his country visits in the Czech Republic (2013), Denmark (2014) and Spain (2013), the CoE Commissioner for Human Rights raised concerns about the institutionalisation of people with mental health problems (also referred to as psycho-social disabilities) and the lack of protection of their human rights. [45] The *Mapping Exclusion* report notes that people with mental health problems 'are still hospitalised for long periods of time in psychiatric hospitals', being prevented from moving 'on to more

[43] The relevant Concluding Observations of the CRPD Committee are listed in Annex 3
[44] ENIL-ECCL Shadow report (n. 23 above) pp. 22 -23
[45] See Annex 4 for a list of the CoE Commissioner for Human Rights country visit reports.

independent, community-based arrangements because these are simply not available'.[46]

3.2.4. Children with disabilities

Concerns about the institutionalisation of children with disabilities within Member States have been raised by a number of organisations. The Committee on the Rights of the Child has done so in relation to Austria (2012), Greece (2012), Hungary (2014), Lithuania (2013) and Portugal (2014).[47] The CRPD Committee has also raised concerns on this point in relation to Hungary (2012) and Lithuania (2016).[48] Both the CRPD Committee (2015)[49] and the CoE Commissioner for Human Rights (2013)[50] have raised concerns about children with disabilities in institutions in the Czech Republic. The CoE Commissioner for Human Rights has also raised concerns about the institutionalisation of children in Estonia (2013) and Romania (2014).[51] EDF considers that children with disabilities are 'disproportionately represented in institutions and EU Member States which ban the institutionalisation of children under a certain age, often allow for exceptions for children with disabilities'.[52]

3.3. Inadequate care for people living in institutions

The DECLOC report 'found that institutional care for disabled people in Europe fell short of acceptable standards and recommended wider use of community based services'.[53] The Ad Hoc Expert Group report emphasised that the institutionalisation of people with disabilities is not an acceptable form of care in the 21st Century:

> *There is a growing recognition - though perhaps falling short of a clear consensus - that no matter how much money is spent on institutions, the characteristics of institutional care are bound to make it extremely difficult to provide adequate quality of life for users, to ensure enjoyment of human rights and accomplish the goal of social inclusion.*[54]

Mapping Exclusion highlights particular concerns in relation to the inadequacy of care for people with mental health problems. It notes that they may be placed in psychiatric hospitals or care homes. Furthermore:

> *Many of these settings, particularly in Central and Eastern Europe are large institutions with diverse residents (including elderly people, people with intellectual and other disabilities, and people who have substance abuse issues) and offer minimal or no treatment but solely custodial care in highly regimented settings. People in institutions have no choice on how to live their lives, they are likely to receive treatment without consent and be restrained chemically and sometimes physically.*[55]

[46] *Mapping Exclusion* (n. 36 above) p. 24.
[47] See (n. 32 above) for the link to the Concluding observations of the Committee on the Rights of the Child.
[48] See Annex 3 for details of the CRPD's Concluding Observations.
[49] See Annex 3 for details of the CRPD's Concluding Observations.
[50] See Annex 4 for CoE Commissioner for Human Rights country reports.
[51] See Annex 4 for CoE Commissioner for Human Rights country reports.
[52] EDF Alternative report (n. 26 above).
[53] The DECLOC report (n. 33 above).
[54] Ad Hoc Expert Group report (n. 3 above) p. 11.
[55] *Mapping Exclusion* (n. 36 above) p. 13.

The serious human rights violations that occur within institutions have been raised by numerous reports.[56] That this is a matter of significant and continuing concern, is emphasised by the CoE Commissioner for Human Rights when explaining why the rights of persons with disabilities is one of his main concerns, in particular, their segregation 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…*
>
> *…The problem is not only the unimaginable suffering, inhuman and degrading treatment persons with disabilities are often subjected to in these institutions, far from any public scrutiny. These are also places where people suffer the indignity of having absolutely no control over their life choices.*[57]

3.4. Guardianship: a significant barrier to community living

A major barrier to community living for people with disabilities is the system of 'guardianship', whereby a court removes, or restricts, the legal capacity of individuals (so that they are not recognised in law as being able act on their own behalf, such as entering into contracts, getting married or voting in parliamentary elections).

The use of guardianship is a common practice across the EU. Concerns about guardianship, particularly plenary guardianship (whereby a person is held to lack capacity and a 'guardian' is authorised to make all decisions on behalf of that person), have been raised by civil society organisations in relation to Austria, Latvia, and Lithuania [58] and by the CoE Commissioner for Human Rights in relation to the Czech Republic, Denmark, Slovakia, Spain and Romania.[59] In its Concluding Observations in relation to the EU, the CRPD Committee raised its 'deep concern that across the European Union, the full legal capacity of a large number of persons with disabilities is restricted'.[60] The CRPD Committee considers that such systems of guardianship are contrary to the CRPD and should be replaced with systems for supporting people with disabilities to make decisions for themselves.[61]

Guardianship is of direct relevance to the institutionalisation of people with disabilities on a number of counts. First, is the connection between legal capacity and Article 19 CRPD. This is illustrated by the 2013 report published by the European Union Fundamental Rights Agency (FRA), *Legal capacity of persons with intellectual disabilities and persons with mental health problems,*[62] in which individuals who had been subject to guardianship reported that

[56] See Annex 2 (Selection of reports about institutionalisation of children and adults in countries accessing Structural Funds and IPA) of the EEG Toolkit (n. 4 above). See also Mental Disability Advocacy Centre (MDAC), *Cage beds and coercion in Czech psychiatric institutions*, 2014.
[57] CommDH/Speech(2014)9, Strasbourg, 2 October 2014.
[58] Shadow report for Austria (2013) noted in Annex IV of the ENIL-ECCL Shadow report (n. 23 above).
[59] CoE Commissioner for Human Rights country reports are listed in Annex 4
[60] The EU Concluding Observations report (n. 15 above) para 36
[61] See Committee on the Rights of Persons with Disabilities General Comment No. 1 (2014) CRPD/C/GC/1 para. 24 - 28
[62] European Union Fundamental Rights Agency (FRA), *Legal capacity of persons with intellectual disabilities and persons with mental health problems*, 2013. See: http://fra.europa.eu/sites/default/files/legal-capacity-intellectual-disabilities-mental-health-problems.pdf

'guardians also exercised decision-making power over where and with whom they lived'. FRA contrasts this with Article 19 CRPD which 'stipulates that persons with disabilities should have the opportunity to choose their place of residence on an equal basis with others and not be obliged to live in a particular living arrangement'.[63] Second, is the connection between the placement in an institution and the loss of legal capacity. For example, as noted in the Slovak ESIF report, the CoE Commissioner for Human Rights raised concerns that 'as matter of practice, almost all persons placed in an institution for persons with intellectual and psychosocial disabilities are deprived of their legal capacity'.[64] This is linked to the third main connection between guardianship and institutionalisation, which is that being subject to guardianship means that decisions about the placement in institutional care are made by the guardian often without consultation with the person concerned.[65]

As noted in the Slovak ESIF report, Slovakia has undertaken some reforms of their guardianship laws. Given that other Member States, are also in the process of reviewing their guardianship (or equivalent) systems, or have already done so, the question whether such reforms have addressed the concerns about the use of guardianship and the barriers to community living is one that merits further research.[66]

3.5. The lack of community-based alternatives to institutional care

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

> *...deplores the fact that certain persons with disabilities have no choice but to live in special homes, given the lack of community-based alternatives, and calls on the Member States to champion arrangements which enable more persons with disabilities to live independently.*[67]

The European Foundation Centre 2010 study on the CRPD notes that research 'in this field has revealed that the existence of national laws that still permit institutionalisation of persons with disabilities hampers significantly their social inclusion and full participation in their society'. It adds:

> *Several national policies are focused on improving institutional care, instead of moving residents of such institutions into the community. In cases where national policies promote independent living for persons with disabilities, the frequent absence of direct payments, or individualised funding schemes, to allow persons with disabilities to manage their own affairs is a significant challenge to the effective implementation of the UN CRPD.*[68]

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[63] i*bid,* 47.
[64] CoE Commissioner for Human Rights of the Council of Europe country report (Slovak Republic 2015). 2. See also *Mapping Exclusion* (n. 36 above) 21
[65] See for example, *Stanev v Bulgaria* (App 36760/06) 17 January 2012. See also [FRA] and *Mapping Exlusion* (n. 36 above) 21.
[66] *Mapping Exclusion* (n. 36 above) noted that legislative reviews were being undertaken by the Bulgaria, Czech Republic, Ireland, Latvia, Lithuania, Malta and Slovakia, as well as Moldova.
[67] European Parliament Resolution of 27 February 2014 on the situation of fundamental rights in the European Union (2012), paragraph 50.
[68] European Foundation Centre (EFC), *Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities VC/2008/1214 – Final Report*, 2010, page 10.

The relationship between the lack of community-based services and institutionalisation was illustrated by the information provided to the CoE Human Rights Commissioner on his visit to Romania, where at the end of 2013 only 1,669 adults with disabilities were receiving community-based support (provided by 57 non-residential institutions), whereas more than 17,000 adults were placed in institutional care. Furthermore, '67% of persons with disabilities placed in an institution remain there for life, while 14% are transferred at some point to other centres'.[69]

As noted in the Slovak ESIF report, community-based services and supports as alternatives to institutionalisation are sorely underdeveloped,[70] with both the CoE Commissioner for Human Rights and the CRPD Committee raising concerns about the thousands of people with disabilities who continue to be institutionalised and the slow process of deinstitutionalisation.[71] A major issue is the way in which services are funded creates incentives for institutional care placements, rather than living in the community. While placement in the institution is subsidised by the state and the regional authority, the same financial support is not available should a person live in their own home.

The inadequate development of community-based services has been raised in relation to a significant number of Member States. Concerns have been raised by civil society organisations in relation to Austria, Belgium, Bulgaria, Denmark, Greece Lithuania and Spain,[72] and by the CoE Commissioner on Human Rights in relation to Estonia,[73] Romania[74] and Spain. As shown by Table 2 below, similar concerns have also been raised by the CRPD Committee in relation to Belgium, Croatia, Czech Republic, Germany, Hungary, Italy, Lithuania, Portugal, Slovakia and Spain.[75]

[69] CoE Commissioner for Human Rights, country report (Romania 2014), see Annex 4.
[70] Referring to the *Implementation of the United Nations Convention on the Rights of Persons with Disabilities in Slovakia: Alternative report of Non-governmental Organisations* (Alternative Report), para 21.
[71] CoE Commissioner for Human Rights of the Council of Europe country report (Slovak Republic 2015) para 55. See Annex 4.
[72] ENIL-ECCL Shadow report (n. 23 above) pp. 23 – 24.
[73] CoE Commissioner for Human Rights, country report (Estonia 2013) See Annex 4.
[74] CoE Commissioner for Human Rights country report (Romania 2013) para. 26. See Annex 4.
[75] See Annex 3 for details of the CRPD's Concluding Observations.

Table 2: CRPD Committee's Concerns: Lack of Community-based Services

Member State & Date	Concerns raised in the Concluding Observations
Belgium (2014)	…very few opportunities for persons with disabilities to live independently owing to a lack of investment and the inadequacy of personal assistance services (para 32).
Croatia (2015)	… recommends that a legal framework be adopted to provide for entitlement to personal assistance services in the community and that a process be initiated to make local communities and mainstream services accessible to persons with disabilities (para 30).
Czech Republic (2015)	… recommends that the State party…allocate sufficient resources for the development of support services in local communities that would enable all persons with disabilities…to choose freely with whom, where and under which living arrangements they will live (para 39).
Germany (2015)	…lack of alternative living arrangements [to institutionalisation] or appropriate infrastructure, which present additional financial barriers for persons with disabilities. (para 41).
Hungary (2012)	…fails to provide sufficient and adequate support services in local communities to enable persons with disabilities to live independently outside a residential institutional setting (para 33).
Italy (2016)	…recommends that the State party…redirect resources from institutionalization to community-based services and increase budget support to enable persons with disabilities to live independently across the country and have equal access to services, including personal assistance. (para 48).
Lithuania (2016)	…lack of sufficient choice and range of adequate support mechanisms, including independent living schemes, to ensure that persons with disabilities can access accommodation within their local community, regardless of their sex, age or impairment… …no programme for individualized personal and financial assistance allowing persons with disabilities to live independently in the community, and a lack of range of community-based service (para 39).
Portugal (2016)	…the National Mental Health Plan 2007-2016…has not yet established support services in the community (para 38).
Slovakia (2016)	… the lack of provision of full support for persons with disabilities to live independently in their communities (para 55)
Spain (2011)	…encourages the State party to ensure that an adequate level of funding is made available to effectively enable persons with disabilities: to enjoy the freedom to choose their residence on an equal basis with others; to access a full range of in-home, residential and other community services for daily life, including personal assistance; and to so enjoy reasonable accommodation so as to better integrate into their communities (para 40).

Source: (UN Committee of the Rights of People with Disabilities (the CRPD Committee[76])

[76] See Annex 3 for details of the Concluding Observations of the CRPD Committee.

3.6. Slow progress towards community living

One of the significant concerns arising from the Slovak ESIF report is that despite policies that emphasise its importance and strategies for its implementation, the progress towards the goal of replacing institutional care with a system that supports community living is very slow. However, reports indicate that this is replicated in other Member States in which institutional care is prevalent, while they also suggest a number of explanations for this problem. These possible reasons, which fall into two broad areas are outlined below.

3.6.1 Problems with planning for, and implementation of, deinstitutionalisation

ENIL-ECCL's 2014 report *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* (the ENIL-ECCL Shadow report) identified a number of concerns. First, (based on the available information) plans for national programmes for deinstitutionalisation had not been finalised for Austria, Belgium, Estonia, Poland, and Romania while in Lithuania the plan had only recently been approved.[77] Second, in some Member States where plans had been approved, the report noted that there were problems with their implementation. One such example, is highlighted in the CRPD Committee's Concluding Observations in relation to Hungary, which noted that in Hungary the time frame for the deinstitutionalisation plan is 30 years and although the use of institutions is prohibited, institutions are defined as being residential settings of 50 beds or more.[78] ENIL-ECCL also raised concerns in relation to the Czech Republic in that deinstitutionalisation strategy includes 'humanisation' of institutions, which would therefore allow for the renovation and building of smaller institutions.[79]

As noted in the Slovak ESIF report, despite the adoption of the Deinstitutionalisation Strategy in 2011 (*Strategy for the Deinstitutionalisation of the System of Social Service and Alternative Care in the Slovak Republic* – 'the DI Strategy'), to date a very small number of institutions (10 out of 800) have been involved in the process. Not all self-governing regions, which own the institutions, support the process and there have been serious delays in the implementation of the strategy.[80] One of the reasons for the delays is that the strategy does not include a timeline for the closure of institutions, which raises concerns about the prospective length of the entire process. It was also noted that following his visit to Slovakia in June 2015, the CoE Commissioner for Human Rights was informed that the planned activities had not at that stage led to one single person being able to move from an institution into the community.

A specific concern in relation to people with mental health problems is raised by *Mapping Exclusion*, which states that 'mental health institutions are either excluded from deinstitutionalisation programmes or are otherwise disadvantaged (e.g. receive less funding

[77] ENIL-ECCL Shadow report (n. 23 above) p. 24. This information was based on reports from the CoE Commissioner for Human Rights visits to Austria and Romania as well as from information provided by civil society organisations.
[78] See Annex 3 for details of the Concluding Observations of the CRPD Committee: Hungary (2012)
[79] ENIL-ECCL Shadow report (n. 23 above) p. 24 This information was provided by ENIL-ECCL partner organisation in the Czech Republic.
[80] The Slovak ESIF report (n. 16 above) p. 12.

etc.)'. The report goes on to suggest that this 'is often linked to the strong stigma attached to people with severe mental health problems'.[81]

3.6.2 Inadequate development of accessible community-based services

A report published by FRA in 2012 considered that there was a need for 'further efforts on deinstitutionalisation' including the introduction of measures 'to ensure that adequate, good quality and freely chosen personalised support for independent living is made available independently of the type of living arrangement'.[82] ENIL-ECCL's Shadow report highlights a number of concerns in relation to the poor availability of services, including inaccessible mainstream services. For example, this has been raised in relation to Denmark (concern that social housing is not accessible to people with disabilities), Spain (mainstream services are less accessible to disabled people in rural areas than in the cities) and Romania (very poor accessibility of public spaces and services to persons with disabilities).[83]

Research carried out by ENIL on the availability of personal assistance in Europe[84] highlights the lack of development of schemes that would enable disabled people to live independently with personal assistance. A significant barrier is the insufficient resourcing of personal assistance schemes, which results in people with disabilities receiving a limited amount of personal assistance; the scheme being limited to people with specific impairments or certain local authorities; the scheme being limited to supporting people with disabilities with their most basic needs; disabled people having no option but to be supported by their family members; and the lack of peer support to enable disabled people to manage their personal assistants.

As noted in Table 3 below, the CRPD Committee has raised concerns about the adequacy of the deinstitutionalisation process in relation to the following Member States: Belgium, Croatia, Czech Republic, Germany, Hungary, Lithuania and Slovakia.

[81] *Mapping Exclusion* (n. 36 above)
[82] European Union Agency for Fundamental Rights (FRA), *Choice and control: the right to independent living. Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States,* 2012, page 11.
[83] ENIL-ECCL Shadow report (n. 23 above) referring to Shadow reports on Denmark (2013) and Spain (2010) – see Annex IV of the ENIL-ECCL Shadow report. See also CoE Commissioner for Human Rights County report (Romania 2014) – see Annex 4 of this study.
[84] European Network on Independent Living, *Personal Assistance Services in Europe*, 2015 and 2013.

Table 3: CRPD Committee's Concerns: Inadequate Deinstitutionalisation Process

Member State & Date	Concerns raised in the Concluding Observations
Belgium (2014)	…lack of deinstitutionalization plans (para 32).
Croatia (2015)	…not all residential institutions, such as small private institutions, wards for long-term care in psychiatric institutions and foster homes for adults, are covered by the deinstitutionalization plan (para 29).
Czech Republic (2015)	… urges the State party to step up the process of deinstitutionalization (para 39) …recommends that the State party take all measures necessary to ensure that policy processes for deinstitutionalization…have a clear timeline and concrete benchmarks for implementation that are monitored effectively at regular intervals (para 40).
Germany (2015)	Recommends…allocate sufficient financial resources to facilitate deinstitutionalization and promote independent living (para 42)
Hungary (2012)	… the State party has set a 30-year time frame for its plan for deinstitutionalization (para 33).
Lithuania (2016)	…recommends that the State party, in close collaboration with organizations of persons with disabilities: (a) Adopt an adequately funded strategy for deinstitutionalization ensuring a range of community-based services for the social inclusion of persons with disabilities, including for children with intellectual and/or psychosocial impairments, including their right to live independently in the community, with the possibility of individualized personal assistance support services in their home; (b) Effectively implement the action plan for the implementation of the national programme for the social integration of persons with disabilities for the period 2013-2019 at all levels of the State; (c) Adopt a moratorium on new admissions of children into institutionalized care; (para 40).
Slovakia (2016)	…progress on the deinstitutionalization process is too slow and partial (para 55) …recommends that the State party provide and implement a timetable to ensure that the implementation of the deinstitutionalization process is expedited, including by putting in place specific additional measures to ensure that community-based services are strengthened for all persons with disabilities, in particular women with disabilities and older persons with disabilities …the State party should ensure that the use of European structural and investment funds complies with article 19 (para 56).

Source: (UN Committee of the Rights of People with Disabilities (the CRPD Committee[85]))

[85] See Annex 3 for details of the Concluding Observations of the CRPD Committee.

3.7. Progress towards community living: CRPD Recommendations

In countries where the institutionalisation of people with disabilities is prevalent, the CRPD Committee expects governments to take concrete action to develop community-based alternatives and support community living, with clear timeframes and measurable indicators.[86] Such recommendations echo the guidance and commentary published by civil society organisations (including the European Expert Group on the Transition from Institutional to Community-based Care) and the European Commission. A list of such guidance is provided in Annex 2.

[86] See for example the CRPD Committee's concluding observations for Austria, Czech Republic and Denmark, (listed in Annex 3).

4. EUROPEAN STRUCTURAL AND INVESTMENT FUNDS AND THEIR ROLE PROMOTING COMMUNITY LIVING

KEY FINDINGS

- Despite their huge potential in providing the catalyst for achieving the shift from systems that institutionalise people with disabilities to the provision of services and supports necessary for community living, in the past EU funds have been invested in institutional care, thereby hindering, rather than supporting the work to promote the social inclusion of people with disabilities.
- The European Commission has sought to address this problem by instigating significant reforms in relation to the regulation of EU Funds.
- Notwithstanding these positive reforms, concerns about the use of such EU funds remain.

4.1. General Information on European Structural and Investment Funds (ESIFs)

The European Structural and Investment Funds (ESIFs) are funds which are used to support the EU's 2020 strategy for smart, sustainable and inclusive growth across the EU.[87] There are five ESIFs: the European Regional Development Fund (ERDF), the European Social Fund (ESF), the Cohesion Fund (CF), the European Agricultural Fund for Rural Development (EARDF) and the European Marine and Fisheries Funds (EMFF).[88] Such funds can be used to support a wide range of initiatives, such as employment, education and poverty reduction.[89] As noted below, the two funds that are of the most relevance to the transition from institutional care to community living are the ERDF and the ESF.

ESIFs are implemented through multi-annual programmes (operational programmes - OPs) over a seven-year period, the current period being 2014-2020, with a budget of €454 billion.[90] The OPs, which are agreed between Member States and the European Commission, set out general and specific objectives, expected results and indicators for monitoring and evaluation, and examples of activities to be supported by the ESIFs. The OPs have been developed in accordance with the Partnership Agreement between the European Commission

[87] For the period 2007-2013 EU Funds, known as Structural Funds (which included the European Development Fund and the European Social Fund) were used to support the implementation of the EU's 'Cohesion Policy' which aimed to 'promote an overall harmonious development and strengthen economic and social cohesion by reducing development disparities between the regions'. See European Commission, Regional Policy http://ec.europa.eu/regional_policy/en/information/legislation/regulations/2007-2013/ (accessed 18/10/16)

[88] The Common Provisions Regulation sets out general rules for the operation of these funds. 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. There are also fund-specific regulations for each fund.

[89] Information on the investment areas covered by ESIFs is provided at: European Commission, 'European Structural and Investment Funds http://ec.europa.eu/contracts_grants/funds_en.htm (accessed 18/10/2016)

[90] See European Commission, 'European Structural and Investment Funds http://ec.europa.eu/contracts_grants/funds_en.htm (accessed 18/10/2016)

and the individual Member States, which sets out the Member State's overall strategic goals and how it intends to use funding from the ESIFs for the period between 2014 and 2020.[91]

4.2. Transition from institutional care to community living: the role of ESIFs

ESIFs have the potential to facilitate the transition from institutional care to community living, by supporting the development of community-based alternatives to institutionalisation, including services that prevent institutionalisation as well as funding the technical support required, such as drafting new legislation and establishing new financial frameworks. The two funds that are of particular importance are as follows:

- *The European Regional Development Fund (ERDF)*[92] can finance investments into the health and social care infrastructure, such as accessible housing; and

- *The European Social Fund (ESF)*[93] can support a range of activities such as the training of staff in the provision of community-based services, provision of personal assistance for people with disabilities, and providing support to people with disabilities in the individual care planning process for moving from institutional care to services that enable them to live in the community and take part in community life.

4.3. Inappropriate use of EU Funds to maintain institutional care

As noted in Chapter 1, significant concerns have been raised about the inappropriate use of EU funds, namely the investment of such funds into institutional care. Such concerns have been raised by civil society organisations since 2007.[94]

4.3.1. Investments to maintain institutional care

In addition to the CRPD Committee, the CoE Commissioner for Human Rights has expressed his concern in 2014 that some European countries were still 'refurbishing existing institutions or even building new ones – sometimes, shamefully, with EU structural funds'.[95] The European Ombudsman considered this issue when pursuing her own-initiative inquiry on the use of EU Funds. Although focusing on the use of EU funds within the context of the Charter of Fundamental Rights of the European Union (EU Charter), the European Ombudsman's comment that 'the Commission should not allow itself to finance, with EU money, actions

[91] For further information on the Partnership Agreements adopted by the 28 EU Member States see Directorate General for Internal Policies, *Metis GmbH*: Jürgen Pucher, Isabel Naylon, Herta Tödtling-Schönhofer, *Research for Regi Committee – Review of the Adopted Partnership Agreements,* November 2015 (IP/B/REGI/FWC/2010-002/LOT01-C01-SC13.

[92] Regulation (EU) No 1301/2013 of the European Parliament and of the Council of 17 December 2013 on the European Regional Development Fund and on specific provisions concerning the Investment for growth and jobs goal and repealing Regulation (EC) No 1080/2006

[93] Regulation (EU) No 1304/2013 of the European Parliament and of the Council of 17 December 2013 on the European Social Fund and repealing Council Regulation (EC) No 1081/2006

[94] See Annex 2 for a list of relevant reports.

[95] CommDH/Speech(2014)9, Strasbourg, 2 October 2014.

which are not in line with the highest values of the Union',[96] is equally applicable to the CRPD.[97] As noted in Chapter 2, the segregation of people with disabilities in institutional care is contrary to Article 19 CRPD. That there is a connection between the CRPD and the EU Charter is highlighted by the guidance recently issued by the European Commission on ensuring respect for the EU Charter when using ESIFs.[98] When referring to 'the principle of integration of persons with disabilities' the guidance notes that the EU is a party to the CRPD and emphasises the need to ensure compliance with this treaty as well as the EU Charter when managing ESIFs.[99]

As the report of the Ad Hoc Expert Group observed, the investment of EU funds into institutional care 'represents a missed opportunity for more systemic change, as it then becomes more difficult to advocate closure and systemic reform'.[100] It also means that EU and other funds are being diverted away from initiatives that are focused on developing community-based services that enable people with disabilities to live and participate in the community. This point is highlighted in the CRPD Committee's Concluding Observations for Hungary in 2012. Having noted its concerns that 'disproportionally large resources, including regional European Union funds' had been dedicated to the 'reconstruction of large institutions, which will lead to continued segregation, in comparison with the resources allocated for setting up community-based support service networks', the CRPD Committee added that it was 'concerned that the State party fails to provide sufficient and adequate support services in local communities to enable persons with disabilities to live independently outside a residential institutional setting'.[101]

Table 4 below sets out concerns raised by the CRPD Committee in relation to the investments into institutional care by EU Member States, highlighting (in **bold**) where such investments include the use of EU funds. Information from other sources highlight similar concerns about the investments of EU funds into institutional care. For example:

- As noted in the Slovak ESIF report,[102] the use of EU Funds in the past financial programming period of 2007-2013 was considered to have 'largely reinforced institutionalisation'[103] (see the case study on Slovakia below).

- A 2015 report by Lumos, *In Our Lifetime How donors can end the institutionalisation of children* noted that in the Czech Republic, 'more than €5.6 million of EU Funds was spent in one county between 2008 and 2012 on renovating baby institutions, children's homes and institutions for children and adults with disabilities', while in 2007, '€140,000 of European aid funding earmarked for deinstitutionalisation in Bulgaria was instead spent on renovating an institution for adults and children with disabilities'.[104]

- A 2013 publication, *Briefing on Structural Funds Investments for People with Disabilities:*

[96] *Decision of the European Ombudsman closing her own-initiative inquiry OI/8/2014/AN concerning the European Commission*, (European Ombudsman (2015) (Ombudsman's own initiative inquiry).
[97] Ombudsman's own initiative inquiry (n. 96 above) 46.
[98] *Guidance on ensuring the respect for the Charter of Fundamental Rights of the European Union when implementing the European Structural and Investment Funds ('ESI Funds')* available at: http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52016XC0723(01)&from=EN
[99] At C269/4 and Annex II.
[100] Report of the Ad Hoc Expert Group (n. 3 above) 14.
[101] CRPD/C/HUN/CO1, para 33.
[102] See (n. 16 above), p. 14.
[103] CoE Commissioner for Human Rights country report (Slovakia) – see Annex 4.
[104] At p. 25. The report is available at: https://wearelumos.org/sites/default/files/In%20Our%20Lifetime_2015_Sept2015_0.pdf

Achieving the Transition from Institutional Care to Community Living, estimated that between 2007 and 2013 a total of at least 150 million Euros were invested into the renovation or building of new institutions for disabled people in the countries of Bulgaria, Hungary, Latvia, Lithuania, Romania and the Slovak Republic.[105]

Table 4: CRPD Committee's Concerns: Investments into Institutional Care

Member State & Date	Concerns raised in the Concluding Observations
Czech Republic (2015)	…continues to invest more resources in institutional settings than in support services that would enable persons with disabilities to live independently in their respective local communities (para 38).
Denmark (2014)	…end the use of State-guaranteed loans to build institution-like residences for persons with disabilities; that it amend the legislation on social services so that persons with disabilities may freely choose where and with whom they live, while enjoying the necessary assistance to live independently; and that it take measures to close existing institution-like residences and to prevent the forced relocation of persons with disabilities, in order to avoid isolation from the community (para 43).
Hungary (2012)	…has dedicated disproportionally large resources, **including regional European Union funds,** to the reconstruction of large institutions, which will lead to continued segregation, in comparison with the resources allocated for setting up community-based support service networks (para 33).
Italy (2016)	… recommends…redirect resources from institutionalization to community-based services and increase budget support to enable persons with disabilities to live independently across the country (para 48).
Lithuania (2016)	…the national budget and **European Union structural funds** have been used in renovating existing institutional facilities and in constructing new ones (para 41) … recommends that the State party further prioritize investing in a social service system for independent living in the community, and immediately **refrain from using national and structural funds of the European Union to renovate, maintain or construct residential institutions for persons with disabilities** (para 42).
Portugal (2016)	…recommends…adopt a national strategy for independent living, including increased investment in living independently in the community rather than in institutions (para 39).
Slovakia (2016)	…recommends that the State party no longer allocate resources from the national budget to institutions and that it reallocate resources into community-based services in accordance with the investment priorities of the European Regional Development Fund (art. 5.9 (a) of European Union regulation No. 1303/2013)[106] (para 56).

Source: (UN Committee of the Rights of People with Disabilities (the CRPD Committee)[107])

[105] See ENIL-ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living,* December 2013, pp. 11 – 12.
[106] This provision is set out in n. 5 above.
[107] See Annex for details of the Concluding Observations of the CRPD Committee.

4.3.2 Replication of institutional care in community-based settings

In addition to the inappropriate use of ESIFs to maintain and expand the traditional large institutions, concerns have been raised about EU funds supporting the development of services that although providing an improved physical environment do not promote community living. Noting that 'it is widely recognised that the institutional culture can be replicated in services based in the community' the 2010 report of the European Coalition for Community Living (ECCL) emphasises that it is 'essential that those engaged in developing alternatives to institutionalisation address how to change the culture as well as the physical environment'.[108] The need to take action to avoid this problem was referred to in the Slovak ESIF report and the suggestion on how this might be addressed is repeated here as it is applicable to all Member States that are seeking to develop community-based alternatives to institutional care:

> *To address this concern requires the provision of a range of community-based services, such as accessible housing; developing a workforce that is committed to the vision of community living (for example, helping people with disabilities develop independent living skills, such as cooking, budgeting and using public transport) and ensuring the people with disabilities are able to choose where, and with whom, they would like to live.*[109]

4.4. Revised Regulations and Guidance on the use of ESIFs

The European Commission has taken significant action to encourage the use of ESIFs to promote the transition from institutional care to community living during 2014-2020, through the revision of the regulations and by supporting the development of guidance for Member States.

4.4.1 The revised regulations governing the use of ESIFs

The revised regulations governing the use of ESIFs for the current financial programming period (2014-2020) include positive reforms, such as greater emphasis on social inclusion and encourage a 'more focused use of the [ESIFs] to support the transition from institutional to community-based care'.[110]

An example of how the regulations highlight the importance of achieving the transition from institutional care to community living is that the regulations require certain '*ex ante* conditionalities' to be fulfilled if the Member State is to receive funding through the ESIFs. Significantly, where such a need has been identified, the Member State must demonstrate that its 'national strategic policy framework for poverty reduction' includes 'measures for the shift from institutional to community-based care'. Such a need has been identified - and therefore this requirement applies to: Bulgaria, Croatia, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Romania, Slovenia and the Slovak Republic. This is because for each of these countries the European Commission Position Papers on the development of Partnership Agreements and programmes for 2014-2020 have identified the

[108] *Wasted Lives* (n. 12 above) p. 18.
[109] Slovak ESIF report (n. 16) See also ENIL-ECCL Shadow report (n. 23 above) pp. 29- 30
[110] EEG Toolkit ((n. 4 above) p. 21

development of community-based alternatives and/or the promotion of independent living as a funding priority.[111]

Accordingly, this means that, in line with the thematic *ex ante* conditionality, these Member States should have in place a strategy which includes 'measures for the shift from institutional to community based care' as a condition for using ESIFs.[112] Guidance on *ex ante* conditionalities issued by the European Commission *Draft Thematic Guidance Fiche for Desk Officers: Transition from Institutional to Community-based Care (Deinstitutionalisation)* ('the Thematic guidance') describes such measures as including 'the development of services based in the community enabling people to live independently and preventing the need of institutionalisation', while in relation to 'children in alternative care… the provision of family-based or family-like care which include family support should be in place'.[113]

4.4.2. Guidance on the use of ESIFs to promote community living

The European Commission has also supported the development of guidance to Member States on how to plan and implement the transition from institutional care to community living, two significant examples being two reports published by the European Expert Group on the Transition from Institutional to Community-based Care, namely the *Common European Guidelines on the Transition from Institutional to Community-based Care* (2012) and the *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care* (2014 revised edition).

In addition, as noted above the European Commission has issued the Thematic guidance, which albeit still appearing to be in draft form, provides a brief guide on what measures could be funded 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 (noted above), and makes similar points to those highlighted in them. In particular, it emphasises the need for Member States to have a strategic vision on how the transition from institutional to community based care will be implemented; highlights the importance of undertaking an analysis of the country situation (covering matters such as the needs of population at risk of institutionalisation, resources (e.g. financial) and causes of institutionalisation), as well as having a focus on social inclusion.

4.4.3 Prohibition of investments in institutional care

Crucially the regulations and guidance from the European Commission make clear that ESIFs must not be invested in institutional care.[114] The Thematic guidance states that such activities are excluded and then adds:

[111] See: http://ec.europa.eu/regional_policy/what/future/program/index_en.cfm
[112] See EEG Toolkit (n. 4 above) p. 22.
[113] European Commission, *Draft Thematic Guidance Fiche for Desk Officers: Transition from Institutional to Community-based Care (Deinstitutionalisation)* ('the Thematic guidance') Version 2 – 27/01/2014
[114] See EEG Toolkit (n. 4 above) p. 24 and European Commission Staff Working Document *Report on the implementation of the UN on the Rights of Persons with Disabilities (CRPD) by the European Union,* June 2014, para 98.

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.[115]

4.5. Community living: Continuing Concerns About the Use of ESIFs

Notwithstanding the positive developments outlined in the above section, a recent review of the Operational Programmes (OPs) in six countries (Bulgaria, Estonia, Hungary, Latvia, Lithuania and Slovakia) for the period 2014-2020 highlights potential problems. The areas of concern identified in this review are set out below.

The use of ESIFs: Key Concerns

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.

iii. **Assessment of the situation: there is little analysis of the situation of people with disabilities, and therefore it is 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 of the situation of people with disabilities and others 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

[115] Thematic guidance (n. 113 above).

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.

ENIL-ECCL 2016 report, *Working Together to Close the Gap Between Rights and Reality: 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*

4.6 Case study: Piloting deinstitutionalisation in Slovakia using ESIF

As has been highlighted in this study, many of the problems identified with the deinstitutionalisation process in the Slovak ESIF report are not unique to Slovakia. The following summary is included in this study in order to summarise the key concerns that have been identified in relation to Slovakia and, by doing so, highlight the pitfalls that other Member States may also encounter and, if so, will need to address in the current financial period of 2014-2020.

The three key issues which had a direct impact on the effectiveness of ESIF in supporting the transition from institutional care to community living in Slovakia during the 2007–2013 programming period are as follows:

- Focus on the renovation and building of large capacity residential institutions
- Problems with coordination of ESF and ERDF in supporting the transformation of institutions to community-based service providers
- Lack of support for the deinstitutionalisation process by the regional authorities which own and run institutions for people with disabilities.

Further details on these three points are set out below, followed by observations on issues that need to be addressed in the current programming period (2014-2020) if the potential of ESIFs to facilitate the transition from institutional care to community living is to be realised.

4.6.1 Focus on the renovation and building of residential institutions

Between 2008 and 2010, 'more than 185 million EUR' were allocated to 'projects related to the reconstruction of existing social services facilities and the construction of new social services facilities'[116], with over 5,000 extra places in institutional care made available as a result.[117]

In 2011, following intervention by the European Commission, and with the support of the European Expert Group on the Transition from Institutional to Community-based Care (EEG), the Slovak Government redirected the 40 million EUR initially planned for the renovation of institutions for adults and older people and building of children's institutions for the support of deinstitutionalisation. The National Deinstitutionalisation Strategy (*Strategy for the Deinstitutionalisation of the System of Social Services and Alternative Care in the Slovak Republic*) was adopted by the Government at the end of 2011.

4.6.2 Inadequate coordination between ESF and ERDF funded programmes

In line with the strategy and the subsequently adopted *National action plan for the transition from institutional to community-based care in the social services system 2012-2015,* 10 institutions received training for the management, staff and users, as well as guidance in preparing transformation plans. The aim of this ESF support was to 'help to replace institutional care for people with disabilities and seniors with community-based services tailored to the individual needs of community residents'.[118] However, not one person has left any of these institutions. This is because none of the institutions involved were able to develop the community-based infrastructure (in other words, housing) to which the residents of the institutions could be relocated. It is understood that the problem stems from the timing of the calls for proposals.

In relation to the ERDF funded activities (development of the community-based infrastructure), the calls for proposals were published 1,5 years before calls for proposals for the ESF funded activities. This meant that at the time they were invited to apply for ERDF funding, the institutions had not benefited from the range of technical support that could have been provided under ESF to support staff to plan and implement the deinstitutionalisation process. Although some institutions applied for funding under the ERDF call for proposals, their applications were unsuccessful for a number of reasons and the funds were redirected to other priority areas.

4.6.3. Lack of support for the deinstitutionalisation process

To achieve the goal of moving from institutional care to community-based services requires a commitment from all the key players.

The Slovak ESIF report highlighted concerns about a reluctance in some regions to commit to the national plan for deinstitutionalisation. This is of great significance given that the traditional large, long-term stay institutions are funded by local authorities, which are also

[116] Strategy for the Deinstitutionalisation of the System of Social Services and Alternative Care in the Slovak Republic (Ministry of Labour, Social Affairs and Family of the Slovak Republic, November 2011) (the DI Strategy) 3.1, p.23.
[117] Ďurana, R., Duháčková, J., Betinský, J. and Burajová, B. (2013) *Monitoring the Absorption of Structural Funds in the Area of Social Services during the Period 2007-2014* (Structural Funds Report 2013). Available at: www.iness.sk/media/file/pdf/MonitoringINESSen.pdf Table 9, p.29.
[118] DI Strategy (n. 116) 3.3 p. 12 – 14.

responsible for the planning and development of community-based services, therefore playing a key role in the implementation of the national deinstitutionalisation process. Accordingly, the lack of support and ownership of the deinstitutionalisation strategy by the self-governing regions has, to date, been one of the key barriers to the process of transition from institutional care to community living in Slovakia. It has also meant that regions were reluctant to apply for ESIF to support the transformation of institutions for which they were responsible, into community-based service providers.

4.6.4 Looking towards the future – improving ESF and ERDF coordination and getting regional authorities on board

The Slovak authorities are seeking to address the problems from the 2007 – 2013 programming period by improving the ESF and ERDF coordination. Thus, in the new programming period, a new National Deinstitutionalisation Project will be launched, which will consist of institutions receiving assistance in developing transformation plans, involving the management and the leadership of the local self-governing regions. Once institutions are selected, they will have a chance to apply for ERDF funding, and will then receive training (for the staff and management) and other measures to support the process of transition. In addition to the institutions involved in the first National Deinstitutionalisation Project, an average of 17 new institutions per year will be involved. The duration of the project will be 66 months, with an indicative budget of 8 million EUR.[119]

To coordinate the activities funded by ESF and ERDF, an interdepartmental working group will be established comprised of representatives of relevant departments as well as civil society organisations. Unfortunately, to date this working group has not been established, which may cause delays to the whole process and jeopardise the quality of implementation of the National Deinstitutionalisation Project. Another issue, noted in the Slovak ESIF report, is the fact that civil society organisations which had been invited to be involved in the deinstitutionalisation process (NGOs and a university) may be asked to co-finance the National Project. Both issues – the working group and the co-financing issue – should be addressed by the Slovak authorities as a matter of priority in order to give the new project a chance to succeed.

[119] Stručný opis národného projektu Deinštitucionalizácia zariadení sociálnych služieb – Podpora transformačných tímov (Draft description of national project Deinstitutionalisation of the social services facilities). As noted in the Slovak ESIF report, this represents a tiny proportion of the institutional care providers in Slovakia, which raises concerns about the length of the deinstitutionalisation process.

5. RECOMMENDATIONS

As noted in the Slovak report, the successful transition from institutional care to the provision of community-based services that promote the social inclusion of people with disabilities requires careful planning and attention to a range of related issues. With the aim of addressing the main problems arising from the use of EU funds in relation to people with disabilities that have been identified in this study, as well as complementing recommendations made by other reports on this topic, the following recommendations are made, first in relation to the European Commission and, second, in relation to Member States. The points raised seek to assist in the work undertaken by the European Commission, the European Parliament and Member States in ensuring that ESIFs can promote, rather than hinder the transition from institutional care to community-based services in a timely manner. Their aim is to ensure that people with disabilities can live and participate in the community as equal citizens – in other words, to realise the right to community living.

5.1. EU institutions

5.1.1. Data Collection to Measure Progress towards Community Living

In order to measure the success of its social inclusion policies, the European Commission must be able to monitor Member States' progress in the transition from institutional care to community living. An essential element of such monitoring is data collection. However, as noted in Chapter 3 of this study, there is a lack of disaggregated data at EU level about the number of people with disabilities in general, and in particular about the number of people in institutions and the number of people receiving community-based services. Currently, the EU-SILC survey includes only those aged 16 and older living in private households, while those in 'collective households and institutions are generally excluded'.

Recommendations on how to improve on data collection were set out in the 2007 DECLOC report.[120] Given their continued relevance, the points raised by the DECLOC report form the basis of the following recommendations, namely that the European Commission should:

- Promote joint work between the Member States and Eurostat to define 'a minimum data set for residential services for people with disabilities'
- Regularly publish statistics on progress in the transition from institutional care to community living
- Work with Member States to identify a single source in each country competent to provide the needed information, and make this information publicly available.

5.1.2. Monitoring ESIF Use to Prevent Investments into Institutions

If the European Commission is to prevent ESIF investments into institutional care in the Member States, it must be able to monitor individual projects and intervene in cases where funds are being invested into services which perpetuate institutionalisation, whether this be by renovating or expanding the existing institutions or by developing services that replicate

[120] The DECLOC report (n. 33 above) p.94 -95.

an institutional culture. The importance of monitoring has been highlighted by the CRPD Committee in the EU Concluding Observations report,[121] which notes the 'need to improve monitoring, as well as to suspend or withdraw funding from projects that fail to comply with the CRPD'. Guidelines have also been issued by the European Ombudsman as part of her own-initiative inquiry into ESIF use. [122] In one of these eight guidelines, the Ombudsman has asked the European Commission to:

> *Apply strictly and without exception the obligation to verify that the management and control systems, including complaint-handling arrangements, are adequate and efficient, that they remain so for as long as programmes are implemented and that weaknesses are duly corrected. This includes systematically requiring that Member States inform the Commission of the results of all complaints concerning ESI Funds, whether they were initially submitted to the Commission or not.*[123]

Enhancing the role of civil society organisations is an essential element of an effective monitoring systems. If the European Commission is to monitor ESF and ERDF support for transition from institutional care to community effectively it must be able to engage with civil society organisations in the Member States with the necessary expertise on both ESIF and the deinstitutionalisation process.

Accordingly, it is recommended that the European Commission:

- Encourages Member States to use technical assistance funding to provide training and other means of raising the capacity of civil society organisations to assist in the monitoring of initiatives funded by ESIF.
- Ensures there is an effective complaints procedure in place where such civil society organisations can lodge complaints.
- Requires Member States to make the information about the calls for proposals, tenders, and the selected projects available online in accessible formats.
- Uses its participation in the Monitoring Committees, missions to the Member States and other opportunities to obtain information about the projects funded and whether they support community living.

5.1.3. Partnership Key to Process of Deinstitutionalisation

Adoption of the European code of conduct on partnership in the framework of the European Structural and Investment Funds is an important step towards improving the involvement of people with disabilities and their representative organisations in all the stages of ESIF use. Accordingly, it is recommended that the European Commission:

- Monitors the implementation of the partnership principle
- Provides guidance to the Member States – by facilitating exchange of good practice, for example – on how to better involve people with disabilities. In particular, the focus should be on improving the involvement of those most marginalised among people

[121] The EU Concluding Observations report (n. 14 above).
[122] The Ombudsman's own-initiative inquiry (n. 96 above). The eight guidelines are available here: http://www.ombudsman.europa.eu/en/cases/decision.faces/en/59836/html.bookmark#hl6
[123] The Ombudsman's own-initiative inquiry (n. 96 above) guideline v).

with disabilities, such as people with intellectual disabilities, people with complex support needs, those in institutions and those with minority background.
- Encourages Member States to involve grassroots organisations representing different groups in the various processes linked to ESIF spending, rather than limiting the involvement of people with disabilities to large umbrella organisations. This may help ensure that investments respond to the needs on the ground.

5.2. Member States

5.2.1. Strategies for Deinstitutionalisation that Promote Community Living

When developing measures for the transition from institutional care to community-based services, Members States should ensure that this includes a comprehensive deinstitutionalisation strategy for the closure of institutions and development of alternative community-based services that enable people with disabilities to participate in community life as equal citizens.

Accordingly, it is recommended that when planning their deinstitutionalisation strategy, Member States ensure that the strategy:

- Draws upon the findings of a country needs assessment (a crucial element for this is data collection - a system should be in place so that up to date and comprehensive information on people with disabilities living in the country is known, for example the number, age and impairment of people with disabilities living in institutions)
- Describes the range of services and supports that will be available once the strategy is implemented (such services to include mainstream, as well as specialised services)
- Incudes all people with disabilities currently placed in institutions (for example, does not exclude people with mental health problems)
- Identifies laws and policies requiring reform, for example guardianship laws, legislative and financial frameworks for the funding and provision of services (these are essential to the shift from institutional care to community-based services) and action needed to avoid potential 'perverse incentives' (in other words, ensure that the funding system does not create financial incentives to institutionalise people with disabilities rather than provide alternative community-based services)
- Sets out an agreed timeline and is underpinned by an agreed budget
- Has the support of key agencies and organisations (such as the relevant Ministries, including finance and health, and organisations of people with disabilities), local and regional authorities.

5.2.2. Effective Project Management for Community Living

A wide range of activities will need to be undertaken at national, regional and local levels. These include (but are not restricted to) legislative and financial reforms; planning for the closure of individual institutions, including the development of community-based services; provision of training of staff so that they are able to help people with disabilities who have been institutionalised develop independent living skills and the preparation of individual support plans for residents of institutions in order to identify their needs for community-based services.

When, how and who will be involved in undertaking the relevant tasks will need to be considered. In addition, as noted in the Slovak ESIF report, problems arise when the projects funded by the differing funding streams are not co-ordinated, for example, the work with institutions in preparation for transformation is not coordinated with the development of housing options.

It is therefore recommended that Member States:

- Ensure that the activities and any ESF and ERDF funding for such activities are co-ordinated so that measures for the development of infrastructure for community living (such as housing or adaptations to ensure accessibility) are accompanied by 'soft measures' (such as funding to train front line staff on the new skills that they will need when supporting people to live in the community, the provision of personal assistance and adequate management of the deinstitutionalisation process).

5.2.3. Services that Promote, not Hinder, Community Living

As noted in this study, there is a danger that the deinstitutionalisation process creates 'mini-institutions' in that although the services are being provided in community-based settings, the institutional culture of larger residential facilities is replicated. An important means of avoiding this problem is to develop of a range of community-based services that focus on social inclusion.

Accordingly, it is recommended that Member States consider:

- Using the ESIF technical assistance funding to involve people with disabilities and other experts in the process of planning the closure of institutions and the development of community-based alternatives, as well as taking action to enable people with disabilities to use mainstream services.

5.2.4. Involve Key Stakeholders: People with Disabilities and Others with Expertise

As outlined above, achieving the transition from institutional care to community living is a complex process which will require the involvement of experts in a range of areas, such as legal, financial and those with experience of establishing and running community-based services. The involvement of people with disabilities is essential, including in the role of peer supporters. This is reflected in the European code of conduct on partnership in the framework of the European Structural and Investment Funds, which requires that people with disabilities and their representative organisation are involved in the planning, implementation, monitoring and evaluation of the use of ESIFs.

Accordingly, it is recommended that Member States:

- Take steps to encourage and support the meaningful involvement of people with disabilities in the planning, implementation and monitoring of ESIF funded projects. As noted above, it is recommended the European Commission develops guidance to assist Member States in meeting their responsibilities in this area.

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ANNEX 1: GLOSSARY

Independent Living

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 people with disabilities 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 people with disabilities flexibility in their daily life. Independent living requires that the built environment, transport 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

Personal Assistance is a tool which allows for independent living. Personal assistance is purchased through earmarked cash allocations for people with disabilities, 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 people with disabilities need to be in line with the current salary rates in each country. People with disabilities must have the right to recruit, train and manage their assistants with adequate support if they choose, and should be the ones that choose the employment model which is most suitable for their 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.

Deinstitutionalisation

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

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 people with disabilities in mainstream settings. People with disabilities 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

The European Coalition for Community Living 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 European Expert Group on the Transition from Institutional to Community-based Care (formerly the Ad Hoc Expert Group) defines 'institutional care' as any residential care where:

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

ANNEX 2: RESOURCES

Resources on deinstitutionalisation and the use of European Structural and Investment Funds

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Resources on deinstitutionalisation and the use of European Structural and Investment Funds in Slovakia

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SOCIA Foundation, Simple Happiness (video). Available at : https://vimeo.com/122460187

ANNEX 3: CONCLUDING OBSERVATIONS OF THE CRPD COMMITTEE

The Committee on the Rights of Persons with Disabilities ('CPRD Committee') examines the periodic reports submitted by States Parties to the CRPD, in order to establish to what extent they have implemented the CRPD. It then issues recommendations, which form the so-called Concluding Observations. To date, the CRPD Committee has reviewed a number of EU Member States, and the European Union itself, and the recommendations it has made in respect of these countries are referred to extensively in this study.

The Concluding Observations can be found using the links below.

Austria:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUT%2fCO%2f1&Lang=en

Belgium:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fBEL%2fCO%2f1&Lang=en

Croatia:
https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/098/80/PDF/G1509880.pdf?OpenElement

Czech Republic:
https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/098/68/PDF/G1509868.pdf?OpenElement

Denmark:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fDNK%2fCO%2f1&Lang=en

European Union:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fEU%2fCO%2f1&Lang=en

Germany:
https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/096/31/PDF/G1509631.pdf?OpenElement

Hungary:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en

Italy:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fITA%2fCO%2f1&Lang=en

Lithuania:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fLTU%2fCO%2f1&Lang=en

Portugal:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=1050&Lang=en

Slovakia:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fSVK%2fCO%2f1&Lang=en

Spain:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fESP%2fCO%2f1&Lang=en

Sweden:
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fSWE%2fCO%2f1&Lang=en

ANNEX 4: COUNCIL OF EUROPE HUMAN RIGHTS COMMISSIONER COUNTRY REPORTS

This study refers to a number of country reports published by the Council of Europe Human Rights Commissioner Nils Muižnieks. Links to the reports used are listed below.

Austria (2012): https://wcd.coe.int/ViewDoc.jsp?id=1970297

Czech Republic (2012): https://wcd.coe.int/ViewDoc.jsp?id=2030637

Denmark (2013): https://wcd.coe.int/ViewDoc.jsp?id=2145355

Estonia (2013): https://wcd.coe.int/ViewDoc.jsp?id=2075361&Site=COE&Back Color Internet=B9BDEE&BackColorIntranet=FFCD4F&BackColorLogged=FFC679

Portugal (2012): https://wcd.coe.int/ViewDoc.jsp?id=1959473&Site=&BackColor Internet =B9BDEE&BackColorIntranet=FFCD4F&BackColorLogged=FFC679

Romania (2014): https://wcd.coe.int/ViewDoc.jsp?id=2208933&Site=COE

Slovak Republic (2015): https://wcd.coe.int/ViewDoc.jsp?p=&id=2363559&Site=COE&BackColorInternet=DBDCF2&BackColorIntranet=FDC864&BackColorLogged=FDC864&direct=true

Spain (2013): https://wcd.coe.int/viewdoc.jsp?id=2106465&site=coe& backcolorinternet =b9bdee&backcolorintranet=ffcd4f&backcolorlogged=ffc679

CAT: QA-04-16-953-EN-C (paper)
CAT: QA-04-16-953-EN-N (pdf)

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