

wasted time
a wasted
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opportunity?
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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

ECCL
European Coalition
for Community Living

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Information about project partners:

Institute for Public Policy (IPP) is a Romanian non-governmental organisation whose aim is to support an increased quality of the processes related to the development of public policies in Romania. They are committed to advancing high quality policies in the following key areas: transparency of the legislative process, reform of the local government system, fight against corruption and promotion of integrity at all local government levels, organisation and operation of election systems and processes, funding of political parties, promoting the rights of people with disabilities. The work in these areas has made IPP one of the most respected and reputed think-tanks in Romania.

The Soteria Foundation has been committed to the needs of people with mental health problems and has provided assistance to their families in Hungary since 1995. It is one of the pioneers in the field of community-based services in Hungary. The Soteria Foundation provides the following services: club houses, community-based social care services for people with mental health problems (with the aim of preventing rehospitalisation) and the Támpont Working Group (helping to find a way back into employment for people with mental health problems).

Founded by a Jesuit priest, Péter Pázmány in 1635, **Eötvös Loránd University (ELTE)** is one of the oldest universities in Hungary. Today, it has eight faculties: the Faculty of Law and Political Sciences, the Faculty of Arts and Humanities, the Faculty of Sciences, the Faculty of Elementary and Nursery School Teacher Training, the Faculty of Education and Psychology, the Faculty of Informatics, the Faculty of Social Sciences, and the Bárczi Gusztáv Faculty of Special Education.

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Foreword

The Structural Funds are financial instruments that the European Commission uses as part of its regional policy to promote economic and social cohesion in the European Union. The funds are earmarked for development purposes, and they are very substantial: the Structural Funds budget package for 2007–2013 is 347.410 billion EUR, which is a third of the total European Union budget.*

In view of how significant the funding is, and the potential impact on people's lives, I am very pleased to introduce the European Coalition for Community Living's report on Structural Funds expenditure in Central and Eastern Europe (CEE). It is time to take a close look at how European Taxpayers' money is being spent across this region, and specifically how this spending affects the lives of hundreds of thousands of people with disabilities.

For the past 15 years, the Open Society Mental Health Initiative (MHI) has invested in the development of community-based alternatives to the institutionalisation of people with mental disabilities across CEE. The development we have supported in this field has gone a long way to challenge the status quo that excludes people with disabilities from society. But in spite of MHI's considerable technical support and investment during the transition period, no CEE government has made a serious commitment to a large-scale shift of government investment towards a range of community-based services that would enable all disabled people to live in their communities. This lack of commitment persists, despite clear evidence that outcomes for people with disabilities are significantly better when they have the opportunity to participate in community life as equal citizens. It is also true in spite of the fact that virtually all CEE countries have policies on social inclusion, and some have policies specifically on deinstitutionalisation.

Given that the European Union has allocated the Structural Funds to *improve* the lives of Europeans, it is important to inquire why some countries continue to use this funding to perpetuate the long-term institutionalisation of people with disabilities, an investment that clearly does not improve their lives. This report considers how Structural Funds can be used to implement policies for deinstitutionalisation. This is because until people with disabilities can leave institutions and live freely in their local communities, they will not be in a position to benefit from other EU and national policies that promote equal opportunities, non-discrimination and social inclusion.

* European Union, The control system for Cohesion Policy, How it works in the 2007–2013 budget period, October 2009; p 5.

The shift from institutional care to a system of community-based support that enables disabled people to live as ordinary citizens – going to school, working, developing friendships, making a home, raising a family, taking part in community life – is a complex process that will take time to implement. It will require careful planning, cross-government collaboration, and the involvement of a wide range of agencies and individuals that are engaged with these issues. To be truly successful, it is essential that disabled people and their families are included in this process.

It is also clear that a significant effort will be required by national governments and the European Commission to agree on the most basic criteria for using Structural Funds in relation to people with disabilities. Central to this agreement must be the principle that *any investment* in residential institutions is a bad investment. Period. Life in an institution can be made more comfortable, but it can never be made into freedom and participation. This is true no matter how much money is invested in infrastructure, or how many new staff are hired, or how much equipment is purchased. Nor will any investments in institutions ever promote ‘social cohesion’, a *raison d’être* of the Structural Funds.

There is an urgent need for governments to take national ownership of the development areas that the Structural Funds will support as part of their national policies, rather than seeing the Structural Funds as something imposed by Brussels from above. These funds are not intended to support ‘pilot projects’. They are intended to support *development* in critical fields, in line with national reform efforts, and must be integrated from the beginning into national public finance systems if the reforms supported by the funds are to be sustainable in the long term. At the national level, it will be essential to strengthen implementation capacities so that Member States manage the Structural Funds from a development perspective rather than in a formalistic, perfunctory manner.

Thankfully, it is no longer a well-kept secret that severe human rights abuses frequently occur in long stay institutions. But this is not the only reason to call for their demise. Quite simply, long stay residential institutions have no place in the Europe of the 21st Century. If EU Member States are to meet the European Union’s objectives on social inclusion for disabled people and their responsibilities under international and European human rights standards as well as EU law, they must take concrete action to end the segregation of disabled people and enable them to exercise their right to community living. The availability of Structural Funds provides a golden opportunity for governments to live up to these responsibilities, and my sincere hope is that they will rise to the occasion.

Judith Klein, Director
Open Society Mental Health Initiative

Introduction

'Across the European Union, many people spend long years in institutional care. Some of them have physical or intellectual disabilities, others suffer from mental health problems and yet others are elderly and frail. There are also many children in institutions, both with disabilities and without.'

Vladimír Špidla, Commissioner for Employment,
Social Affairs and Equal Opportunities (2004–2009)¹

1. Introduction

Commissioner Špidla's observation is taken from the 'Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care ('the Ad Hoc Expert Group Report'). The report sets out the reasons why those European Union (EU) Member States that continue to rely on institutional care for disabled people need to take action to transfer to a system that provides community-based services as alternatives to institutionalisation. It includes specific recommendations on the use of EU funding mechanism known as 'Structural Funds', stating that these funds should be used 'for the transition from institutional to community-based care'.² Furthermore, the report recommends that guidelines should be developed on the use of such funds, which should:

*'Make clear that projects which aim to build, enlarge or perpetrate institutions are not in line with the Convention on the Rights of Persons with Disabilities and EU's own policies on equal opportunities, social inclusion and discrimination, and are therefore not eligible for funding.'*³

This recommendation reflects the concern that, in some EU Member States, Structural Funds are being used to renovate long stay institutions for people with disabilities and build new residential institutions, rather than developing community-based alternatives to institutionalisation.

2. Scope and purpose of this report

In this report, the European Coalition for Community Living (ECCL) seeks to explain why there is such concern about the inappropriate use of Structural Funds in the EU Member States of Central and Eastern Europe (CEE).⁴ It argues that the use of Structural Funds to renovate long stay residential institutions for people with disabilities,⁵ or build new residential institutions, rather than develop community-based alternatives, is contrary to EU policy objectives, EU law and European and international human rights standards. It also highlights areas in which the rules on the operation of Structural Funds have created unnecessary barriers to establishing projects that would develop alternatives to institutional care.

The report draws upon relevant information that has been sent to us by members of ECCL. In particular, we are indebted to our partners in this project, the Soteria Foundation⁶, Hungary and the Institute for Public Policy (IPP), Romania, who are currently undertaking research on the use of Structural Funds in relation to services that support the social inclusion of people with mental health problems and/or intellectual disabilities in these countries. They have kindly shared with us relevant information that they have obtained through their research.

Information about the use of Structural Funds in other CEE countries has been very difficult to obtain. Although ECCL contacted a large number of non-governmental organisations, very few had information relevant to this report.

Accordingly, this report does not claim to provide comprehensive information on the use of Structural Funds in relation to disabled people currently living in residential institutions. This would require detailed and extensive research across all EU Member States with access to Structural Funds. Our purpose has been to consider the information that is available, and seek to draw attention to the serious implications of the use of Structural Funds to build new and/or renovate existing residential institutions rather than invest them in the development of community-based alternatives.

It is clear from the information we have obtained, that further research is required on this particular use of Structural Funds. For this reason, one of our recommendations is that research is commissioned to evaluate how Structural Funds are being used in relation to the provision of social care to disabled people. This is discussed in more detail in Chapter 5 below.

Recommendations on the future use of Structural Funds

Chapter 5 sets out our recommendations on how Structural Funds could be better used to facilitate the transfer from institutional care to community-based services. Such services should seek to enable disabled people to live their lives as equal citizens – going to school, working, developing friendships, making a home, raising a family, taking part in community life and seeking to fulfil their personal aspirations.

3. Why this report is necessary

Despite the EU and Member States' policies that emphasise the need to protect the rights of disabled people and promote their social inclusion, disabled people in CEE continue to be placed in large remote residential institutions where their exclusion from society is virtually absolute. The use of Structural Funds to build new institutions or renovate existing institutions is a major concern because this perpetuates the segregation of disabled people. Action must be taken to address this unacceptable situation.

Poor progress in moving to a system of community-based services

Although the European Commission has been consistent in emphasising its commitment to promoting the rights of disabled people, making 'equal opportunities for disabled people a reality',⁷ and promoting their social inclusion,⁸ there is insufficient acknowledgement of the vast gap between such objectives and the reality for the hundreds of thousands of people living in residential institutions. For example, the EU Joint Report on Social Protection and Social Inclusion makes some reference to the poor progress in moving from institutional care to a system of community-based services but this is fairly oblique:

*'Dependent people prefer long-term care in a residential or community setting rather than institutional care, but in many countries institutional care still accounts for more than half of public expenditure.'*⁹

As Chapter 2 highlights, the situation for many disabled adults and children (as well as non-disabled children) in such institutions is dire.

Community-based models provide better outcomes

Once the comparison is made on the basis of comparable needs of the residents and the quality of care provided, 'there is no evidence that community-based models are inherently more costly than institutions'. Furthermore, when properly set up, community-based systems of independent and supported living should deliver better outcomes than institutions.¹⁰

However, the process of shifting from institutional care to a system of community-based services is complex and requires careful planning as well as a commitment of resources. This is where Structural Funds can provide the means to initiate such work. Unfortunately, to date, the potential role of Structural Funds has not been realised. In fact, their use has sometimes hindered the creation of community-based services.

4. The potential role of Structural Funds

Those CEE countries that are members of the EU, and eligible for such assistance, can use Structural Funds to help them develop a system of community-based services. The Ad Hoc Expert Group Report describes the potential of Structural Funds to assist in this area:

*'The European Social Fund can provide funding for the training (and re-training) of staff while the European Regional Development Fund (ERDF) can simultaneously be used for developing social infrastructure which will support the new community-based services.'*¹¹

The European Commission summarises the objectives of these two Structural Funds, the European Social Fund (ESF) and the European Regional Development Fund (ERDF):

*'The [ESF] is the main financial instrument to assist Member States to achieve goals established in the European employment strategy and the disability action plan...the [ERDF] finances productive investments leading to the creation or maintenance of jobs, infrastructure and local development initiatives and the business activities of small and medium-sized enterprises.'*¹²

Despite such potential, the Ad Hoc Expert Group Report pointed to concerns about the misuse of Structural Funds in relation to the institutionalisation of disabled people:

*'Member States should ensure that funds from the ERDF are not used to build new segregating residential institutions and that their use for improving the infrastructure of existing ones, if allowed at all, is tied with investment into systemic care reform and does not exceed 10% of the overall expenses.'*¹³

Failure to make use of the potential of Structural Funds to develop community-based alternatives to institutional care will be a wasted opportunity and an inefficient use of substantial amounts of money. Of more fundamental importance, those most in need for these changes to take place – the disabled adults and children placed in institutions – will be the ones to suffer. They will continue to be segregated in residential institutions, excluded from society; denied the opportunity to live their life as other citizens do.

Endnotes

- 1 Foreword to the Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care, September 2009 (further referred to as 'the Ad Hoc Expert Group Report'). The Ad Hoc Expert Group consists of representatives of the following organisations: Children's High Level Group, European Older People's Platform – AGE, the Confederation of Family Organisations in the EU – COFACE, the European Association of Service Providers – EASPD, the European Coalition for Community Living, the European Disability Forum, Inclusion Europe and Mental Health Europe.
- 2 The Ad Hoc Expert Group Report; p. 20.
- 3 The Ad Hoc Expert Group Report; p. 22.
- 4 Structural Funds are available to certain EU Member States. For details, see: http://ec.europa.eu/regional_policy/sources/graph/poster2007/eu.pdf. Eight CEE countries joined the European Union in 2004 (Estonia, the Czech Republic, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia). Two joined in 2007 (Bulgaria and Romania). The main focus of Chapter 3, which sets out key issues about the use of Structural Funds, is on the situation in Hungary and Romania.
- 5 We use the terms 'disabled people' and 'people with disabilities' interchangeably to reflect the differing views in Europe (in the United Kingdom people tend to prefer 'disabled people' but in many other parts of Europe the preferred term is 'people with disabilities').
- 6 The research was conducted by the Soteria Foundation and the Faculty of Social Sciences at Eötvös Loránd University (ELTE). The research team is referred to in this report as 'Soteria-ELTE'.
- 7 Communication from the European Commission on the situation of disabled people in the European Union: the European Action Plan 2008–2009 COM/2007/738 ('COM/2007/738'); p. 3.
- 8 COM/2007/738; p. 5.
- 9 Council of the European Union, Joint Report on Social Protection and Social Inclusion 2009, 13 March 2009, 7503/09; p. 13.
- 10 Mansell J, Knapp M, Beadle-Brown J and 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; p. 97 (further referred to as 'the DECLOC report').
- 11 The Ad Hoc Expert Group Report; p. 20.
- 12 European Communities, Ensuring accessibility and non-discrimination of people with disabilities: Toolkit for using Structural and Cohesion Funds, European Commission, Directorate-General for Employment, Social Affairs and Equal Opportunities, Unit G.3, 2009 (referred to as 'The Toolkit'); p. 13.
- 13 The Ad Hoc Expert Group Report; p. 20.

The Institutionalisation of Disabled People in Central and Eastern Europe

'...many central and eastern European countries provide institutions of very poor quality and currently have proposals to renovate, upgrade and extend them using international funds instead of replacing them with services to support people in the community.'

Position Statement of the Comparative Policy and
Practice Special Interest Research Group of IASSID¹

This chapter considers the situation of disabled people who are living in residential institutions, explains why their institutionalisation is unacceptable and highlights the requirements on Governments to take action to develop community-based alternatives.

1. The situation of people living in residential institutions

Lack of information on people living in residential institutions

It is not known exactly how many disabled people are institutionalised across Central and Eastern Europe (CEE). A recent study, 'De-institutionalisation and community living – Outcomes and Costs: report of a European Study' ('the DECLOC Report') estimated that across the EU Member States and Turkey there are nearly 1.2 million disabled children and adults living in long stay residential institutions.² The figure is likely to be an underestimate given that most EU Member States keep only partial data about the number of people in institutions and three countries provided no data to the researchers.

The findings from DECLOC indicate that the two largest groups of people in institutions are people with mental health problems and people with intellectual disabilities (also known as 'learning disabilities'). However, the DECLOC report found that for half the number of places that were recorded, the residents' 'disability group' was not known.³ Given the lack of clear data, this report will use the generic term 'disabled people' when referring to residents of long stay institutions.

Figures for the Member States of CEE are set out in the table below:

The number of people with disabilities in long stay residential institutions⁴

	Places	Size <30	Size >30	Not classified
Bulgaria	13,269	216	11,540	1,513
Czech Republic	66,865		9,858	57,007
Estonia	22,421	1,805	7,243	13,373
Hungary	24,390	1,114		23,276
Latvia	10,053			10,053
Lithuania	45,464	180	14,924	30,360
Poland	73,741			73,741
Romania	32,783	214	28,348	4,221
Slovakia	12,252	716	3,142	8,394
Slovenia	821			821

Another study estimated that there are 150,000 children living in residential care settings across the EU, such as “special schools’, infant homes, homes for mentally or physically disabled, homes for children with behavioural problems, institutions for young offenders, after-care homes’.⁵ The Ad Hoc Expert Group Report notes that while in most Western European countries most children in public care are placed in family-based settings this is not the case in CEE ‘where residential-care settings still predominate’.⁶ This means that children without parental care, as well as those with disabilities, are often placed in institutions.

The Soteria–ELTE research team states that as of 2006 approximately 18,000 disabled people lived in institutions in Hungary and only 6.5% of these were living in group homes.⁷ The Hungarian legislation defines a group home as a family-size housing programme with 8–12 (maximum 14) residents.⁸ In relation to people with mental problems, only 230 of the just over 8,100 people lived in group homes, all of which are based in the grounds of large residential institutions and are managed by staff from the institution.

In Romania, according to information provided by the Institute for Public Policy (IPP), which is based on the quarterly statistic reporting prepared by the National Authority for People with Handicap (NAPH) in 2009,⁹ the total number of people with mental disabilities (adults) was 181,730 (103,467 people with intellectual disabilities and 78,263 people with mental health problems). This is 27.2% of the total number of disabled people living in Romania. Out of this total number, 12,731 (7%) live in residential institutions – the vast majority in large residential institutions, whereas only 670 persons (5.2%) live in group homes.

Institutionalisation: prevalence of serious human rights abuses

Residents of the long stay residential institutions in CEE have been removed from their families and local communities and are often subjected to severe human rights abuses. Often the institutions are located in remote parts of the country, with little or no public access.

Numerous reports over the last decade have brought to light the horrific reality of institutional care for many disabled adults and children in this region. They have shown the appalling living conditions (for example poorly maintained buildings, lack of heating, malnutrition and unhygienic sanitation), use of physical restraints, the physical and sexual abuse of some residents by other residents and sometimes staff, inadequate clothing, involuntary placements subject to no independent review; the lack of privacy and the absence of rehabilitative or therapeutic activities. A list of such reports is set out in Annex 1.

Inadequate reforms to date

In her article, *‘Institutions Remain Dumping Grounds for Forgotten People’*,¹⁰ Yana Buhner Tavianer describes the situations she found in institutions for adults with intellectual disabilities and mental health problems in Bulgaria, Romania and Serbia. She concluded that in all the institutions she visited, reform is patchy. While renovations had been carried out in most of the institutions this did not necessarily benefit all the residents. In one institution for 90 women with mental health

problems and/or intellectual disabilities in Bulgaria, she found that the area in which 30 of the 'most disabled' residents lived had been left untouched. These women:

'...are not allowed to eat with the others. Instead, they are given their food behind the fence that is usually locked, effectively turning it into a cage.'

Buhrer Tavanier found that apart from the provision of psychiatric medication there was little treatment or therapy in these institutions. Any improvement in overall standards of care and 'programmes preparing people for a return to the world all seem a long way away'. She concluded:

'This investigation suggests that they [the Governments of Bulgaria, Romania and Serbia] are still failing to meet international standards. Inadequate policies result in underfunding and a failure to recruit qualified, motivated staff. Residents are not being treated so much as controlled. Many are gradually destroyed by constant exposure to harmful, high-dosage medication. People do not leave their beds for years. Children are being kept tied down for most of the time. Living conditions are appalling beyond imagination. And the process of deinstitutionalisation is as phlegmatic, that death still is the only reliable way out.'

2. Institutional culture: dehumanising and undermines rights and freedoms

In their position paper on deinstitutionalisation and community living, Mansell et al¹¹ note that at the beginning of the deinstitutionalisation process, institutions had the following defining characteristics:

- They were large establishments serving tens, hundreds or even thousands of people.
- They were physically and socially segregated from the wider society.
- Whether by policy or for want of alternative sources of support, residents were not easily able to leave them to live elsewhere.
- Material conditions of life were worse than for most people in the wider society.

The Ad Hoc Expert Group Report makes similar observations:

'Typical characteristics of "institutional culture" have been described and analysed by pioneering researchers some four decades ago. It has long been argued that institutional care segregates users and tends to be characterised by depersonalisation (removal of personal possessions, signs and symbols of individuality and humanity), rigidity of routine (fixed timetables for waking, eating and activity irrespective of personal preferences or needs), block treatment (processing people in groups without privacy or individuality) and social distance (symbolising the different status of staff and residents).¹² Residents of such institutions develop passive ("institutionalised") behaviour in their adaptation to these routines, to boredom and to a lack of meaningful activities.'¹³

Many of the long stay residential institutions in CEE share these characteristics. However, the suggestion that the way forward is to renovate, upgrade and extend these institutions is not supported by experts in the deinstitutionalisation process. Noting that it is sometimes argued that smaller, more modern buildings, with higher staff ratios and expenditure provide a good quality of life for their residents, Mansell et al state:

'This position is not supported by the available empirical data.'

By way of illustration, they point to a recent in-depth study of institutions in France, Hungary, Poland and Romania, which showed that:

*'...although there were differences between institutions in different countries, they provided similarly poor outcomes for residents as institutions studied in the UK, USA and Sweden in the 1970s.'*¹⁴

The Ad Hoc Expert Group Report reiterates these points:

'...the institutional model of care is increasingly seen as inadequate. 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.'

3. Ensuring the institutional culture does not extend to the community

It is widely recognised that the institutional culture can be replicated in services based in the community.¹⁵ It is therefore essential that those engaged in developing alternatives to institutionalisation address how to change the culture as well as the physical environment. For example, while the types of residential services that are required will need to be considered, the focus of any such services must be on enabling disabled people to live and participate in society. The involvement of disabled people and their families will be essential.

Thus the aim of the system of community-based services must be to provide the support that disabled people need to achieve their aspirations and engage in community life. We refer to this as the right to 'community living'. This is described in the box below.

Community Living

*People with disabilities are able to live in their local communities as equal citizens, with the support that they need to participate in every-day life. This includes living in their own homes or with their families, going to work, going to school and taking part in community activities.*¹⁶

4. Institutionalisation versus community living

While Governments have a responsibility to take action to address human rights abuses and the failures to provide appropriate care, simply renovating such institutions ignores the fundamental objection to institutionalisation: that the unjustified segregation of disabled people is in itself a severe infringement of their rights.

Whatever the level of quality of care that is provided, a person who is removed from their family and home to reside in an impersonal environment, isolated from the outside world and deprived of opportunities to develop relationships or achieve personal aspirations is subjected to a severe infringement of their rights and freedoms. Article 19 (Living independently and being included in the community) of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) makes clear that the unjustified segregation of disabled people in institutions is in itself a human rights violation. It requires that services for disabled people should 'support living and inclusion in the community' and aim to 'prevent isolation or segregation from the community'.

The need to ensure that EU funding complies with the CRPD was highlighted by the European Parliament in its Resolution on the situation of fundamental rights in the European Union. The Parliament urged the European Commission:

*'...to ensure that funding provided to Member States for the provision of facilities for people with disabilities meets the criteria of the UN Convention on the Rights of Persons with Disabilities, with funding being provided for appropriate community/family based services and options for independent living.'*¹⁷

The human rights implications of using Structural Funds to maintain a system that institutionalises disabled people are discussed in more detail in Chapter 4 below.

Endnotes

- 1 Jim Mansell et al, Deinstitutionalisation and Community living: Position Statement of the Comparative Policy and Practice Special Interest Research Group of International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, Vol 54, Part 2, 104–112, February 2010.
- 2 The DECLOC Report; p. 25.
- 3 The DECLOC Report; p. 29.
- 4 These figures are taken from the DECLOC report (Table 5 – Size of residential establishments summarised from official data classifications, p. 26). Table 1 of the report (p. 12) provides information on the availability of the data, showing that this is very uneven.
- 5 The Ad Hoc Expert Group Report, referring to a 'recent compilation of national surveys on the situation across the EU by EUROCHILD'. See: [http://www.eurochild.org/index.php?id=208&tx_ttnews\[tt_news\]=271&tx_ttnews\[backPid\]=185&cHash=92a7bc14dc](http://www.eurochild.org/index.php?id=208&tx_ttnews[tt_news]=271&tx_ttnews[backPid]=185&cHash=92a7bc14dc)
- 6 The Ad Hoc Expert Group Report; p. 9.

- 7 Bugarszki Z, Eszik O, Soltéz Á and Sziklai I, One Step Forwards, Two Steps Backwards, Deinstitutionalisation of large institutions and promoting community-based living in Hungary through the use of the Structural Funds of the European Union, February 2010 (further referred to as 'the Soteria–ELTE report').
- 8 There are two types of group homes: group homes for nursing and care (providing intensive supervision and care) and rehabilitation group homes.
- 9 Available in Romanian at <http://www.anph.ro/tematica.php?id=13&idss=41>.
- 10 Yana Buhner Tavanier, '*Institutions Remain Dumping Grounds for Forgotten People*', Newsletter of the European Coalition for Community Living, Issue no. 10, October 2009; p. 3.
- 11 Jim Mansell et al, Deinstitutionalisation and Community living: Position Statement of the Comparative Policy and Practice Special Interest Research Group of International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, Vol 54, Part 2, 104–112, February 2010; p. 105.
- 12 King, R. D., Raynes, N. V. and Tizard, J. (1971) Patterns of residential care: Sociological studies in institutions for handicapped children. London: Routledge and Kegan Paul.
- 13 The Ad Hoc Expert Group Report; p. 8.
- 14 The Ad Hoc Expert Group Report, referring to the Included in Society report; p. 10.
- 15 Jim Mansell et al, Deinstitutionalisation and Community living: Position Statement of the Comparative Policy and Practice Special Interest Research Group of International Association for the Scientific Study of Intellectual Disabilities, Journal of Intellectual Disability Research, Vol 54, Part 2, 104–112, February 2010; p.105.
- 16 European Coalition for Community Living, Creating Successful Campaigns for Community Living, An advocacy manual for disability organisations and service providers, November 2008; p. 71.
- 17 European Parliament resolution of 14 January 2009 on the situation of fundamental rights in the European Union 2004–2008 (2007/2145(INI)), paragraph 82.

The Role of Structural Funds: Promoting Inclusion or Exclusion?

'Based on my sixteen years experience in the disability field in Romania, I consider that promoting community living is the only way to make a difference. Investment in the renovation of existing institutions would be an extremely poor investment. The plan must be to close these institutions and to begin investment in the development of community-based alternatives.'

Laila Onu, Executive Director,
Pentru Voi Foundation, Timișoara, Romania¹

The purpose of this chapter is to highlight the key concerns about the current use of Structural Funds in relation to situation of disabled people in institutions. Our overall concern is that the huge potential of Structural Funds to develop community-based alternatives to institutional care is not being realised fully, or at all in some cases. In some countries Structural Funds are being used to maintain the system of institutional care.

The use of Structural Funds needs to be considered in the context of broader issues relating to each particular country. However, this chapter seeks to identify issues that are likely to be common amongst the CEE countries in which the institutionalisation of disabled people remains the dominant form of care. This is based on the findings of research undertaken in Hungary by the Soteria-ELTE research team ('Soteria-ELTE') and in Romania by the Institute for Public Policy (IPP), as well as information received from other non-governmental organisations working in CEE, and through ECCL's work in this area over the past few years.

The key concerns considered in this chapter are as follows:

- Lack of clear direction on developing alternatives to institutional care
- Residential institutions are being reconstructed, expanded and built
- Restrictive interpretations of the rules for Structural Funds
- Barriers to the development of community-based services
- Lack of transparency in the operation of Structural Funds
- Problems with the monitoring and evaluation of Structural Funds

1. Lack of clear direction on developing alternatives to institutional care

Unless Governments have a clear plan for the development of community-based services, there will be no real change in their current system of institutionalised care.

Both Soteria-ELTE (Hungary) and the IPP (Romania) have concluded that many of the problems arising from the use of Structural Funds in this area appear to stem from the lack of clear direction from the Government.

Uncertainty of direction: Hungary

Soteria–ELTE’s analysis of Government policy since Hungary joined the EU² suggests a lack of commitment to implementing, and/or a failure to understand the need for, a clear deinstitutionalisation³ strategy. They also highlight past policies and funding arrangements that contradict the Government’s stated intent of developing alternatives to institutional care.

For example, during the period 2004–2006 the Hungarian Government’s policies and practice contradicted each other. No EU funds were used to close the large institutions and develop community-based alternatives to institutionalisation. This was because at that time, EU regulations did not specifically cover social services and therefore the documents outlining Hungary’s social policy on its accession to the EU in 2004 did not include such plans. Other type of community-based services, such as day centres and vocational rehabilitation programmes were mentioned and were later financed through Structural Funds. However, during this time national funds were being used to invest in the existing residential institutions rather than develop alternatives, despite the existence of Hungarian legislation requiring the closure of the large long stay institutions by 2010. In fact, during the period 1999–2006 22 billion HUF (81 million EUR⁴) was invested in institutional care.

Within the Cohesion Policy’s current programming period (2007–2013), Hungary’s Operational Programme for Social Infrastructure includes programmes for ‘deinstitutionalisation’.⁵ However, the subsequent call for proposals made clear that both the reconstruction of existing institutions and the establishment of new institutions would be covered by these funds. As discussed below, following interventions by Hungarian non-governmental organisations (NGOs) and experts in deinstitutionalisation, the Government withdrew the call for proposals and agreed to work with experts, including representatives of the NGOs to develop new proposals that would promote alternatives to institutionalisation.

While welcoming the Hungarian Government’s willingness to revise their proposals and work more closely with Hungarian NGOs and other experts, Soteria–ELTE consider that the Government’s inconsistent approach to ‘deinstitutionalisation’ has led to an unacceptable waste of resources. Given the limited resources that are available, this is extremely frustrating for those seeking to effect the necessary reforms:

‘While in 2004–2006 8 billion HUF (29.7 million EUR) were spent on the establishment of new large institutions and expansion of existing ones, the development plan of the following year⁶, without scruples, declared the need for deinstitutionalisation of large institutions, and allocated 10 billion HUF (37 million EUR) from EU funds. Even countries that are richer than Hungary cannot afford such a contradictory development policy.’⁷

Soteria–ELTE consider that it is essential that the Hungarian Government makes a clear commitment to the closure of the large long stay institutions in Hungary. Noting the discrepancies of some policies between people with mental health problems and other groups of disabled people, they stress the need for such commitments to cover all disabled people. Soteria–ELTE also pointed out that legislation alone is not enough:

‘Experience shows that a decision on deinstitutionalisation laid down in a comprehensive law which covers a period of 12 years does not provide a guarantee.’

Uncertainty of direction: Romania

IPP considers that a fundamental problem with the arrangements in Romania is the lack of a clear objective in the national strategy for 'deinstitutionalisation'. This is because although the National Strategy for People with Disabilities⁸ refers to the development of community-based services and includes social integration as an objective, it does not make explicit the requirement to replace the existing residential institutions with community-based services.

In IPP's view this omission needs to be addressed by inserting in the National Strategy for People with Disabilities a clear statement of the Government's commitment to deinstitutionalisation. This must be supported by the appointment of a high ranking official, such as the Secretary of State for Social Assistance, to take forward the work to realise this goal.

Focus on 'modernisation' of residential institutions: Romania

A major concern arising from IPP's research into the use of Structural Funds in Romania is the emphasis on the modernisation of the residential institutions. The Regional Operational Programme 2007–2013 (ROP) makes no reference to the development of community-based alternatives to residential institutions, but specifically includes 'investment in already existing residential centres'.

Priority Axis 3.2.3 of the ROP (entitled 'Improvement of Social Infrastructure') identifies 'the need to invest in the rehabilitation, modernisation and equipping of the buildings where social services are delivered'.⁹ The wording in this section gives the impression that the Government views such institutions as being a perfectly appropriate means of providing care, stating that these institutions 'provide for long term housing, ensuring thus a proper framework for the hosting and taking care of persons in difficulty'.¹⁰

As part of its research, IPP interviewed representatives of the General Directorates for Social Assistance and Child Protection (GDSACP) (the public agencies responsible for adult and children's social services). Some of the representatives suggested that the driving force behind projects to renovate residential institutions is the need to ensure that the institutions comply with the new prescribed quality standards for social services and that Structural Funds provide an opportunity to finance such works. In fact, the ROP encourages such projects. It states that 'the need for investment follows the setting up of minimum quality standards for social services, which will need to be fulfilled by the residential social centres'.¹¹

The concern that this approach was likely to lead to greater investment in institutions at the expense of the development of community-based services was highlighted by two organisations (Pentru Voi and Inclusion Romania), who work with people with intellectual disabilities. They called upon the Romanian Government to amend the wording of the Operational Programme so that funding could be directed to the development of community-based services, in accordance with the National Strategy for People with Disabilities, rather than invested in unsustainable institutions.¹² They highlighted the crucial importance of Structural Funds in facilitating the process of transforming the existing system of institutional care:

*'To date, the major obstacle to the development of community-based alternative services has been a lack of funding. With the availability of the Structural Funds, Romania has a unique opportunity to bring its social welfare system in line with international standards that are based on respect for basic human rights.'*¹³

ECCL wrote to the then Commissioner for Regional Policy, Ms Danuta Hübner and the then Commissioner for Employment, Social Affairs and Equal Opportunities Vladimír Špidla raising similar concerns, requesting changes to the wording of Priority Axis and asking that Structural Funds be used to develop community-based services rather than being invested in institutions.¹⁴

Despite such strong concerns being raised by Romanian and European non-governmental organisations, the ROP was approved by the Commission without any revision.

An example of collaboration: Bulgaria¹⁵

A current initiative in Bulgaria provides an example of how the European Commission can facilitate collaboration across different agencies for the development of plans to establish community-based services and to consider how Structural Funds can best be used to implement these plans.

In early 2009, the European Commission launched a collaborative exercise with the Bulgarian Government. This involved the European Commission's Directorate General for Regional Policy and Directorate General for Employment, Social Affairs and Equal Opportunities taking an active role in the implementation of Bulgaria's Operational Programme for Regional Development (OPRD) (2007–2013). The European Commission decided to intervene following the poor response of the agencies responsible for managing long stay institutions for children to a call for proposals for the renovation of the social infrastructure. The Commission wanted to ensure that the available funding was used to address the situation of children in long stay institutions in the light of a BBC documentary that had depicted the appalling conditions, poor quality of care and extreme neglect of children with disabilities in one of these institutions.¹⁶

This OPRD covers a range of areas including investments into social infrastructure, with a budget of 1.6 billion EUR. The European Commission and the Bulgarian Ministry of Regional Development and Public Works agreed that approximately 20 million EUR from the OPRD would be allocated to investments into alternative services for children currently living in residential institutions due to poverty, disability or lack of access to other services. It was also agreed that additional funding would be allocated from the European Social Fund (ESF) for staff training.

The Commission Directorates of Regional Policy and of Employment had worked together, in consultation with civil society representatives, to draft an Action Plan which proposed that the Structural Funds (European Regional Development Fund (ERDF) and ESF) should be invested to support the process of de-institutionalisation in Bulgaria. This allowed investments to be made in both the infrastructure (funded under the ERDF) and in the training of staff who will work in the newly established services (funded under the ESF).

In addition, the European Commission and the Bulgarian authorities convened a workshop to discuss the practicalities and challenges in the implementation of the Action Plan and share information on best practice in developing community-based services from other countries. Participants included European and international civil society representatives. Following the workshop an inter-ministerial working group was established to assist the Managing Authority¹⁷ in the planning and implementation of the project.

2. Residential institutions are being reconstructed, expanded and built

In the light of reports identifying the appalling living conditions and abuse in many long stay residential institutions in CEE, Governments have taken action to improve the physical environment of the institutions. However, as the Ad Hoc Expert Group Report notes, this common reaction presents difficulties in achieving longer term and more substantial reform of services for disabled people. This is because, having made significant investments in the existing residential institutions, the authorities are reluctant to close them down. The report identifies this 'over-investment in current institutional arrangements' as one of the key challenges in achieving transition from institutional to community-based care:

*'While such changes can in some instances ameliorate the quality of life of users, often such investment represents a missed opportunity for more systematic change, as it then becomes more difficult to advocate closure and systemic reform.'*¹⁸

Maintaining residential institutions: cannot promote social inclusion

Regulations on the use of Structural Funds make clear that these funds must be geared towards promoting social inclusion:

*'The action taken under the Funds shall incorporate, at national and regional level, the Community's priorities in favour of sustainable development by strengthening growth, competitiveness, employment and social inclusion and by protecting and improving the quality of the environment.'*¹⁹

Although projects may use terms that suggest wider and more socially inclusive objectives, their ability to achieve them is doubtful if the planned activities of the project are limited to carrying out works that improve the physical environment of a residential institution.

For example, a project for the 'modernisation' of an institution in Romania includes general objectives such as improving the quality of the infrastructure for social services in the locality and equal access for citizens to social services. However, the project is focused on carrying out construction works at the institution with the 'beneficiaries' of the project being the residents of the institution. It is therefore not clear how the project's general objective of improving the quality of social services in the county and ensuring the county population's access to services is to be met fully, if at all. The overall budget allocated for this project is 533,000 EUR.²⁰

In Latvia, a long stay institution for 168 people in the Talsi district was renovated using 1,433,985 EUR of ERDF funds (from the programming period 2004–2006). The project ‘Development of alternative social rehabilitation service in the long term care institution “Lauciena” in Talsi district’²¹ was funded under the priority of the Operational Programme entitled ‘Development of alternative social care and social rehabilitation services’.

Concerns have been raised about the use of Structural Funds in Latvia for the current programming period (2007–2013) by Zelta (Resource Centre for People with Mental Disability). This non-governmental organisation notes that the greatest part of the Ministry of Welfare’s budget for its ‘Programme for the development of social care and social rehabilitation services for persons with mental disabilities²² for 2009–2013’ (the ‘WM programme’) is allocated to institutional care. While recognising that improving the conditions will be good for those people who are currently resident in the social care homes, Zelta comments:

‘But on the whole, the WM programme is insufficiently geared towards deinstitutionalisation and furthering the integration of mentally disabled people into society.’²³

Continuing the institutionalisation of disabled people

In Latvia, ERDF monies are being used to fund the renovation of a building to replace an institution that was destroyed by a fire in 2007, in which twenty-six residents died. The new institution will have places for 60 people.²⁴ ZELDA comments that while this project may meet the objectives of improving the living conditions for people with mental disabilities:

‘Unfortunately, however, it must be concluded that the establishment of an expanded social care home will continue to promote the institutionalisation and isolation of persons with mental disabilities, thereby contravening the spirit of the UN Convention on the Rights of Persons with Disabilities.’²⁵

In Romania, a residential institution for 50 people with mental health problems is being constructed on the site of an institution for children with disabilities. The aim of this project is stated to be improving the social infrastructure for services for people with severe mental health problems. The residents of this institution will be young people (both men and women) who are about to leave the child protection system and are not considered able to be reintegrated with their families.

The project gives information about the physical environment, such as that the bedrooms will be limited to a maximum of three people, the institution will be accessible for wheelchair users and there will be a room for visitors. However, there is less detail about the day to day living arrangements for the residents. Although the project documents refer to a range of activities, including education, social integration/reintegration and recovery (such as independent life skills, personal care and professional therapy), there is no information on who will be responsible for providing such services. Given the stated aim of the project, it is of concern that this is not deemed worthy of explanation.

Such examples illustrate the problem identified by the Ad Hoc Expert Report – that directing funds to institutional care makes it more difficult to advocate for the development of alternative

services and the closure of the institution. Having considered the activities outlined in two projects to modernise residential institutions, IPP's assessment is that these are intended to enable the institutions to continue to function for the foreseeable future, rather than seeking to provide improved living conditions for the interim, while community-based services are being developed.

Projects are not developed within a wider strategy for social care

The examples above highlight concerns that the projects funded by Structural Funds do not address how the quality of care to the residents will be improved, adequately, or at all. In addition, information suggests that such projects are developed without sufficient consideration being given to how such projects will relate to the existing care system.

For example, in Latvia, during the 2004–2006 programming period, “half-way houses” were built on the grounds of six long stay institutions. The intention was for these houses to be the stepping-stone to residents moving into the community. Sustento, an umbrella body for disability organisations in Latvia, explains why the objective of this project has been thwarted:

‘The aim of the houses is to enable residents of long term residential institutions to learn the skills necessary for independent living (such as cooking, personal hygiene etc.). However, because the houses were built on the grounds of institutions, its residents continued living in segregation from the outside community. They also face the problem of not having anywhere to go after leaving the halfway houses, as the necessary housing (and other services) in the community have not been developed. For this reason, instead of staying in the halfway house for half a year, as was originally planned, the term has been prolonged to one year.’²⁶

Challenging initiatives likely to promote institutional care

In Romania, the priorities set out in the ROP refer specifically to the modernisation of institutions, thereby encouraging funding applications for such activities. IPP has therefore suggested that the Romanian Government should revise the ROP so that it reflects the priorities set out in the National Strategy for People with Disabilities, namely to develop community-based services. This would ensure that Structural Funds are directed towards developing community-based services, rather than modernising institutions. The general regulations for Structural Funds permit such a revision.²⁷

In Hungary, the situation is not as clear cut. Although the Operational Programme for Social Infrastructure is explicit on the need to close the large institutions, with funding allocated to such programmes, this was not reflected in the Action plans and the calls for proposals for these programmes. The documents revealed that the funding could be provided for new large institutions to be built (with limits of 50 places for persons with disabilities and 100 places for people with mental health problems). The plans also included the ‘modernisation’ of institutions of up to 225 residents.

This leads Soteria–ELTE to conclude that there is a fundamental difference between the Hungarian Government’s interpretation of ‘deinstitutionalisation’ and that of those working in the field. They are concerned that the Government’s concept of the services that are required to replace the old long stay residential institutions does not accord with the *‘homely living environment within the community, as specified in the European professional recommendations’*. In fact, the criteria for the services that, in theory, are intended to replace the long stay institutions will allow new large institutions to be built.²⁸

The Hungarian Government has responded positively to the views of Hungarian non-governmental organisations and others working in this area. Following a public consultation on the call for proposals for the modernisation programme, the government agreed to limit funding to the smaller institutions (maximum of 50 places). However, Soteria–ELTE note that of the total available funds for this programme (178.3 million HUF – 660,300 EUR) only 5.2% (34,335 EUR) was allocated to residential institutions for disabled people; with 81% of the funds being allocated to services for the elderly and child protection.²⁹

Another public consultation was issued on the draft call for proposals for ‘deinstitutionalisation of large institutions’ programme. This was delayed until October 2009 due to disagreements on the interpretation of a provision of the Structural Funds regulations concerning the purchase of property (this is discussed below). The amount allocated to this call for proposals was 13 billion HUF (48 million EUR), the total budget allocated for the seven year programme.

Despite the name of this programme – ‘deinstitutionalisation of large institutions’, the draft call for proposals would have allowed new institutions with up to 150 places to be established (subject to certain conditions: *‘in the inner-city areas in non-segregating environment’* and with *‘accessibility of public transport within 1 km’*).

In response to this draft call for proposals, a group of Hungarian NGOs, together with national and international experts on deinstitutionalisation, wrote to the Government outlining their grave concerns and requesting that it ‘urgently reconsider its plans to invest in institutions and commit the available funding to the development of community-based services and deinstitutionalisation’.³⁰

This led to the withdrawal of the call for proposals. In addition, a working group was set up to look at new proposals that would support the work to close the large residential institutions. The proposals are likely to provide that any new establishments will be limited to facilities with no more than 20 places and group homes, and that there will be no modernisation of institutions of more than 50 places.

While such steps are positive, Soteria–ELTE are concerned that recent developments are less promising. Soteria–ELTE note that some of the changes to the legislation on the deinstitutionalisation strategy are counter to the Government’s commitment to deinstitutionalisation.³¹ For example, whereas the maximum number of places for an institution was previously limited to 150 places, the changes recently introduced will allow an institution to have more places than this maximum so long as each building is for no more than 150 people. Also, as from January 2011, new residential placements will have to be provided by establishing group homes (with a maximum of 14 people per home). Although this provision is very positive on paper, Soteria–ELTE are concerned

that in practice it will do little to promote the social inclusion of the people living in such homes. This is because the majority of the group homes that have been built to date are situated in the grounds of existing long stay institutions.

Soteria–ELTE therefore conclude:

‘Starting from the examined documents and the realised facts, it is obvious that, despite the general rhetoric, the government’s intention to expand large institutions and establish new ones does not diminish, but, in fact, occasionally gains new momentum, and takes a reverse direction only as a result of external, public pressure.’³²

3. Restrictive interpretations of the rules for Structural Funds create barriers to the development of community-based services

An area that presents problems with using Structural Funds to develop alternatives to institutions is the interpretation of the rules that govern the use of such funds to purchase new property or build new premises.

Situation in Romania

In Romania, IPP notes that the Regional Operational Programme, funded through the ERDF, prohibits the purchase of buildings and property (where this would be in excess of 10% of the total eligible costs of the project) as well as the construction of new premises. It is for this reason that most of the projects that relate to people with mental disabilities (people with mental health problems and/or intellectual disabilities)³³ concern the renovation of institutions.

IPP’s research suggests that such restrictions on the use of ERDF resources lead to an investment in institutions rather than encouraging innovative projects that seek to develop services outside the current institutional system. Although there is no prohibition on the development of new services, the bar on purchasing new premises creates an added disincentive for seeking funding to develop community-based services.

Situation in Hungary

A similar situation exists in Hungary. The Soteria Foundation and other NGOs have sought to clarify the correct interpretation of the rules governing the use of ERDF for the purchase of land and property.

Article 7 of the ERDF regulations states that expenditure ‘for the purchase of land for an amount exceeding 10% of the total eligible expenditure for the operation concerned’ is not eligible for funding from the ERDF.³⁴ The Hungarian NGOs have written to both the Hungarian National Development Agency (the Managing Authority for the ERDF in Hungary) and the European

Commission's Directorate General for Regional Policy on this issue. The area in which there are conflicting views is whether this provision refers to just land or whether it includes the purchase of properties. This is significant because the purchase of a property is likely to exceed the 10% limit. In the Hungarian Civil Liberties Union's view the:

*'10% limit on the purchase of property is contrary to the stated objectives of ERDF, namely the social inclusion and equal opportunities and also has a negative impact on the cost-efficiency of these projects.'*³⁵

In the context of developing community-based services, this restriction is problematic, because it means that Structural Funds cannot be used to purchase apartments in blocks of flats or houses in the community, where disabled people currently living in institutions could move.

Situation in other countries

ECCL is aware that there is a difference of opinion between EU Member States on how this provision should be interpreted. For example, so far as we are aware there are no such restrictions on projects that will be co-financed under ERDF in Bulgaria. Furthermore, on 13 July 2009, the Czech Republic launched a Call under the Integrated Operational Programme entitled 'Services in the area of social integration'. This is financed under ERDF and will include the purchase and renovation of buildings for the housing of beneficiaries without a 10% ceiling on the purchase of property.³⁶

Restrictions on expenditure on housing

Another provision of the regulations that impedes the development of alternatives to institutionalised care is the strict eligibility criteria for a contribution from the ERDF in projects involving housing. Even where the project is eligible, the percentage of the ERDF allocation that can be used for housing is very small.³⁷ This will be a severe impediment to projects that wish to enable disabled people to live in the family-like homes in their local communities.

Although the regulations on the use of the ERDF have recently been amended, in recognition of the need to promote the social integration of marginalised communities in all EU Member States, the changes do little to address the concerns about their application. The limits on the amount of the ERDF that can be used remain. While projects can be used for renovation and change of use, this does not seem to allow the purchase of buildings.³⁸

4. Barriers to the development of community-based services

This section considers the barriers to the development of community-based services. While Structural Funds are not necessarily the cause, their continued use to maintain the system of institutional care leaves the barriers to the development of community-based services unchallenged. In some cases they may exacerbate the problems.

Legal and financial systems tied to institutional care

One practical problem with the development of community-based services in countries where the traditional means of providing care is to place disabled people in institutions, is the lack of a legal and financial framework within which these new services can operate. This creates a 'perverse incentive' in favour of institutionalisation, meaning that the system is geared towards placing disabled people in institutions rather than providing them with the support to live in their own homes and engage in community life. For example, rigid rules and financial mechanisms may create problems for non-governmental organisations wishing to establish community-based services.

The Ad Hoc Expert Group Report comments:

*'In some EU countries, excessively rigid legislative and administrative rules (e.g. on financing, security or hygiene) make it difficult to provide services in other settings than in large institutions.'*³⁹

The need to remove obstacles to the provision of community-based services was identified in the DECLOC report. It made a number of recommendations to address this, including the need to:

*'Create opportunities for new organisations to get involved in providing services in the community, outside the existing framework of institutional care, to pioneer the new models of support needed...'*⁴⁰

*'...Create arrangements for contracting for innovative, local services, so that existing rules designed for institutional care systems are waived or modified to permit the development of services in the community'*⁴¹

The observation that the current rules and regulations still favour institutional care was a key message arising from IPP's interviews with representatives of the General Directorates for Social Assistance and Child Protection (GDSACP) about their views on the use of Structural Funds in Romania. IPP explains how this situation impacts on the use of Structural Funds:

'Currently there are very few community-based services and the laws and regulations concerning social services focus on the provision of institutional care. Furthermore, because GDSACPs are responsible for ensuring that the institutions in their area comply with the prescribed minimum standards, they are encouraged to apply for funding under the Structural Funds programmes to carry out the refurbishments necessary to meet these standards. Without any clear direction on the need to develop community-based alternatives to institutions, seeking funding for the renovation of the existing institutions takes priority.'

Resistance from within the existing institutional care system

One of the main barriers to initiating the changes necessary to establish community-based services as alternatives to institutional care is very often the attitude of the individuals involved in managing the existing large residential institutions. They do not want the changes to take place. This might

be for a number of reasons, ranging from disagreeing with the view that disabled people have the right to community living, to concerns that they will lose their jobs and status.

The significance of such resistance was recognised in the DECLOC report which included recommendations to address these specific points. For example, it urged the EU Member States to:

*'Create financial incentives for local government to get involved in the inclusion of disabled people in their own communities.'*⁴²

Soteria–ELTE comment that it is not surprising that people who are part of the institutional care system are reluctant to embrace reforms that are designed to remove it. They also point to the connection between the large institutions and local government, suggesting that the county level local self-government officials may also regard the changes as a threat to their status:

*'...by eliminating such enormous institutions [local authorities] would lose an important part of their own legitimacy. While an institution that accommodates 150 to 200 people, or a whole group of such institutions, may justify the maintenance of a separate administrative level, 15 homes in the county of the size of a family house would apparently not. We do not claim that the maintenance of such institutions is the only task local self-governments have, but we do claim that without it their position would further weaken.'*⁴³

IPP notes that the situation is similar in Romania. There are large numbers of administrative staff involved in maintaining residential institutions who have an interest in preserving the current system. They also note that there is a severe lack of professional staff with the skills to provide services in the community.

Acknowledging the need to address the resistance of individuals and agencies involved in the management of the existing system of institutional care, Soteria–ELTE suggest that the Hungarian Government should encourage debate on the differing policy views on the future of services for people with disabilities. Such debates should include how to ensure the most effective use of Structural Funds in the development of community-based alternatives to institutionalisation.

IPP encourages a more professional approach to the whole process of social policy making in Romania. Given the problems with the existing system, IPP suggests:

*'Instead of keeping a never ending discourse on the need to rationalise resources and provide care in institutions, which ultimately dehumanise the residents, the facts need to be addressed. Reality has shown that community living is the only way to achieve social inclusion. Furthermore, the figures speak for themselves: information on the reasons for individuals leaving the residential care system show that in 2008 in nearly 70% of these cases, the cause was death, as compared to less than 15% of the residents leaving as a result of family integration or re-integration.'*⁴⁴

Complex tendering process for projects financed by Structural Funds

In CEE countries the few community-based services that are available are often provided by non-governmental organisations (NGOs). While the NGOs working in the EU Member States of this region may be eligible for funding from Structural Funds, the rules and procedures for applying for funding may prevent them from seeking such assistance. The complexity of the rules governing the tendering process and the substantial amount of administrative time involved in preparing the applications are likely to create problems for small community-based service providers. The barriers created by the rules and procedures concerning the application for projects funded by Structural Fund are highlighted by Soteria–ELTE:

*'It takes a significant amount of effort for an organisation or service-maintainer to understand the application process and to adjust the support opportunities to their own strategic development plans.'*⁴⁵

5. Lack of transparency in the operation of Structural Funds

Information on the use of Structural Funds can be difficult to obtain.

IPP has resorted to requesting information from the relevant agencies, for example the Management Authorities for the Regional Operational Program and the Human Resources Development Operational Program under the Freedom of Information legislation.

Soteria–ELTE have analysed the data publicly available from the Hungarian Development Agency. However, their request for more detailed information has thus far been refused. Various reasons have been given for non-disclosure, ranging from: data was not collected in a way that would enable them to provide the information requested, it would take up too much staff time to provide the information requested, they would need to charge for the photo-copying costs, as well as stating that providing the information would breach their duty of confidentiality to their clients.

In ECCL's experience the difficulty in obtaining information about the use of Structural Funds is common. Over the last few years we have contacted numerous disability organisations working in CEE to ask them how Structural Funds were being used in their countries. Very few had such information. It would seem that it is particularly difficult to obtain information about social infrastructure projects that are funded through ERDF.

6. Monitoring and evaluation of Structural Funds

The importance of organising partnerships with relevant organisations, such as national and local authorities and bodies representing civil society is emphasised by the Structural Funds General Regulation 1083/2006.⁴⁶ The Commission's Toolkit for using Structural Funds expands on this by stating that such partnership arrangements must cover all phases of the projects: preparation,

implementation, monitoring and evaluation and 'provide a high quality of consultation'. The Toolkit points out that it is the responsibility of Member States to engage with its partners, adding:

*'Thus the most effective way to participate in the monitoring of Structural Funds implementation is to find adequate representatives in the national and regional structures. The participation of organisations representing people with disabilities is strongly encouraged.'*⁴⁷

Despite this, ECCL has been informed by a number of disability organisations that while disability groups are represented on the Monitoring Committees in their countries, there is little opportunity to influence decisions. This is confirmed by IPP who notes that participation of organisations on the Monitoring Committees is of a formal nature, and their views are not taken into account in the decision-making process.⁴⁸

Soteria–ELTE consider that the implementation of Structural Funds should be monitored more closely by independent organisations, for example non-governmental organisations.

IPP notes that in Romania there are no coherent efforts to evaluate the impact of projects funded through Structural Funds. In their view, the main concern of the Romanian Government is that Structural Funds are spent within the agreed timetable. They pay much less attention to how the financing priorities support the strategy for the reform of social services and the principles of the UN Convention on the Rights of Persons with Disabilities.

IPP suggests that monitoring should focus on the mid and long-term impact of the projects funded by Structural Funds, and that they should be measured against priorities set out in the relevant strategies (such as the National Strategy for People with Disabilities). Similar approaches have been taken in other countries. For example, in the Czech Republic, the 'Criteria for De-institutionalisation' are attached to call for proposals under the Integrated Operational Programme 'Services in the area of social integration'.⁴⁹ If such criteria to support the implementation of the relevant deinstitutionalisation strategies are developed in cooperation with civil society and in the light of European and international human rights standards, such approach could help solve some of the concerns about the operation of Structural Funds that have been raised in this chapter.

Endnotes

- 1 Pentru Voi Foundation, Letter dated 1st November 2006 to the United States Congressional Commission on Security and Cooperation in Europe.
- 2 The Soteria–ELTE report; p. 7.
- 3 See Glossary for a definition of this term.
- 4 The amounts in Euros are meant to provide an indication of the size of the projects. Because of the fluctuating exchange rates, we are not in a position to provide exact amounts in Euros.
- 5 The Soteria–ELTE report; p. 35.
- 6 This is referring to the New Hungary Development Plan (UMFT), adopted by the Government in October 2006. This development plan defined directions for development for the period 2007–2013.

- 7 The Soteria–ELTE report.
- 8 The full title of the strategy is ‘the National Strategy for protection, integration and social inclusion of disabled persons for the period 2006–2013’.
- 9 Government of Romania, Ministry of Development, Public Works and Housing, Regional Operational Programme 2007–2013, 2007, Priority Axis 3.2.3: Improvement of social infrastructure; p. 128 (‘Romania’s Regional Operational Programme 2007–2013’).
- 10 Romania’s Regional Operational Programme 2007–2013; p. 133.
- 11 Romania’s Regional Operational Programme 2007–2013; p. 132.
- 12 Pentru Voi Foundation, Letter to Mr. Călin Popescu Tăriceanu, Prime Minister, dated 30 October 2006.
- 13 Pentru Voi Foundation and Inclusion Romania, Letter to Mr. Hans Gert-Pöttering, President of the European Parliament, 2007.
- 14 European Coalition for Community Living, Letters to Commissioners Danuta Hübner and Vladimír Špidla, dated 31st October 2006.
- 15 This information is based on presentations given by Carsten Rasmussen from DG Regional Policy at the Workshop ‘Leaving No Child Behind’ in Bansko, Bulgaria (23–24 September 2009) and during DG Regio Open Days 2009 at the Workshop ‘Structural Funds support for institutional care reform’ (6 October 2009), and the Ad Hoc Expert Group Report; p. 20.
- 16 BBC documentary Bulgaria’s Abandoned Children, directed by Kate Blewet. See: <http://www.bbc.co.uk/bbcfour/documentaries/features/bulgarias-children.shtml>
- 17 See Glossary for a definition of this term.
- 18 The Ad Hoc Expert Group Report; p. 14.
- 19 Article 3(1) of the Council Regulation (EC) No 1083/2006 of 11 July 2006 laying down general provisions on the European Regional Development Fund, the European Social Fund and the Cohesion Fund and repealing Regulation (EC) No 1260/1999 (further referred to as ‘the Structural Funds General Regulation 1083/2006’).
- 20 For the purpose of comparison, the Pentru Voi Foundation consider that for about 1.6 million EUR (which is the sum of this project and that mentioned under the heading ‘*Continuing the institutionalisation of disabled people*’), Romanian authorities could purchase around 35 four-room apartments in the community (with the exact number depending on the city). This would provide housing for 140 persons who currently live in residential institutions.
- 21 Project Nr. 2005/9/VPD1/ERAF/CFLA/GS/1.4.6.2./0001/0008.
- 22 This term is used in some countries to refer to people with mental health problems and people with intellectual disabilities.
- 23 ZELDA Newsletter, 4th Issue, September 2009; p. 3.
- 24 The building was renovated in two phases, and in the second phase 632,220 EUR were invested. This information was provided to ECCL by Sustento – the Latvian Umbrella Body of Disability Organisations.
- 25 ZELDA Newsletter, 4th Issue, September 2009; p. 4.
- 26 This information was provided to ECCL by Sustento – the Latvian Umbrella Body of Disability Organisations.
- 27 Article 33 of the Structural Funds General Regulation 1083/2006.
- 28 The Soteria–ELTE report; p. 16.

- 29 The Soteria–ELTE report; p. 25.
- 30 Open Letter regarding the use of the EU Structural Funds to build and refurbish institutions for people with disabilities, sent to Mr. Gordon Bajnai, Prime Minister and Mr. László Herczog, Minister of Social Affairs and Labour, dated 9 October 2009.
- 31 Act III of 1993, and. Act XXVI of 1998.
- 32 The Soteria–ELTE report; p. 34.
- 33 This is the target group for IPP’s research.
- 34 Article 7(1)(b) of the Regulation (EC) No 1080/2006 of the European Parliament and of the Council of 5 July 2006 on the European Regional Development Fund and repealing Regulation (EC) No 1783/1999, 31 July 2006.
- 35 European Coalition for Community Living, Letter to Mr. Marco Orani, DG Regio, European Commission, dated 10 November 2009.
- 36 This point was made during DG Regio Open Days 2009 at the Workshop ‘Structural Funds support for institutional care reform’ (6 October 2009).
- 37 Article 7(2) of the Regulation (EC) No 1080/2006 of the European Parliament and of the Council of 5 July 2006 on the European Regional Development Fund and repealing Regulation (EC) No 1783/1999, 31 July 2006. The allocation is set out in 7(2)(b) ‘the allocation to housing expenditure shall be either a maximum of 3% of the ERDF allocation to the operational programmes concerned or 2% of the total ERDF allocation’.
- 38 European Parliament legislative resolution of 10 February 2010 on the proposal for a regulation (EC) No .../2009 of the European Parliament and of the Council amending Regulation (EC) No 1080/2006 on the European Regional Development Fund as regards the eligibility of housing interventions in favour of marginalised communities (COM(2009)0382 – C7-0095/2009 – 2009/0105(COD)).
- 39 The Ad Hoc Expert Group Report; p. 9.
- 40 The DECLOC Report; p. 104.
- 41 The DECLOC Report; p. 104.
- 42 The DECLOC Report; p. 104.
- 43 The Soteria–ELTE Report; p. 35.
- 44 Based on data obtained by IPP from all GDASCs in 2007 and 2008. See Institute for Public Policy, Benchmarks for measuring effectiveness of social services for adults with mental disabilities in the context of social inclusion policies, January 2010 (available only in Romanian).
- 45 The Soteria–ELTE Report; p. 12.
- 46 See Article 11, the Structural Funds General Regulation 1083/2006.
- 47 The Toolkit; p. 17.
- 48 Based on IPP’s research and answers provided to ECCL by disability organisations in the course of this project.
- 49 Ministry of Labour and Social Affairs of the Czech Republic, Call for proposals under the Integrated Operational Programme, Area of Intervention 3.1. Services in the area of social integration, Annex 1B, Criteria for Transformation, Humanisation and Deinstitutionalisation of Selected Social Care Services.

Using Structural Funds to Maintain Institutional Care: A Comparison with EU Law and Policy, and Human Rights Standards

'Untold amounts of money have been used to build and maintain institutions. Deinstitutionalisation challenges us to re-engineer social support to ensure that it does not become a gilded cage. In practical terms, this means a commitment to the ideal of community living and the provision of the means to make it happen.'

Gerard Quinn¹

This chapter considers the practice of allocating Structural Funds to programmes that build new, or ‘modernise’ existing, long stay residential institutions. It does so in the light of European Union law and policy as well as European and international human rights standards.

Overview: Key issues of concern

In Chapter 2 we highlighted the serious human rights abuses that occur in institutions in CEE: that in many institutions across this region, the living conditions are appalling, the quality of care is very poor and the residents are cut off from the outside world. We also drew attention to the general consensus that institutional care is no longer acceptable: evidence shows that the culture that develops in institutions dehumanises the residents and, irrespective of the quality of care, the quality of life for residents is likely to be very poor.

Chapter 3 gives examples of Structural Funds being allocated to programmes that invest in long stay institutions, thereby maintaining a system of institutional care. The findings from our partners’ research in Hungary and Romania identify key concerns such as a lack of clear direction on developing alternatives to institutional care; residential institutions being reconstructed, expanded and built rather than resources being used to develop community-based services; projects that purported to promote social inclusion but in reality failed to do so; and barriers to the development of community-based services, such as legal and financial rules that are geared towards institutional care and restrict the development of community-based alternatives.

This report has focused on the situation of disabled people in residential institutions in CEE because the institutionalisation of disabled people continues to be prevalent across this region. The main reason why disabled people continue to be placed in institutional care is because there are little, to no, alternative services available in community settings. Unless and until action is taken to ensure that community-based alternatives to institutionalisation are available in these countries, the policy objectives of the EU and Member States to promote the social inclusion of disabled people, and the wide range of related activities to support such objectives, will be meaningless.

Summary of this chapter

While the situation will differ between countries and each case will need to be considered on the basis of its particular circumstances,² this chapter seeks to identify general concerns about the use of Structural Funds to build new, or renovate existing, residential institutions. For reasons discussed in more detail below, it is argued that by using Structural Funds in this way, which maintains an archaic system that perpetuates the social exclusion of disabled people, the European Union (EU) and Member States are failing to meet their European and international obligations. In particular, ECCL considers that this practice is likely to be:

- **Contrary to States' obligations to protect human rights:** Institutional care leads to serious human rights abuses. Furthermore, the unjustified segregation of disabled people is in itself a serious infringement on individuals' rights and freedoms.
- **Contrary to States' obligations to challenge discrimination and promote equality of opportunity:** The unjustified segregation of disabled people in institutions, often for life, runs counter to States' obligations to challenge discrimination and promote equality of opportunity. Furthermore, institutional care reinforces the long-standing and pervasive prejudice and discrimination against disabled people.
- **Contrary to States' obligations to promote community living:** By building new, or renovating existing, residential institutions, States are diverting resources away from the development of community-based services and other initiatives that are needed to ensure that disabled people are able to live in the community and participate fully in society.

1. Protecting human rights

This section considers States' obligations to protect the human rights of disabled people. It seeks to show why, irrespective of the quality of care provided, or the standards of the living conditions in institutions, the continued practice of institutionalising disabled people is contrary to human rights standards.

In particular, this chapter argues that in the light of the introduction of the UN Convention on the Rights of Persons with Disabilities (CRPD) the fundamental objection to the institutionalisation of disabled people is that their unjustified segregation is in itself a severe infringement of their rights. This view is supported by the policy objectives of both the EU and the Council of Europe which seek to promote community living.

For this reason, ECCL considers that the use of Structural Funds to build new institutions or renovate existing residential institutions is contrary to States' obligations to protect the human rights of disabled people.

European Union: Human rights and disability

Through their membership in the European Union and ratification of human rights treaties, Member States have undertaken to respect and promote the human rights of their citizens and protect them from discrimination.³ The importance of these obligations is emphasised by the Treaty of Lisbon:

*'The Union is founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights, including the rights of persons belonging to minorities. These values are common to the Member States in a society in which pluralism, non-discrimination, tolerance, justice, solidarity and equality between women and men prevail.'*⁴

The European Commission has been consistent in emphasising its commitment to promoting the rights of disabled people. Since 2003, its overall objective has been ‘to make equal opportunities for disabled people a reality’.⁵ The EU was involved in the negotiations on the CRPD and was one of the first signatories to this human rights instrument. The implementation of the CRPD will be part of the European Commission’s strategic approach to disability:

‘Given the strong convergence between the European approach to disability and the UN Convention, the [Disability Action Plan] will contribute to its practical implementation at European level, while complementing national actions. In particular, actions in the areas of employment, social services, independent living, accessibility, and development aid will contribute to the implementation of the UN Convention.’⁶

European Convention on Human Rights

All Member States of the EU have ratified the ECHR. This means that their citizens can take complaints to the European Court of Human Rights (‘the ECtHR’). The decisions of the ECtHR are legally binding on the States concerned. As discussed below, case-law emerging from the ECtHR covers issues relevant to this report. The ECHR is also of direct relevance to the EU. This is because the European Court of Justice (ECJ) has emphasised that respect for human rights forms an integral part of the general principles of Community law. This reflects the range of international human rights treaties to which Member States are party, the most important of these being the ECHR.⁷

The UN Convention on the Rights of Persons with Disabilities

All EU Member States have signed the CRPD and to date 12 have ratified it.⁸ The CRPD includes a range of rights such as the promotion of equality and protection from discrimination, the right to privacy, freedom from torture or cruel or degrading treatment, access to justice, participation in political and public life, education and employment. While Article 19 (see Box on page 44) sets out specific requirements on States to enable disabled people to live and participate in the community, the theme of ‘living independently and being included in the community’ is integral to the CRPD.⁹

The emphasis that is given to the right of disabled people to be supported to live in the community and participate fully in society is often described as the right to ‘independent living’ or, as used in this report, ‘community living’.¹⁰

Although the CRPD is the first international human rights treaty to include the explicit right of all disabled people to live and participate in the community as equal citizens, this is not a new right. By providing that all disabled people have the right to live and participate in the community, Article 19 of the CRPD reflects the increasingly widespread recognition within the UN human rights agencies that such a right exists. For example, under the heading ‘Equalization of opportunities’, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly in 1993 state:

‘Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.’¹¹

Article 19 – Living independently and being included in the community

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

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

The promotion of community living: a common objective

Article 19 of the CRPD is of great significance because it enshrines the right to community living in an international human rights treaty. However, both the EU and the Council of Europe emphasised the importance of promoting community living prior to the introduction of the CRPD. The EU aims to ‘develop concrete actions in crucial areas to enhance the integration of people with disabilities’.¹² The Council of Europe’s disability action plan identifies community living as a key goal:

‘People with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community.’¹³

Unjustified segregation is a human rights violation

As discussed in Chapter 2, numerous reports have highlighted the wide ranging and severe human rights violations within residential institutions in CEE. While Governments have a responsibility to take action to address human rights abuses and the failures to provide appropriate care, simply renovating the buildings and improving the standards of care within such institutions, is not enough.

Institutionalisation: an infringement of rights and freedoms

Irrespective of the conditions within an institution, a system which segregates people on the basis of their disability, removes them from their families and local communities and excludes them from opportunities that are available to non-disabled people, such as education and employment, is an infringement of disabled people’s rights and freedoms. Article 19 of the CRPD makes clear

that the unjustified segregation of disabled people is in itself a severe infringement of disabled people's rights. Requiring disabled people to live in residential institutions also engages rights under the ECHR, in particular Article 5 and Article 8 (these are discussed below).

Institutionalisation: contrary to the CRPD

Article 19 provides that all disabled people have the right to live and participate in the community. States are required to 'take effective and appropriate measures' to facilitate disabled people's 'full enjoyment' of this right, and to achieve their 'full inclusion and participation in the community'.¹⁴ Article 19 also requires that disabled people have access to community support services necessary to support their social inclusion and to 'prevent isolation or segregation from the community'.¹⁵

The goal of ensuring that disabled people have the necessary support to live and participate in society is emphasised by other key rights of the CRPD. For example, Article 26 requires States to take appropriate measures, such as rehabilitation services and programmes:

'...to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.'

Furthermore, States must take steps to prevent action that is contrary to the rights set out in the CRPD. They must:

*'...refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention.'*¹⁶

Using Structural Funds to maintain institutional care: contrary to CRPD

States that have ratified the CRPD are bound by the obligations set out in this treaty. Those that have signed but not yet ratified are required to 'refrain from acts that would defeat the object and purpose of the treaty'.¹⁷

For the reasons set out below, in ECCL's view the use of Structural Funds to maintain institutional care not only contravenes the rights set out in the CRPD, in particular Article 19, but also defeats the object and purpose of the CRPD. By using Structural Funds in this way, Member States are perpetuating a system that excludes disabled people from society and prevents them from exercising their right to community living. They have an obligation to remedy this situation, whether or not they have yet ratified the CRPD.

Institutionalisation: Implications for the European Convention on Human Rights

Many of the rights set out in the ECHR are of direct relevance to the human rights violations within institutions that are described in Chapter 2. For example, the appalling living conditions, malnutrition and unhygienic sanitation would engage Article 3 (freedom from torture or inhuman or degrading treatment or punishment) and in some cases Article 2 (the right to life).

This section focuses on two ECHR rights that are of particular significance to the institutionalisation of disabled people: Article 5 (the right to liberty) and Article 8 (the right to private and family life). It does so by posing key questions to be considered:

i. Does the placement in the institution amount to a deprivation of the person's liberty?

Article 5 of the ECHR (the right to liberty) is relevant where the placement of an individual in an institution amounts to a deprivation of liberty. This Article permits 'deprivation of liberty' (also referred to as 'detention') in limited and specified circumstances only.¹⁸ Accordingly, States must ensure that any situation in which a person is required to live in a residential institution complies with Article 5.

Deprivation of liberty (detention)

Given the paucity of information on residents of institutions¹⁹ it is not known exactly how many disabled people are institutionalised across CEE nor is it possible to assess how many people in institutions are detained. However the numbers are likely to be substantial, particularly given the European Court of Human Rights (ECtHR) rulings on what amounts to detention. In determining whether a person is detained, the ECtHR takes into account a range of factors, 'such as type, duration, effects and manner of implementation of the measure in question'.²⁰ Individuals may be deprived of their liberty even if they do not resist their placement²¹ or are permitted to leave the facility on frequent occasions.²²

Evidence suggests that the majority of disabled adults in institutions are people with mental health problems and/or intellectual disabilities.²³ Although Article 5 allows a person to be deprived of their liberty on the grounds that they are 'of unsound mind' (a term which includes 'mental health problems' and 'intellectual disabilities') this is not in itself sufficient for the detention to be lawful. The ECtHR requires three minimum conditions to be met: that objective medical evidence has shown that the person has a mental disorder; that this is of a nature or degree warranting compulsory confinement and the person can be detained only so long as such mental disorder persists.²⁴ There must also be a periodic review of the person's detention by an independent judicial body.²⁵

Guardianship²⁶

Residents of institutions in CEE may have been placed in the institution on the authority of their guardian. In *Shtukaturov v Russia* the ECtHR found that the applicant was detained, having noted that he was 'confined to hospital for several months, he was not free to leave and his contacts with the world were seriously restricted'. The fact that under domestic law the applicant was considered to be 'voluntarily confined' because his guardian had authorised the admission to the psychiatric hospital was not relevant to the question whether or not the situation amounted to a deprivation of liberty under the ECHR.²⁷

ii. What alternatives have been considered?

The ECtHR has emphasised that the detention of an individual is a very serious measure. Accordingly, detention will only be justified:

*'...where other, less severe measures have been considered and found to be insufficient to safeguard the individual or public interest which might require that the person concerned be detained.'*²⁸

Whether or not a person's placement in an institution amounts to a deprivation of liberty under Article 5, it will engage Article 8 (right to private and family life). This is because the characteristics of institutions constitute a significant interference with a person's private and family life, such as the lack of privacy and restrictions on their ability to interact with family and friends. The ECtHR has stressed that there must be a clear justification for any interference with Article 8, which must relate to the specific aims of this right, such as the protection of health or morals and the protection of the rights and freedoms of others.

In deciding whether there was any justification for the interference with Article 8, the ECtHR will consider a variety of factors including the impact on the individual and whether there were any less intrusive measures that could have been taken that would have achieved the desired outcome. For example, in *Kutzner v Germany* the ECtHR found that the removal of the children of parents with mild intellectual disabilities breached Article 8 because there were insufficient reasons for such a serious interference with the parents' family life. One of the factors taken into account by the ECtHR in reaching this decision was its concern that the authorities had not given sufficient consideration to the additional measures of support that could have been provided as an alternative to the 'most extreme measure' of separating the children from their parents.²⁹

The ECtHR has held that in some situations States are required to take action to ensure that an individual's rights are protected. These 'positive duties' under Article 8 arise when the State's failure to adopt certain measures has a direct impact upon an individual's life by interfering with that person's '*right to personal development and his or her right to maintain relations with other human beings and the outside world*'.³⁰

In deciding whether such positive duties have arisen in matters concerning the allocation of resources, the ECtHR generally accords States a wide 'margin of appreciation'.³¹ However, the ECtHR has stressed that even where the margin of appreciation is wide, it is for the ECtHR to determine whether the ECHR rights in question have been curtailed:

*'...to such an extent as to impair their very essence and deprive them of their effectiveness; that they are imposed in pursuit of a legitimate aim; and that the means employed are not disproportionate.'*³²

These points are relevant in considering how the ECtHR might approach any future potential cases that seek to challenge the practice of institutionalising disabled people, for reasons such as the failure to develop community-based alternatives. Although, to date, the ECtHR has not considered this issue, given the broad scope of Article 8, ECCL considers that this right could form the basis for such challenges.

For example, the ECtHR has noted that there is international recognition of the need to protect disabled people, as reflected in the adoption of the CRPD.³³ This, together with the right to community living as articulated in Article 19 of the CRPD and the general consensus on the need

to move from institutional care to a system of community-based services,³⁴ may lead the ECtHR to consider it necessary to examine the reasons why a State has not taken reasonable steps to put in place community-based alternatives to institutional care.

A Government's decision to use Structural Funds to build new institutions or renovate existing institutions may be found to have failed to comply with the positive obligations under Article 8 on the basis that as a result of the failure to use such funding to develop alternative community-based services, disabled people have to be placed in (or continue to reside in) institutions.³⁵

2. Challenging discrimination and promoting equality of opportunity and social inclusion

This section examines States' obligations to challenge discrimination and promote equality as well as their commitment to promote social inclusion. It seeks to show why ECCL considers that the practice of using Structural Funds to build new institutions or renovate existing residential institutions fails to take these undertakings into account sufficiently, or at all.

European Union law and the use of Structural Funds

In determining the scope and purpose of the programmes to be financed by Structural Funds, the EU and Member States must take into account their obligations to challenge discrimination and promote equality of opportunity and social inclusion. The key relevant issues are considered below.

i. Principles of non-discrimination and equality of opportunity

The European Commission emphasises the 'long tradition' of European action to 'ensure equality among individuals'. This action is based upon the shared values of EU Member States:

*'Common to all our European societies is a fundamental recognition that every individual is of equal worth and should have fair access to the opportunities of life. Discrimination undermines these shared values.'*³⁶

A fundamental principle of Community law and all the major human rights instruments is to protect individuals from discrimination. Although the precise definition of 'discrimination' differs between treaties and type of discrimination being addressed, a common feature is that States are required not only to prohibit discrimination but may also be required to take affirmative action to counter existing discrimination against certain parts of the population.

The prohibition of discrimination and right to equal treatment are principles that form part of well-established Community law. Article 13 of the Treaty of Amsterdam (1999) authorises the EU to take action to combat discrimination based on sex, race or ethnic origin, religion or belief, disability, age or sexual orientation. This has provided the basis for six main directives to date, for example, the Employment Equality Directive.³⁷ The European Commission has issued a proposal for a new directive which will outlaw other forms of discrimination on the grounds of age, sexual orientation, disability and religion or belief.³⁸

ii. General Regulations: preventing discrimination and promoting social inclusion

The use of the Structural Funds is governed by regulations adopted by the European Parliament and the Council of the European Union. Regulation (EC) No 1083/2006 ('the General Regulations') sets out the general provisions for the European Regional Development Fund (ERDF) and the European Social Fund (ESF).³⁹ There are also separate regulations, setting out the specific tasks and governance provisions for each of the Structural Funds.⁴⁰ These regulations are legally binding on all Member States and have the same status as national law.⁴¹

Preventing discrimination

Article 16 of the General Regulations (Equality between men and women and non-discrimination) is of particular importance to the question of whether the use of Structural Funds to build new institutions or renovate existing institutions is discriminatory under Community law. It requires Member States to take action to prevent discrimination on various grounds including disability:

'The Member States and the Commission shall take appropriate steps to prevent any discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation during the various stages of implementation of the Funds and, in particular, in the access to them. In particular, accessibility for disabled persons shall be one of the criteria to be observed in defining operations co-financed by the Funds and to be taken into account during the various stages of implementation.'

The precise scope of Article 16 is not clear because neither 'disability', nor 'discrimination' is defined in the General Regulations. So far as we are aware, there is no EU case law on the meaning of these terms in the context of these regulations generally or Article 16 specifically. However, some guidance can be gleaned from broader EU law particularly in relation to the Employment Equality Directive. When considering this directive in relation to disability, the European Court of Justice (ECJ) has stated:

*'...the concept of 'disability' must be understood as referring to a limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life.'*⁴²

While the issues covered under Article 16 are much broader than employment, the ECJ's definition provides some indication of how 'discrimination' under the General Regulations may be interpreted. Notwithstanding concerns about the 'medical model' approach of the ECJ to impairment,⁴³ individuals who have been placed in institutions on the grounds that they have physical, intellectual or psychological impairments are likely to fall within the definition of disability however limited the scope of the definition being applied. The definition of 'disability' in the proposed EU discrimination directive reflects the definition set out in the CRPD:

*'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.'*⁴⁴

Under the Employment Equality Directive, the concept of discrimination in relation to disability includes 'direct discrimination', 'indirect discrimination' and 'harassment'.⁴⁵ The proposed

EU discrimination directive includes 'denial of reasonable accommodation' in the definition of discrimination.⁴⁶

It is not clear whether 'discrimination' under Article 16 would encompass these aspects of discrimination and so far as we are aware, no guidance has been issued on this subject. However, the European Commission's *'Ensuring accessibility and non-discrimination of people with disabilities: Toolkit for using EU Structural and Cohesion Funds'* ('the Toolkit') makes clear that Article 16 is intended to underpin the EU policy objectives of addressing social exclusion and disability discrimination:

*'This article offers an opportunity and a positive framework for the promotion of equality, non-discrimination and in particular the implementation of accessibility for people with disabilities and for involving organisations representing people with disabilities.'*⁴⁷

The use of Structural Funds to maintain the system of institutional care for disabled people is inconsistent with these positive goals.

Promoting social inclusion

The EU's social inclusion policies highlight the need to develop quality services and to use the Structural Funds (especially the European Social Fund) to support social inclusion measures in the EU Member States.⁴⁸ For example, the Open Method of Coordination for Social Protection and Social Inclusion stresses the importance of mainstreaming social inclusion policies into all relevant public policies, including Structural Fund programmes.⁴⁹ The General Regulations also cover social inclusion. Article 3 states:

*'The action taken under the Funds shall incorporate, at national and regional level, the Community's priorities in favour of sustainable development by strengthening growth, competitiveness, employment and social inclusion and by protecting and improving the quality of the environment.'*⁵⁰

The emphasis on promoting the social inclusion of disabled people is underpinned by the EU Charter of Fundamental Freedoms, with which Member States must comply when implementing EU law.⁵¹ Article 26 (Integration of persons with disabilities) of the Charter states:

'The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.'

The CRPD will also be relevant to the application of Structural Funds in relation to projects concerning disabled people. The European Commission's Toolkit highlights the connection between Article 19 and the use of Structural Funds:

*'The UN Convention as a whole, and specifically Article 19 favours independent living in the community instead of expanding residential institutions. This means, for example, that investing EU Funds in solutions which oppose and hamper community living of people would act against the Convention. This would be a violation of fundamental rights of people with disabilities, leading to more exclusion.'*⁵²

The Toolkit makes clear that the use of Structural Funds to modernise or build long stay residential institutions for disabled people is contrary to the CRPD. Such use also conflicts with the EU's social inclusion policies.

In some circumstances action will be required to address the poor living conditions in residential institutions and any risks to the health and safety of the residents. However, given that such remedial work would need immediate funding, Structural Funds are not the appropriate mechanism for financing such emergency initiatives. We make specific recommendations on the use of Structural Funds in Chapter 5.

Challenging the use of Structural Funds to maintain institutional care

This section considers issues that will be of particular relevance to the question whether the use of Structural Funds to invest in long stay residential institutions complies with EU law. In the light of the areas outlined above (the fundamental principles of non-discrimination and equality of opportunity, and the General Regulations requirements on preventing discrimination and promoting social inclusion) we suggest that the following questions must be addressed by the EU and Member States when determining the types of projects that Structural Funds can support:

i. Has the requirement to take all appropriate steps to prevent discrimination on the basis of disability been met?

As discussed above, the need to protect individuals from discrimination is recognised by Community law and all the major human rights instruments, albeit the definitions of discrimination vary. Some key issues arising from the CRPD, ECHR jurisprudence and a decision of the US Supreme Court in relation to the Americans with Disabilities Act 1990 are set out below.

The Convention on the Rights of Persons with Disabilities

Addressing disability discrimination is a fundamental principle of the CRPD. In meeting their obligations to 'ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability' States must take all appropriate measures:

- *'...to modify laws, regulations, customs and practices that constitute discrimination against persons with disabilities'⁵³*
- *'...to eliminate discrimination on the basis of disability by any person, organization or private enterprise'⁵⁴*

The CRPD requires States to prohibit all discrimination on the basis of disability,⁵⁵ which is defined as:

'...any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.'

The European Court of Human Rights' approach to discrimination

The ECtHR has taken an increasingly robust approach to discrimination.⁵⁶ For example, in relation to alleged discrimination on the grounds of race, it stated:

'...no difference in treatment which is based exclusively or to a decisive extent on a person's ethnic origin is capable of being objectively justified in a contemporary democratic society built on the principles of pluralism and respect for different cultures'.⁵⁷

It has made similar points in relation to sex discrimination, holding that:

'... very weighty reasons would have to be put forward before such a difference of treatment [on grounds of sex] could be regarded as compatible with the Convention'⁵⁸

Furthermore, in the recent case of *Glor v Switzerland*, the ECtHR emphasised its role in protecting the rights of disabled people and confirmed that Article 14 (freedom from discrimination) protects persons with disabilities.⁵⁹ In that case, the ECtHR decided that the nature of the case merited a more detailed scrutiny of the basis of the Government's decision to treat a person differently due to their disability, to ascertain whether it was justified or not. Noting that the State's action might not be compatible with the necessity to fight against discrimination towards disabled people and to promote their full participation and integration into society, the ECtHR concluded that in such cases the 'margin of appreciation' for States to establish different legal treatment for disabled persons is significantly reduced.⁶⁰

The ECtHR's emphasis on the importance of challenging discrimination towards disabled people and on promoting their full participation in society, highlight the potential of Article 14 (in conjunction with Article 8) to form the basis of a complaint that seeks to challenge policies and practice that lead to disabled people's segregation, such as the use of Structural Funds to maintain institutional care. If such a case were to be considered, comments from the ECtHR also suggest that Article 14 may be relevant even if the respondent State did not intend to marginalise or otherwise unfairly treat disabled people when developing its policies for social inclusion and other areas relevant to the use of Structural Funds. If there is evidence that demonstrates that these policies had such a result, Article 14 may be engaged:

'...a general policy or measure that has disproportionately prejudicial effects on a particular group may be considered discriminatory notwithstanding that it is not specifically aimed at that group.'

The need to address 'unnecessary institutionalization': *Olmsted v LC*

Chapter 3 of this report identified the 'perverse incentive' in favour of institutionalisation created by legal and financial systems that were geared towards placing disabled people in institutions rather than providing them with the support to live in their own homes and engage in community life. An analogous situation was considered by the US Supreme Court in *Olmsted v LC* (1999).⁶¹ In this case, the State of Georgia's funding arrangements favoured institutional placements, rather than community-based independent living placements. The Court considered that such arrangements contravened the Americans with Disabilities Act 1990 which (amongst other things) prohibits discrimination in the provision of public services.

Whilst making clear that factors such as the available resources and the equitable use of resources needed to be taken into account, the US Supreme Court stressed the importance of policies being rational and fair and of the basic principle that ‘unnecessary institutionalization’ should be avoided if possible.

The role of Structural Funds

The comments the US Supreme Court made in relation to available resources and the equitable use of such resources is of particular relevance to the use of Structural Funds in CEE. As Soteria–ELTE point out in Chapter 3, one of the most frustrating aspects of the current use of Structural Funds is that they are being wasted. They are being used to maintain an archaic institutional system rather than to initiate and develop a system of community-based alternatives. Governments in CEE have limited resources and many areas that require development. However, this is where Structural Funds can alleviate these funding pressures by providing the resources that Governments lack.

ii. Have the obligations under Article 19 of the CRPD been met?

The CRPD provides strong support for the view that the segregation of disabled people in institutions, on the basis of their disability alone,⁶² amounts to discrimination. As discussed above, the emphasis of Article 19 is that disabled people must have access to a range of community-based services that support their social inclusion and prevent their isolation or segregation from the community.⁶³

Responsibility on States to take effective action

Although States will not be expected to comply fully with all aspects of Article 19 immediately, they will be required to demonstrate that they are taking concrete steps to realise the rights set out in this article, using the maximum of their available resources to do so. This reflects the understanding that some rights in the CRPD, such as Article 19, are likely to take time to achieve in full. Accordingly, the CRPD requires States to take measures with a view ‘to achieving progressively the full realisation of these rights’ (referred to as ‘progressive realisation’).⁶⁴

However, the lack of resources does not justify inaction. In the case of CEE countries, where institutional care predominates, ECCL considers that States should, as a matter of priority, plan what action they will need to take to meet their obligations under Article 19. This should include the planning and development of community-based services as alternatives to institutionalisation and the closure of the long stay residential institutions.

Implementation of Article 19 is linked to other key rights

In the light of the obligations set out in the CRPD, ECCL considers that States should prioritise the steps required to develop alternatives to institutionalisation. The implementation of Article 19 is significant in itself, but its implementation is also relevant to a number of key provisions of the CRPD that require immediate application, for example, Article 14 (Liberty and security of person) and Article 23 (Respect for the home and the family). The implementation of these rights is dependent on the State’s progress in ensuring the right of disabled people to choose where and with whom to live, and to participate in the community.

The Office of the United Nations High Commissioner for Human Rights points out the significant changes that will be required in countries where institutional care is still predominant:

*'The recognition of the right of persons with disabilities to independent living and community inclusion requires the shift of government policies away from institutions towards in-home, residential and other community support services.'*⁶⁵

This comment confirms that the use of Structural Funds to build or renovate long stay residential institutions is contrary to the obligations under Article 19 to promote community living.

iii. Has the requirement to incorporate the Community's priorities in favour of social inclusion been met?

Residents of long stay institutions are probably one of the most socially excluded groups. It is unlikely that they receive any benefit from EU and Government policies that promote social inclusion, such as access to quality services, vocational training and support to gain employment.

ECCL is aware that in some projects concerning the renovation of residential institutions or construction of new institutions, the residents have been assessed as being in need of institutional care.⁶⁶ It is clear that when there are no alternatives to institutions it is likely that people with support needs for which their families are unable to provide, will be considered to require institutional care. It is this conundrum that Structural Funds have the potential to help to break. They can support the development of community-based alternatives to institutional care.

Comments by the US Supreme Court in the case of *Olmstead* (discussed above) which concerned the institutionalisation of disabled people illustrate the vicious circle in which residents of institutions in CEE are trapped:

*'The identification of unjustified segregation as discrimination reflects two evident judgments: Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life...'*⁶⁷

In CEE countries, the assumption that the residents of institutions are unable to live in the community remains unchallenged because there are no supports in the community.

In ECCL's view there is no justification for Structural Funds being used for programmes that perpetuate the segregation of disabled people in institutions.

iv. Has the priority of 'increasing the quality of life' obligations under the European Regional Development Fund Regulations been taken into account sufficiently?

Article 4(11) of Regulation 1080/2006 (European Regional Development Fund – ERDF) states that one of the priorities of the ERDF is 'investments in health and social infrastructure which contribute to regional and local development and increasing the quality of life'.

As noted in Chapter 2 there is a propensity for the culture of such institutional environments to lead to the dehumanisation of the residents and to engender human rights abuses. The report of an in-depth study of institutions in France, Hungary, Poland and Romania, *Included in Society*, highlights the potential for institutionalisation to lead to serious human rights abuses of the residents:

*'In this situation, where the organisation becomes relatively isolated from the wider community, practices develop that should be unacceptable, such as keeping people in bed all day or the use of cage beds to confine people.'*⁶⁸

Furthermore, evidence shows that improving the physical environment or even increasing the numbers of qualified staff does not necessarily address this negative 'institutional culture'.⁶⁹

The US Supreme Court in the case of *Olmstead* (discussed above) highlighted a significant concern about the negative effect of institutionalisation:

*'...confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.'*⁷⁰

The concern that living in a residential institution is likely to diminish a person's capacity to engage in community life outside an institution is especially true for many residential institutions across CEE where there are little, or no, therapeutic activities or provision of independent living skills.

In ECCL's view by using Structural Funds to renovate or build new residential institutions, the EU and Member States are at risk of failing to comply with the requirement to 'increase the quality of life' of the residents of such institutions.

4. Duty to promote community living

This section explains why the use of Structural Funds to build new institutions or renovate existing institutions is contrary to States' obligations to promote community living. It seeks to demonstrate that while the CRPD provides greater detail on the nature and scope of the right to community living, the obligation to ensure respect for this right applies to all EU Member States, whether or not they have ratified this treaty.

Community living and the CRPD

A central tenet of the CRPD is that disabled people should be able to receive the support that they need to enable them to achieve their aspirations and engage in community life. By ratifying the CRPD, States have made a commitment to ensuring that disabled people can live, and participate fully, in their communities. They must give legal recognition to the right of disabled people to live in the community and must develop services and support and an action plan to enable people to live in the community.

The requirement that States take concrete steps to move from a system of institutional care to the provision of services and support in the community that promote social inclusion is made explicit in the CRPD. Article 19 requires States to ‘take effective and appropriate measures’ to facilitate disabled people’s right to live in the community and ‘full inclusion and participation in the community’. In order to achieve this objective States must ensure that disabled people have access to a range of community support services. Article 19 also makes clear that the provision of services is not enough in itself. Such services must be *‘necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community’*.

The general obligations under Article 4 require that States adopt appropriate legislative, administrative and other measures to implement these rights.⁷¹ Accordingly, States must be proactive in developing laws, policies and practices that reflect the rights under the CRPD. This underpins the requirement under Article 19 that States take concrete steps to move from institutional care to community-based services. States that have ratified the CRPD have undertaken to:

‘...ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability’

The development of the right to community living

There has been increasing recognition both internationally and within Europe of the need to promote the right of disabled people to be supported to live in the community and participate fully in society. For example, in 1994 the Committee responsible for overseeing States’ compliance with obligations under the International Covenant on Economic, Social and Cultural Rights (ICESCR) noted that, in order to comply with the obligations under the ICESCR, States should have ‘social policy programmes which enable persons with disabilities to live an integrated, self determined and independent life’. In relation to the right to physical and mental health (Article 12 ICESCR) the Committee stated that disabled people should have access to, and benefit from, medical and social services that will help them:

‘...to become independent, prevent further disabilities and support their social integration. Similarly, such persons should be provided with rehabilitation services which would help them “to reach and sustain their optimum level of independence and functioning”.’⁷²

The existence of the right to community living was more firmly articulated by Paul Hunt, the former Special Rapporteur on the Right to Health, when he argued that the ‘right to community integration’ derived from the right to health and other human rights.⁷³ Although he was focusing on people with ‘mental disabilities’ (people with mental health problems and people with intellectual disabilities), these comments apply to all disabled people:

‘Community integration better supports their dignity, autonomy, equality and participation in society. It helps prevent institutionalisation, which can render persons with mental disabilities vulnerable to human rights abuses and damage their health on account of the mental burdens of segregation and isolation. Community integration is also an important strategy in breaking down stigma and discrimination against persons with mental disabilities.’⁷⁴

The right to community living is reflected in Article 26 of the EU Charter of Fundamental Freedoms (discussed above), which Member States must comply with when implementing EU law. Article 15 of the Revised European Social Charter (The right of persons with disabilities to independence, social integration and participation in the life of the community) is also significant. It requires States:

*'...to promote [persons with disabilities] full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.'*⁷⁵

Thus the right to community living was recognised by UN treaty bodies, the EU Charter of Fundamental Rights, as well as the Revised Social Charter (which some Member States have ratified)⁷⁶ prior to the introduction of the CRPD. Accordingly, EU Member States should take action to promote community living whether or not they have ratified the CRPD.

Furthermore, as argued above, the use of Structural Funds to maintain institutional care excludes disabled people from society and prevents them from exercising their right to community living. This not only contravenes the rights set out in the CRPD, in particular Article 19, but also defeats the object and purpose of the CRPD. Accordingly, all Member States, whether or not they have yet ratified the CRPD, should ensure that Structural Funds are not used in this way.

The role of Structural Funds in promoting community living

As discussed above, the right to community living highlights the importance of ensuring that disabled people receive the support that they need to achieve their aspirations and engage in community life.⁷⁷ It is clear therefore that community living is not focused solely on the physical location of where a person lives. However, for those people who are currently living in long stay institutions, their access to community life is severely restricted due to the place in which they live. In many cases residents' lives are confined within the walls of the institution.

Thus, for some people in CEE, where they live is a crucial, if not deciding factor, on whether they can exercise their right to community living. For this reason it is essential that Structural Funds are used to finance programmes for the development of community-based services as alternatives to institutional care. This was recognised by the Council of Europe's Parliamentary Assembly resolution that called upon member States of the Council of Europe to:

*'...commit to the process of deinstitutionalisation by re-organising services and reallocating resources from institutions to community-based services.'*⁷⁸

By building new institutions or renovating existing institutions, States are diverting resources away from the development of community-based services and other initiatives that are needed to ensure that disabled people are able to live in the community and participate fully in society. Structural Funds (both ERDF and ESF) should be used to provide the financial and technical support that Governments need to develop a new system of community-based care.

The use of Structural Funds to invest in existing long stay residential institutions must be reviewed as a matter of priority. ECCL considers that Structural Funds should not be used to redevelop or build new institutions. Where interim measures are necessary to address the risks to residents' health or safety, other funding that can be made available immediately should be used. Furthermore, action taken must be part of a wider programme that is directed to the development of alternative services in the community and has a clear timetable for the closure of the institution.

6. Conclusion

Upon their ratification of human rights treaties and on accession to the European Union, States have undertaken obligations to protect human rights, challenge discrimination and promote community living.

In some circumstances, these obligations require States to take positive action to ensure that their citizens' rights and freedoms are protected. As highlighted in this chapter, in the case of disabled people, such action must include the development of community-based alternatives to institutionalisation. The use of Structural Funds to invest in archaic residential institutions runs counter to these obligations and risks subjecting disabled people to continued human rights violations, discrimination and social exclusion.

The recommendations in Chapter 5 seek to identify what needs to be done to end this misuse of Structural Funds and ensure that in the future they are applied to programmes that enable all disabled people to live and participate in the community as equal citizens.

Endnotes

- 1 Gerard Quinn, *Editorial*, Newsletter of the European Coalition for Community Living, Issue no. 1, July 2006; p. 1.
- 2 It is beyond the scope of this report to consider the wide ranging complaints mechanisms that could be engaged in relation to this practice.
- 3 See, for example, the International Covenant on Civil and Political Rights (1966), the International Covenant on Economic, Social and Cultural Rights (1966), the Convention on the Rights of the Child (1989) and the Convention on the Elimination of All Forms of Discrimination against Women (1979).
- 4 Treaty of Lisbon amending the Treaty on European Union and the Treaty establishing the European Community, signed at Lisbon, 13 December 2007, 2007/C 306/01.
- 5 Communication from the Commission to the Council, the European Parliament, the European and Economic and Social Committee and the Committee of the Regions, Situation of disabled people in the European Union: the European Action Plan 2008–2009, COM(2007) 738 final, 26 November 2007.
- 6 COM (2007) 738 Final.
- 7 See 'The rising prominence of fundamental rights in the European Union Treaties' at: http://ec.europa.eu/justice_home/fsj/rights/treaties/fsj_rights_treaties_en.htm. See also paragraph 30 of case C-442/00 *Ángel Rodríguez Caballero v Fondo de Garantía Salarial (Fogasa)* where the ECJ stated that 'according

to settled case-law fundamental rights form an integral part of the general principles of law whose observance the Court ensures’.

- 8 The following EU Member States have ratified the UN Convention on the Rights of Persons with Disabilities: Austria, Belgium, Czech Republic, Denmark, Germany, Hungary, Italy, Portugal, Slovenia, Spain, Sweden and the UK. Romania has so far not ratified. (This information was accessed from the UN website on 7 March 2010.)
- 9 See, for example, the general principles in Article 3, Article 9 and Article 26 of the United Nations Convention on the Rights of Persons with Disabilities (‘the CRPD’).
- 10 See the Glossary for ECCL’s definition of this term.
- 11 The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Adopted by the United Nations General Assembly, forty-eighth session, resolution 48/96, annex, of 20 December 1993, paragraph 25.
- 12 Communication from the Commission to the Council, the European Parliament, the European and Economic and Social Committee and the Committee of the Regions, Equal opportunities for people with disabilities: A European Action Plan COM(2003) 650 Final, 30 October 2003.
- 13 Council of Europe Committee of Ministers, Recommendation Rec(2006)5 of the Committee of Ministers to Member States on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006–2015, 5 April 2006.
- 14 For further analysis of Article 19, see European Coalition for Community Living, *Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities*, August 2009.
- 15 Article 19(b) of the CRPD.
- 16 Article 4(d) of the CRPD.
- 17 United Nations, Vienna Convention on the Law on Treaties, Article 18.
- 18 Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms, Article 5(1).
- 19 See discussion in Chapter 2 above.
- 20 *H.L. v. the United Kingdom*, no. 45508/99 (Sect. 4), ECHR 2004-IX – (5.10.04), paragraph 89.
- 21 *De Wilde, Ooms and Versyp v. Belgium* – 12 (18.11.70, 18.6.71).
- 22 *Ashingdane v. the United Kingdom* – 93 (28.5.85).
- 23 The DECLOC Report; p 29. See also a viewpoint by Thomas Hammarberg, the Council of Europe Commissioner for Human Rights, ‘*Society has an obligation to support abandoned children and offer them a positive home environment – also when budget resources are limited*’, 28 December 2009.
- 24 *Winterwerp v. the Netherlands* – 33 (24.10.79).
- 25 *X v. the United Kingdom* – 46 (5.11.81).
- 26 Under the system of ‘guardianship’ people deemed to lack capacity to make decisions for themselves are appointed guardians who will make decisions on behalf of the person. The powers of the guardian vary across jurisdictions but in general they are wide-ranging, with little, to no, safeguards for the person deemed to lack capacity to make decisions for themselves. The Mental Disability Advocacy Center has undertaken research on the use of guardianship in a number of CEE countries including Bulgaria and Hungary: www.mdac.info/en/guardianship. See also United Nations (2003) Report of the Secretary General: Progress of efforts to ensure the full recognition of human rights of persons with disabilities A/58/181
- 27 *Shtukaturov v. Russia*, no. 44009/05 (Sect. 1), ECHR 2008-.. – (27.3.08), paragraphs 104–110.

- 28 *Witold Litwa v. Poland*, no. 26629/95 (Sect. 2), ECHR 2000-III – (4.4.00), paragraph 78.
- 29 *Kutzner v. Germany*, no. 46544/99 (Sect. 4), ECHR 2002-I – (26.2.02), paragraphs 69–81.
- 30 *Sentges v The Netherlands* (2002) Application no. 27677/02; p. 6.
- 31 See, for example, *Sentges v The Netherlands* (2002) Application no. 27677/02.
- 32 *Hirst v. the United Kingdom (no. 2)* [GC], no. 74025/01, ECHR 2005-IX – (6.10.05), paragraph 62.
- 33 *Glor v. Switzerland*, no. 13444/04 (Sect. 1), ECHR 2009-.. – (30.4.09).
- 34 See discussions in Chapter 2 above.
- 35 Clements L and Parker C, *The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?*, *European Human Rights Law Review*, Issue 4(2008) 508–523; p. 516.
- 36 Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions – Non-discrimination and equal opportunities: A renewed commitment COM2008/0420 final, 2 July 2008; p. 1.
- 37 Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.
- 38 Commission Staff Working Document accompanying the Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, Summary of the Impact Assessment, COM(2008) 426 final.
- 39 The Structural Funds General Regulation 1083/2006.
- 40 See Regulation (EC) No 1080/2006 of the European Parliament and of the Council of 5 July 2006 on the European Regional Development Fund and repealing Regulation (EC) No 1783/1999, and Regulation (EC) No 1081/2006 of the European Parliament and of the Council of 5 July 2006 on the European Social Fund and repealing Regulation (EC) No 1784/1999.
- 41 See: http://ec.europa.eu/community_law/introduction/what_regulation_en.htm
- 42 Case C-13/05 *Sonia Chacón Navas v. Eurest Colectividades SA* Ref case, paragraph 43.
- 43 European Commission (Waddington L and Lawson A), *Disability and non-discrimination law in the European Union, An analysis of disability discrimination law within and beyond the employment field*, July 2009.
- 44 Council of the European Union, Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, (19a) Brussels, 11 February 2010, 2008/0140 (CNS), at: <http://register.consilium.europa.eu/pdf/en/10/st06/st06092.en10.pdf>; see also Commission of the European Communities, Proposal for a Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation, COM(2008) 426 final, 2 July 2008, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52008PC0426:EN:HTML>
- 45 Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation.
- 46 2008/0140 (CNS) and COM (2008) 426 final.
- 47 The Toolkit; p. 14.
- 48 Council of the European Union Joint Report on Social Protection and Social Inclusion 2009, 13 March 2009, 7503/09 and Commission Recommendation of 3 October 2008 on the active inclusion of people excluded from the labour market (notified under document number C(2008) 5737).
- 49 See http://ec.europa.eu/employment_social/spsi/docs/social_inclusion/2006/objectives_en.pdf
- 50 Article 3 of the Structural Funds General Regulation 1083/2006.

- 51 With its entry into force, the Treaty of Lisbon has made the EU Charter of Fundamental Rights legally binding. (The United Kingdom and Poland chose to opt out of the Charter. See: <http://www.euractiv.com/en/future-eu/treaty-lisbon/article-163412>).
- 52 The Toolkit; p. 8.
- 53 Article 4(b) of the CRPD.
- 54 Article 4(e) of the CRPD.
- 55 Article 5(2) of the CRPD.
- 56 See Article 14 of the European Convention on Human Rights. This Article only applies in relation to the exercise of other rights set out in the ECHR.
- 57 *D.H. and Others v. the Czech Republic* [GC], no. 57325/00, ECHR 2007-XII – (13.11.07), paragraph 176.
- 58 *Schuler-Zgraggen v. Switzerland* – 263 (24.6.93), paragraph 68.
- 59 *Glor v. Switzerland*, no. 13444/04 (Sect. 1), ECHR 2009-.. – (30.4.09), paragraph 80.
- 60 *Glor v. Switzerland*; paragraph 84.
- 61 *OLMSTEAD V. L. C.* (98–536) 527 U.S. 581 (1999) 138 F.3d 893.
- 62 However, in relation to children, the Ad Hoc Expert Report notes that some children are institutionalised on the basis of lack of parental care.
- 63 Article 19(b) of the CRPD.
- 64 See United Nations, *From Exclusion to Equality – Realizing the Rights of Persons with Disabilities*, 2007; pp. 18–19 and the European Coalition for Community Living Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities, 2009; p. 8.
- 65 Human Rights Council, *Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and The Secretary-General, Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*, A/HRC/10/48, 26 January 2009, paragraph 50.
- 66 For example, one of the projects reviewed by IPP stated that the residents could only be cared for in the institutional system.
- 67 *OLMSTEAD V. L. C.* (98–536) 527 U.S. 581 (1999) 138 F.3d 893.
- 68 Freyhoff G, Parker C, Coué M, Greig N. (2004) *Included in Society: Results and recommendations of the European research initiative on community-based residential alternatives for disabled people*. Brussels: Inclusion Europe.
- 69 Jim Mansell et al, *Deinstitutionalisation and Community living: Position Statement of the Comparative Policy and Practice Special Interest Research Group of International Association for the Scientific Study of Intellectual Disabilities*, *Journal of Intellectual Disability Research*, Vol 54, Part 2, 104–112, February 2010, and the Ad Hoc Expert Group Report.
- 70 *OLMSTEAD V. L. C.* (98–536) 527 U.S. 581 (1999) 138 F.3d 893.
- 71 Article 4(a) of the CRPD.
- 72 The Committee on Economic, Social and Cultural Rights, General Comment 5, December 9, 1994, paragraph 34.
- 73 Commission on Human Rights, Economic Social and Cultural Rights, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, E/CN.4/2005/51, 11 February 2005, paragraph 85.

- 74 E/CN.4/2005/51, paragraph 85.
- 75 Council of Europe, European Social Charter (Revised), Article 15(3).
- 76 The European Social Charter (Revised) has been ratified by the following EU Member States: Belgium, Bulgaria, Estonia, Finland, France, Hungary, Ireland, Italy, Lithuania, Malta, Netherlands, Portugal, Romania, Slovakia, Slovenia and Sweden. See: http://www.coe.int/t/dghl/monitoring/socialcharter/Presentation/Overview_en.asp.
- 77 Jim Elder Woodward, *'From the Rolling Quads to Direct Payments'*, Newsletter of the European Coalition for Community Living, Issue No. 2, November 2006; p. 3.
- 78 Council of Europe, Parliamentary Assembly, Resolution 1642(2009), Access to rights for people with disabilities and their full and active participation in society, paragraph 8.1.

Looking Forward – Using Structural Funds to Promote Community Living: Conclusions and Recommendations

'In order to enable active participation of persons with disabilities in society, it is necessary that they are given the opportunity to interact with the community. The practice of placing children and adults with disabilities into institutions undermines their inclusion as they are kept segregated from the rest of society and suffer serious damage to their healthy development and obstruction of the exercise of other rights. Deinstitutionalisation is a prerequisite to enabling people with disabilities to become as independent as possible and take their place as full citizens with the opportunity to access education and employment, and a whole range of other services.'

Parliamentary Assembly of the Council of Europe ¹

This chapter sets out our conclusions on the current use of Structural Funds and our recommendations on the steps that need to be taken to ensure that in the future, Structural Funds support programmes that enable all disabled people to live and participate in the community as equal citizens.

These conclusions and recommendations are based on the discussions in this report, in particular the findings of our partners, IPP and Soteria–ELTE, set out in Chapter 3, and the concerns raised in Chapter 4 that the use Structural Funds to build new, or renovate existing, residential institutions, is contrary to EU policy objectives, EU law and human rights standards. They are as follows:

I. The potential of Structural Funds to effect positive change:

Structural Funds have the potential to make a significant positive impact on the situation of people with disabilities by facilitating the development of community-based services as alternatives to institutional care. Such services should seek to enable disabled people to live their lives as equal citizens – going to school, working, developing friendships, making a home, raising a family, taking part in community life and seeking to fulfil their personal aspirations.

Accordingly, we recommend that:

- The current use of Structural Funds is reviewed as a matter of priority. Structural Funds must not be used to build new long stay residential institutions or renovate existing residential institutions. When interim measures are needed to address risks to residents' health or safety, other funding that can be made available immediately should be used. The action taken must be part of a wider programme that is directed to the development of alternative services in the community and has a clear timetable for the closure of the institution;
- The priorities included in Structural Funds' Operational Programmes must explain how they will support the implementation of the EU social inclusion policies, the national strategies for social inclusion of people with disabilities and the UN Convention on the Rights of Persons with Disabilities;
- The 'Guidelines on the use of Structural Funds and other EU funding instruments for deinstitutionalisation' recommended by the Ad Hoc Expert Group should be developed.² These guidelines should provide Member States with examples of how Structural Funds and other EU funding instruments can be used to support projects that deliver good quality services in the community and promote the social inclusion of people with disabilities.

II. Removing the barriers to the development of community-based services:

This report has identified a range of barriers to the development of community-based services as alternatives to institutional care. A major concern raised by both IPP and Soteria–ELTE is the confusion over the interpretation of the Structural Funds regulations concerning the purchase of property or the construction of new premises.

Providing people with a place to live is an essential component of deinstitutionalisation. Projects to develop community-based services as alternatives to institutions will therefore need to purchase or otherwise acquire housing that is located in local communities.

Accordingly, we recommend that:

- The Structural Funds regulations are reviewed and restrictions on investments into new housing and the purchase of existing housing removed;
- Investments into the social infrastructure (funded with European Regional Development Fund (ERDF)) are combined with the training of staff (funded with European Social Fund (ESF)), in order to create a workforce that will be able to provide the newly developed services in the community, and to ensure that institutional practices are not replicated in the new services.

III. Role of non-governmental organisations and experts:

The process of transferring the focus of care from institutions to the community is complex. It requires careful planning and the involvement of a range of individuals and organisations, including disabled people and their families. Non-governmental organisations that have experience of providing community-based services should be given a key role as they will be able to provide support and advice to local public authorities and other non-governmental organisations in establishing good quality and sustainable community-based services.

Accordingly, we recommend that:

- People with disabilities and their representative organisations are involved in the planning, implementation, monitoring and evaluation of the relevant Operational Programmes;
- Non-governmental organisations providing community-based services for people with disabilities are consulted on how to make the application/tendering process of Structural Funds programmes more accessible;
- As recommended by the Ad Hoc Expert Group report, a pool of independent experts on deinstitutionalisation is established to provide technical assistance to the European Commission and the Member States when allocating resources from the Structural Funds.

IV. Monitoring and evaluation:

To ensure that projects supported with Structural Funds lead to a better quality of life for people with disabilities, good monitoring and evaluation systems must be in place. The involvement of disabled people and their representative organisations is crucial at all levels – local, national, regional and European.

Accordingly, we recommend that:

- The remit and procedures of the Monitoring Committees for Structural Funds programmes enable non-governmental organisations representing people with disabilities to contribute to the work of the committees and decision-making process.

V. Transparency and further research:

This report has highlighted the lack of comprehensive information about the use of Structural Funds in relation to disabled people currently living in residential institutions and to the difficulty of obtaining information about projects that have been, or currently are being funded through Structural Funds.

Accordingly, we recommend that:

- Data about the projects funded with Structural Funds (such as a description of activities, information about the organisation being funded and the target group, project results and the budget) is collected and published. At the national level, such information should be publicly available from the Managing Authorities;
- Research is commissioned to evaluate how Structural Funds are being used in relation to the provision of social care services for people with disabilities.

VI. Awareness raising:

A key step in ensuring that Structural Funds are not used to strengthen the system of institutional care is raising awareness that all people with disabilities have the right to live in the community, with choices equal to others.

Accordingly we recommend that:

- Training on the UN Convention on the Rights of Persons with Disabilities (CRPD) and how Structural Funds can facilitate the implementation of the CRPD is provided to the relevant directorates at the European Commission and in the Member States (for Managing Authorities and Monitoring Committees of the relevant Operational Programmes). People with disabilities and their representative organisations should be closely involved in the planning and delivery of such training.

Endnotes

- 1 Council of Europe, Parliamentary Assembly, Access to rights for people with disabilities and their full and active participation in society, Report, Social, Health and Family Affairs Committee, Doc. 11649, 8 August 2008, paragraph 44.
- 2 The Ad Hoc Expert Group Report; p. 21.

Structural Funds: An Overview¹

Structural Funds are the funds used to support the implementation of the EU's strategy to reduce disparities between the regions of Europe, known as the Cohesion policy.²

For the period 2007–2013, the Cohesion Policy is focused on economic growth and jobs. The policy seeks to achieve a 'balance and sustainable development of Europe's regions' by investing in jobs and growth, but it also seeks to 'improve and modernise public administrations, to enhance transparency, and to foster good governance'.³ The two funding mechanisms that support the Cohesion Policy that are of relevance to the development of community-based services are the European Social Fund (ESF) and the European Regional Development Fund (ERDF).

- European Social Fund (ESF): was established to reduce differences in prosperity and living standards across the EU, thereby advancing economic well-being. It 'supports projects that promote employment and help citizens advance their education and skills, improving their job prospects'.⁴ It assists EU Member States to achieve goals established in the European employment strategy and disability action plan.⁵ It can also be used to train staff working with people with disabilities.
- European Regional Development Fund (ERDF): this 'finances productive investment leading to the creation or maintenance of jobs, infrastructure and local development initiatives and the business activities of small and medium sized businesses'.⁶ The ERDF can finance 'investments in health and social infrastructure which contribute to regional and local development and increasing the quality of life'.⁷ As discussed in this report, in some countries it has been applied to finance the construction of new residential institutions or renovate existing residential institutions.

The European Commission's 'Ensuring accessibility and non-discrimination of people with disabilities: Toolkit for using EU Structural and Cohesion Funds' ('the Toolkit') explains the process for the implementation of Structural Funds. Each Member State is required to prepare a national strategic reference framework (NSRF) which outlines the State's priorities for the use of Structural Funds for the current period (2007–2013) in line with relevant Community guidelines and programmes. Member States then 'prepare more detailed fund specific operational programmes, which identify concrete priorities for action, including financial allocations in the different areas'.

New regulations were adopted for the period 2007–2013. One general regulation applies to all the funds, setting out the common rules for programming, managing, controlling and evaluating the new cohesion policy.⁸ There are also specific regulations for each of the Structural Funds.⁹

Endnotes

- 1 For more information about how Structural Funds work, please see the European Disability Forum, Disabled people's organisations and the European Structural Funds 2007–2013 (Toolkit for disability mainstreaming), DOC EDF 06/09–10/2006. European Union, Regional Policy, Inforegio Panorama, EU Cohesion Policy 1988–2008, Investing in Europe's future, No 26 June 2008; p. 4.

- 2 European Union, Regional Policy, Inforegio Panorama, EU Cohesion Policy 1988–2008, Investing in Europe’s future, No 26 June 2008; p. 4.
- 3 Investing in Europe’s future; p. 4.
- 4 European Commission, What social Europe can do for you, Factsheet on EU Funding Programmes; p. 37.
- 5 The Toolkit; p. 13.
- 6 The Toolkit; p. 13.
- 7 Article 4 of the Regulation (EC) No 1080/2006 of the European Parliament and of the Council of 5 July 2006 on the European Regional Development Fund and repealing Regulation (EC) No 1783/1999, 31 July 2006.
- 8 The Structural Funds General Regulation 1083/2006. See also the Toolkit; p. 13.
- 9 See Regulation (EC) No 1080/2006 of the European Parliament and of the Council of 5 July 2006 on the European Regional Development Fund and repealing Regulation (EC) No 1783/1999, and Regulation (EC) No 1081/2006 of the European Parliament and of the Council of 5 July 2006 on the European Social Fund and repealing Regulation (EC) No 1784/1999.

Selection of Human Rights Reports
on People with Disabilities in
Long Stay Residential Institutions
in Central and Eastern Europe

Romania

Center for Legal Resources, *Report Concerning Observance of Rights and Liberties of Persons Committed to Healthcare and Social Establishments for People with Mental Disabilities* (2009)

Center for Legal Resources, *Protection Mechanisms for Persons with Mental Disabilities in Medical-Social Institutions – Illusion to Reality* (2007)

Mental Disability Rights International, *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities* (2006)

Center for Legal Resources/UNICEF, *Monitoring the Rights of Mentally Disabled Children and Young People in Public Institutions* (2006)

Amnesty International, *Romania, State Duty to Effectively Investigate Deaths in Psychiatric Institutions* (2005)

Hungary

MDAC – Mental Disability Advocacy Center, *Guardianship and Human Rights in Hungary, Analysis of Law, Policy and Practice* (2007)

MDAC – Mental Disability Advocacy Center, *Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries* (2003)

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Latvian Centre for Human Rights, *Human Rights in Mental Health Care in Baltic Countries* (date not given)

Mental Disability Rights International, *Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities* (2007)

Latvian Centre for Human Rights, *Monitoring Report on Closed Institutions in Latvia* (2006)

Vann B and Šiška J, *From 'Cage Beds' to Inclusion: The Long Road for Individuals with Intellectual Disability in the Czech Republic* (2006)

UNICEF, *Children and Disability in Transition in CEE/CIS and Baltic States* (2005)

Bulgarian Helsinki Committee, *The Archipelago of the Forgotten: Social Care Homes for People with Mental Disorders in Bulgaria* (2005)

Freyhoff G, Parker C, Coué M and Grieg N, *Included in Society – Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People* (2004)

Disability Monitor Initiative South East Europe, *Beyond De-institutionalisation, The Unsteady Transition towards an Enabling System in South East Europe* (2004)

Amnesty International, *Bulgaria, Far From the Eyes of Society: Systematic Discrimination against People with Mental Disabilities* (2003)

Human Rights Monitoring Institute/Global Initiative on Psychiatry/Viltis/Vilnius Centre for Psychological and Social Rehabilitation, *Human Rights Monitoring in Closed Mental Health Care Institutions* (2005)

Glossary¹

Cohesion policy

The Cohesion policy is the European Union's strategy to reduce disparities between regions in Europe. Cohesion policy financing is delivered through seven-year **operational programmes** from three Structural Funds. These are the European Regional Development Fund (ERDF), the European Social Fund (ESF) – both explained in Annex 1 – and the Cohesion Fund. (The Cohesion Fund is used to finance transport and environmental infrastructure and it is not covered in this report). The seven-year periods are known as **programming periods**, with the current one running from 2007 until 2013.

Community-based services

This term refers to a range of services which ensure that people with disabilities can live and participate in the community on an equal basis with other citizens. They include not only special services for people with disabilities (such as early intervention, personal assistance, rehabilitation, family support services etc.), but also services for the general population (such as housing, education, health care, transport etc.), which must be made responsive to the needs of people with disabilities.²

Community living

The term 'community living', also known as 'independent living' is used in this report to describe the goal that:

*'People with disabilities are able to live in their local communities as equal citizens, with the support that they need to participate in every-day life. This includes living in their own homes or with their families, going to work, going to school and taking part in community activities.'*³

Deinstitutionalisation⁴

Deinstitutionalisation is a term that is used to describe the process of replacing institutional care with community-based services. It involves not only the closure of residential institutions but the development of community-based alternatives. Its aim is to enable people to leave residential institutions and help them to live in the community by creating the necessary supports. Deinstitutionalisation policies must recognise the variety of needs of people with disabilities and ensure that people are given the support that they need to live an ordinary life in the community.

Deinstitutionalisation does not end with the closure of institutions. Ongoing work is required to ensure high-quality, individualised support for people with disabilities to live and participate in the community. It is important to ensure that institutional practices are not replicated in the community.

Institution

There are various approaches to defining an institution. In this report we have used the term 'residential institution' to make clear that we are referring to premises which have been established to provide long term care for disabled people. Some definitions are based on the number of places in a facility, e.g. an institution is a facility with 30 or more places. This definition can be useful for collecting data, describing trends and monitoring progress in **deinstitutionalisation**. For example, it was used in the DECLOC report, referred to in Chapter 2. However, an institution is not defined only by its size. As explained in Chapter 2, the number of people housed in a particular establishment, while an important factor, is only one of the factors to be taken into account.

For this reason, ECCL uses a definition adapted from the one developed by People First of Canada (their definition focused on people with intellectual disabilities, whereas ours covers all disabled people):

'An institution is 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 exercise control over their lives and their day-to-day decisions. An institution is not defined by its size'.

Structural Funds management

The Structural Funds are managed in partnership between the European Commission and the Member States, through a de-centralised system. The Member States decide how the money is used, while the Commission has a supervisory role and ensures that spending is in line with the agreed strategic priorities and financial rules. The Departments responsible for supervising Structural Funds are the Directorate General for Regional Policy (responsible for the European Regional Development Fund (ERDF) and the Directorate General for Employment, Social Affairs and Equal Opportunities (responsible for the European Social Fund (ESF)). At the European level, Structural Funds are regulated by the general regulation common to all the funds and by specific regulations for each fund (see Annex 1).

Managing Authority

This is the national, regional or local public authority or another public or private body that has been designated by the Member State to manage the operational programme of one of the Structural Funds. Managing Authorities can assign some responsibilities to an **intermediate body** (this can be a non-governmental organisation), to serve as a link to beneficiaries implementing projects.

Monitoring Committee

The Member States, in cooperation with the Managing Authorities, establish Monitoring Committees for each **operational programme**. The role of Monitoring Committees is to monitor the effectiveness and quality of implementation of the programmes. This includes: approving criteria for selecting the projects, reviewing the progress towards targets set out in the programmes, evaluating the results of the implementation and approving the annual and final reports. Monitoring Committees can propose revisions of the operational programme to the Managing Authority.

According to the Structural Funds regulations, non-governmental organisations can be involved in all the stages of Structural Funds spending, including monitoring and evaluation. In the Toolkit for using EU Structural and Cohesion Funds, the European Commission points out that participation of organisations representing people with disabilities in the monitoring of Structural Funds implementation is strongly encouraged.⁵

Operational Programme

This is the document submitted by a Member State and approved by the European Commission, which sets out the Member State's strategy, together with a set of priorities, for how Structural Funds will be used. A single priority covering a group of related activities is called a **priority axis**.

People with disabilities

When referring to people with disabilities (or disabled people), this report uses the definition from the UN Convention on the Rights of Persons with Disabilities (CRPD). Article 1 of the CRPD states that persons with disabilities:

'include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

References to the term **mental disability** are made in this report, where this is a term used by the organisation being cited. This term is used to refer to people with intellectual disabilities and mental health problems.

Endnotes

- 1 The information on Structural Funds provided in this Glossary is taken from the Structural Funds General Regulation and the EU publication 'The control system for Cohesion Policy – How it works in the 2007–2013 budget period?', 2009.
- 2 See ECCL's Focus on Article 19 of the UN Convention on the Rights of Persons with Disabilities, 2009.
- 3 See European Coalition for Community Living, Creating Successful Campaigns for Community Living, An advocacy manual for disability organisations and service providers, November 2008.
- 4 The definitions of 'deinstitutionalisation' and 'institution' are taken from ECCL's advocacy manual 'Creating Successful Campaigns for Community Living' (see previous footnote).
- 5 The Toolkit; p. 17.

Notes

About the European Coalition for Community Living

The European Coalition for Community Living (ECCL) is a Europe-wide initiative working towards the social inclusion of people with disabilities by promoting the provision of comprehensive, quality community-based services as an alternative to institutionalisation.

ECCL's vision is of a society in which people with disabilities live as equal citizens, with full respect for their human rights. They must have real choices regarding where and with whom to live, choices in their daily lives and real opportunities to be independent and to actively participate in their communities.

Membership in ECCL is open to all organisations, individuals and institutions committed to the promotion of the right of people with disabilities to be included in society. To join ECCL, please visit www.community-living.info or write to the ECCL Coordinator at coordinator@community-living.info.

Since January 2008, ECCL has been a project of the European Network on Independent Living (ENIL).

Members of ECCL's Advisory Council

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