

wasted time
wasted money
wasted lives

a wasted opportunity?

A Focus Report on how the current use of Structural Funds perpetuates the social exclusion of disabled people in Central and Eastern Europe by failing to support the transition from institutional care to community-based services

Executive Summary

ECCL

European Coalition
for Community Living

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1. Introduction

This report highlights the serious concern that European Union (EU) funding (referred to as 'Structural Funds') is being used in the EU Member States of Central and Eastern Europe (CEE)¹ to renovate, or build new, long stay residential institutions for people with disabilities², rather than develop community-based alternatives.

Despite 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 segregated in large, remote, residential institutions where their exclusion from society is virtually absolute. The report argues that the practice of using Structural Funds to maintain this system of institutional care is contrary to EU policy objectives, EU law and European and international human rights standards. It also highlights concerns that 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 provided by members of ECCL. We are particularly indebted to our partners in this project, the Soteria Foundation, Hungary, who has worked with the Faculty of Social Sciences at Eötvös Loránd University (ELTE) ('Soteria-ELTE'), and the Institute for Public Policy ('IPP'), Romania. They have kindly provided us with relevant information obtained through their research in this area.

The 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 investing them in the development of community-based alternatives.

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. 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.

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

1 Structural Funds are available to certain EU Member States. 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 of this report, which sets out key issues about the use of Structural Funds, is on the situation in Hungary and Romania.

2 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').

– the disabled adults and children placed in residential institutions – will be the ones to suffer. They will continue to be segregated, excluded from society; denied the opportunity to live their life as other citizens do.

2. The Institutionalisation of Disabled People in Central and Eastern Europe

It is not known exactly how many disabled people are living in residential institutions across CEE but on the basis of a recent study, it is hundreds of thousands of people.³ 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; use of physical restraints, 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.

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 residential institutions, is not enough. Experts in the deinstitutionalisation process dispute the suggestion that smaller, more modern buildings, with higher staff ratios and expenditure provide a good quality of life for their residents, pointing out that this is not supported by available empirical data.⁴

A change of culture as well as the physical environment is essential in order to avoid the negative characteristics of institutional care being replicated in community-based services. Thus the aim of the new services must be to provide the support that disabled people need to achieve their aspirations and engage in community life.

3. The Role of Structural Funds: Promoting Inclusion or Exclusion?

While the use of Structural Funds needs to be considered in the context of broader issues relating to each particular country, this report identifies some key issues that are likely to be common amongst CEE countries where the institutionalisation of disabled people remains the dominant form of care. Our key concerns, which are based on the findings of our partners' research in Hungary and Romania, as well as information received from other non-governmental organisations working in this region, are as follows:

3 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. 25.

4 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.

- **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 institutional care. Both Soteria-ELTE (Hungary) and IPP (Romania) concluded that many of the problems arising from the use of Structural Funds appear to stem from the lack of clear direction from Government on the need to plan for, and implement policies on, the replacement of residential institutions with community-based services.
- **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 these institutions. However, 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. Directing funds to institutional care therefore makes it more difficult to advocate for the development of alternative services and the closure of the institutions. In addition, this approach ignores the fundamental objection to institutional care: that irrespective of the conditions within an institution, the unjustified segregation of disabled people is a serious infringement of their rights.
- **Restrictive interpretations of the rules for Structural Funds:**

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. This is a serious problem given that the provision of accommodation will be a crucial element of support for many disabled people on leaving institutional care.
- **Barriers to the development of community-based services:**

While Structural Funds are not necessarily the cause of these problems, 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. For example, rigid rules and financial mechanisms that are geared towards institutional care may create problems for non-governmental organisations wishing to establish community-based services. Such organisations may also find it difficult to make use of Structural Funds given the complexity of the rules governing the tendering process and the substantial amount of administrative time involved in preparing the applications.
- **Lack of transparency in the operation of Structural Funds:**

Information on the use of Structural Funds can be difficult to obtain. The Managing Authorities for Structural Funds seem unwilling to provide information relating to projects that have been funded through Structural Funds and very few disability organisations have information about the use of Structural Funds in their countries.
- **Monitoring and evaluation of Structural Funds:**

Despite the emphasis on the involvement of civil society in the preparation, implementation, monitoring and evaluation of the programmes funded by Structural Funds (known as 'Operational Programmes'), there is little evidence that this is working effectively. Although

disability groups are represented on the Monitoring Committees in their countries, they report that their views are not taken into account and there is little opportunity to influence decisions.

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

Upon their ratification of human rights treaties and 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. In the case of disabled people, such action must include the development of community-based alternatives to institutionalisation.

While the situation will differ between countries and each case will need to be considered on the basis of its particular circumstances, this report identifies general concerns about the use of Structural Funds to build new, or renovate existing, residential institutions. By using Structural Funds in this way, rather than applying them to the development of community-based alternatives to institutional care, ECCL considers that the EU and Member States are failing to meet their European and international obligations. For the reasons summarised below, investing in archaic residential institutions runs counter to these obligations and risks subjecting disabled people to continued human rights violations, discrimination and social exclusion.

ECCL considers that this practice is likely to be:

- **Contrary to States' obligations to protect human rights:**
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. Institutional care leads to serious human rights abuses. The UN Convention on the Rights of Persons with Disabilities (CRPD) makes clear that the fundamental objection to the institutionalisation of disabled people is that their unjustified segregation is in itself a severe infringement of their rights. It is also contrary to the policy objectives of both the EU and the Council of Europe which seek to promote community living.
- **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, as well as their commitment to promote social inclusion. 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. 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.

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

Our conclusions, together with our recommendations to the European Commission and the Member States, are set out below.

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:

- 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.⁵ 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.

5 Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009).

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

There are a range of barriers to the development of community-based services as alternatives to institutional care. A major concern that needs to be addressed is the confusion over the interpretation of the Structural Funds regulations concerning the purchase of property or the construction of new premises.

Accordingly, we recommend:

- 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, and non-governmental organisations that have experience of providing community-based services.

Accordingly, we recommend:

- 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:

- The remit and procedures of the Monitoring Committees for Structural Funds programmes must 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:

There is a lack of publicly available comprehensive information on use of Structural Funds in relation to disabled people currently living in residential institutions.

Accordingly, we recommend:

- 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) should be 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.

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