



Briefing on Structural Funds Investments for People with Disabilities:

Achieving the Transition from Institutional Care to Community Living

ECCCL
European Coalition
for Community Living

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1. Introduction

This briefing highlights key problems with Structural Funds¹ investments for people with disabilities in six European Union (“EU”) Member States: Bulgaria, Hungary, Latvia, Lithuania, Romania and the Slovak Republic in the current programming period, 2007–2013.² It also makes recommendations on actions that need to be taken to ensure that such investments are not repeated in the next Structural Funds programming period, 2014–2020. This is particularly timely since Member States and the European Commission (“EC”) are now negotiating Partnership Agreements and Operational Programmes that detail how Structural Funds will be invested in meeting the targets of the EU’s strategy, *Europe 2020 – A Strategy for Smart, Sustainable and Inclusive Growth* (“Europe 2020”)³, in employment, research and development, climate and energy sustainability, education and fighting poverty and social exclusion. While this brief focuses on Structural Funds for people with disabilities, many points are relevant to other groups who risk being institutionalised.

The information in this briefing is based on information provided by partner organisations of the Open Society Foundations – Mental Health Initiative (“MHI”) and/or the European Network on Independent Living – European Coalition for Community Living (“ENIL-ECCL”) in Bulgaria (the Centre for Independent Living – “CIL”), Hungary (Hungarian Civil Liberties Union – “HCLU”), Latvia (Resource Centre for People with Mental Disability “ZELDA” – RC ZELDA), Lithuania (the Lithuanian National Forum of the Disabled – “LNF” and the Mental Health Perspectives – “MHP”), Romania (Institute for Public Policy – “IPP”) and Slovakia (Social Reform Foundation – “SOCIA”).⁴ The points raised in this briefing complement the recommendations and guidance provided by previous publications on this topic:

- ECCL’s March 2010 report, *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* (“Wasted Lives”).
- Two November 2012 reports of the European Expert Group on the Transition from Institutional to Community-based Care (“the EEG”), the *Common European Guidelines on the Transition from Institutional to Community-based Care* (“the Common European Guidelines”), and the *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care* (“the Toolkit”).⁵

The need for action to promote “Community living”

The purpose of this briefing is to set out the crucial role Structural Funds investments can and must play in achieving the policy objective of shifting the provision of care for people with disabilities from institutions to community-based services (“Community living”). Community living means that people with disabilities have access to services and support that enable them to live in the community and participate in life as equal citizens. Fighting poverty and social exclusion, a key objective of Europe 2020, “cannot be achieved without addressing the 1.2 million Europeans who spend their lives in residential institutions, segregated and excluded from the rest of the society”.⁶ Establishing community-based alternatives to institutionalisation is also vital given the severe human rights violations that occur in institutions, as evidenced by numerous reports.⁷

Structural Funds can support the systemic change required to make Community living a reality by funding a range of initiatives, in particular the development of new services, including services that prevent institutionalisation, delivering training for staff, as well as providing technical support for reforming legislative and financial frameworks that are necessary for Community living. If invested this way, Structural Funds can promote the development of person-centered community-based services for the individuals who need them. Although it is not always the case that community-based services are cheaper than institutional care, “community-based systems of independent and supported living, when properly set up and managed, deliver better outcomes for the people who use them”.⁸ Investment in Community living therefore makes for a better and more cost-efficient use of Structural Funds.

“Transition from institutional to community-based care” has been identified as one of the priorities in the European Disability Strategy 2010 – 2020, with Structural Funds and the Rural Development Fund identified as key to supporting “the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions”.⁹ In the Social Investment Package¹⁰, which provides guidance to the Member States on how to reach the Europe 2020 targets, the EC asks for Structural Funds to be used for “human capital development, including employment, social inclusion [...] accessibility of social, education and health services” and for the needs of disadvantaged groups to be addressed with “coordinated action” by Structural Funds.

Most importantly, Structural Funds investments must comply with EU law, including the Convention on the Rights of Persons with Disabilities (“the CRPD”), since its ratification by the EU.¹¹ All of the EU Member States have signed the CRPD, and 25 have ratified it, including the countries covered in this briefing.

Article 19 of the CRPD requires that people with disabilities have access to community services that support their social inclusion and “prevent isolation or segregation

from the community". Large long-stay residential facilities, common across Central and Eastern Europe, including the six countries covered in this briefing, isolate residents from society, and are often in remote locations. Compliance with Article 19 requires the development of community-based services that obviate the need for such institutions. Since Structural Funds investments must be CRPD¹² compliant, they cannot be invested in institutional care.¹³

New opportunities for Structural Funds to promote Community living

On 20 November 2013, the European Parliament approved a new set of regulations governing the use of Structural Funds, referred to as the Cohesion Package 2014 – 2020. For the first time, the Structural Funds regulations include an explicit reference to the transition from institutional care to Community living, which falls within the thematic objective of "Promoting social inclusion and combating poverty and any discrimination" (Article 9 of the Common Provisions Regulation on the use of Structural Funds¹⁴). Crucially, the new regulation introduces the concept of "ex-ante conditionalities": specified conditions that must be met for Structural Funds to be available to Member States. For the thematic objective "Promoting social inclusion and combating poverty and any discrimination", Member States must demonstrate the "existence and implementation" of a "national strategic policy framework for poverty reduction". The criteria for fulfilling this condition refer specifically to "the transition from institutional to community-based care".¹⁵ If such needs are identified, Member States must include "measures for the shift from institutional to community-based care" when acting under this objective. The EC's position papers on the development of Partnership Agreements for 2014–2020 for the six countries covered in this briefing identify the development of community-based alternatives as a funding priority.¹⁶

The new provisions in the Structural Funds regulations for 2014–20 and the EC's efforts to promote Community living, as set out in its position papers on Bulgaria, Hungary, Latvia, Lithuania, Romania and Slovakia, are very positive. However, as the examples in this briefing show, there are still potential problems that need to be addressed to ensure that the mistakes of the previous programme are not repeated. Member States must put these EU funds to good use and the EC must be vigilant in ensuring that they do so.



2. Key Concerns Arising during the 2007–13 Financing Period

Structural Funds: Supporting Institutional Care Rather than Community Living

The most significant problem with Structural Funds investments during the current financing period is that in some countries they have been used to renovate, and/or build new, long-stay residential institutions. MHI/ENIL-ECCL partners report that Structural Funds have been invested in such projects in Hungary, Latvia, Lithuania, Slovakia, Bulgaria and Romania. Other organisations have expressed similar concerns in the Czech Republic.¹⁷ In some cases the projects clearly stated that they are for renovation and expansion of such institutions, whereas other projects that appear to be for the development of community-based alternatives create replicas of institutions in smaller settings. CIL highlights this as a particular concern in Bulgaria, noting that services called “community-based” were established on the grounds of large long-stay residential institutions.

Main Reasons for Investing in Institutions

Understanding why Structural Funds have been invested in institutions rather than in community-based alternatives is essential if such investments are to be avoided in future. There is a wide range of factors that are likely to have contributed to this practice, despite widespread consensus that institutions provide outmoded, unacceptable services. Four factors that have been of major significance in Bulgaria, Hungary, Latvia, Lithuania, Romania and Slovakia are:

Main reasons for investing in institutions

- a) Lack of governments’ vision for the transition to Community living
- b) Focus on poor physical conditions, resulting in renovation of institutions
- c) Lack of co-ordination of different EU funds
- d) Other systemic barriers to Community living

2.a Lack of Governments' Vision for the Transition to Community Living

Without a clear choice and concrete plans to develop community-based services, there will be no change in the existing system of institutional care.

Chapter 3 of the Common European Guidelines states that governments should prepare a strategy that sets out the overall framework for guiding the necessary reforms in three key areas: the closure of institutions, the development of community-based services (including prevention of institutionalisation) and inclusive mainstream services. Action plans can then be prepared to specify what must be done to achieve the objectives set out in the strategy, including timeframes and monitoring and evaluation.

The *Wasted Lives* report identified the lack of vision for developing community-based alternatives as being of significant concern in Hungary and Romania. That concern remains today. For example:

- In **Romania**, IPP reports that to date, the government has made no explicit commitment to deinstitutionalisation. However, it is currently developing a new disability strategy for 2014–2020 and has indicated that the transition from institutional care to community-based services will be included.
- In **Hungary**, the government maintains a contradictory approach to deinstitutionalisation. The Hungarian Government defines an institution as being a residential setting for 50 plus people: in 2012, it introduced a prohibition on establishing new institutions with more than 50 beds and on renovating institutions with 50 plus beds.¹⁸ This is at odds with the definition used by the Common European Guidelines (discussed below at page 15), which emphasises that the more people live in one place, the more impersonal the care is likely to be, and the less likely residents have opportunities to choose how, where and with whom they wish to live. Despite this prohibition, the HCLU reports that a number of institutions with more than 50 beds have received funding, totalling at least €2.5 million, through the Social Infrastructure and other Operational Programmes (such as OP Environment and Energy). HCLU also highlights a major misconception among some institution directors who argue that there is need for larger institutions for people who need more intensive care due to the nature of their disabilities (such as those who need 24-hour care).

Additional examples of the lack of vision have been highlighted in Latvia, Lithuania and Bulgaria:

- **Latvia:** RC ZELDA reports that while the draft Social Services Policy for 2014-2020 includes the goals of deinstitutionalisation and the development of community-based services, a significant amount of money is to be invested in institutions, albeit

from the national budget, not Structural Funds. Although institutions cannot be closed before the needed community-based services are in place, and the two systems will therefore run in parallel for a time, any investment in institutional care must be considered carefully. This is because such investments will mean that resources are committed to institutional care rather than developing the alternatives. It is imperative that investments, whether from EU or national funds, are used to promote, not thwart, Community living. Governments will need to demonstrate that the action taken in this area complies with their obligations under the CRPD, in particular Article 19.¹⁹

- **Lithuania:** LNF and MHP report that while the Operational Programme for the Promotion of Cohesion (2007–13) provides for Structural Funds investments to develop community-based services for people with psychosocial disabilities, it also includes investment in institutions. The stated justification for the use of Structural Funds investments to renovate institutions is that they are “public sector buildings” that need renovations to reduce their energy consumption. (This issue is discussed below under “Lack of co-ordination”)
- **Bulgaria:** The service of “personal assistant” and “social assistant”, funded partly by the Human Resource Development Operational Programme, have as their main objective “to provide care in a family environment for disabled people (or seriously ill people living alone) by hiring unemployed people to work as personal and social assistants”. More specifically, the personal assistant service “aims to provide employment for unemployed relatives, who are engaged in care of a disabled member of their family”.²⁰ While this service aims to reduce the number of people in institutions, it assumes that people with disabilities wish to employ their relatives. It therefore does not promote the right of people with disabilities to choose their personal assistants. CIL, which piloted user-controlled personal assistance between 2001 and 2005, considers this a missed opportunity to support the full inclusion and participation of people with disabilities in Bulgaria.

In Bulgaria, Hungary and Latvia, projects that purport to be for deinstitutionalisation and the development of community-based services include investments in institutions:

- **Bulgaria:** CIL reports that the focus of implementing the deinstitutionalisation strategy for children has been to close the institutions, but no action has been taken to make mainstream public services inclusive for disabled children and adults. This was also reflected in the use of the European Social Fund (“ESF”), which supported services within the residential facilities for children, not in the mainstream. To date, Structural Funds have not been invested to “develop appropriate housing policies, to make adaptations in mainstream schools, to ensure accessibility of public transport for all citizens, to change public attitudes and build a more inclusive and accepting society”. Unless these areas are addressed, CIL is concerned that resources (including EU funding) will continue

to be directed into institutional-type services. Furthermore, the National Network for Children (“the NNC”) has raised substantial concerns about the current deinstitutionalisation project for children that consists of building 149 group homes for 12 children each, with an additional two “emergency placements”. In its April 2012 statement, the NNC states:

“We are convinced that ‘community-based services which are with high quality and respond to their (of the service users) individual needs’ can’t be provided with such conditions. Such a capacity in combination with the insufficient funding creates real opportunities to replace the large-scale institutions with small ones.”²¹

- **Hungary:** The Hungarian Government’s view that residential facilities can accommodate up to 50 people has meant that projects supported by Structural Funds, which purport to be for deinstitutionalisation, in fact result in the building of new, smaller institutions. HCLU reports that under the project “Deinstitutionalisation of Social Care Homes for Disabled and Psychiatric Patients”, six large social care homes will be closed with funding of €19.34 million, with the 652 residents moved into 19 flats, forty group homes and six “living centres”. The “living centres” will house up to 25 residents. (Originally the Government’s intention was that such centres would house up to 50 people. Although applicants for the funding lowered this number to 25 residents, it is still different from supported living arrangements and too high to result in services that are CRPD compliant – in effect they will create small institutions). HCLU interprets this as the government’s intention to continue the institutional model. It highlights as positive, however, that a significant amount of funding will be spent on flats and group homes in the community.
- **Latvia:** RC ZELDA’s report *The Accessibility and Costs of mental health and social care community-based services compared to institutional care in Latvia* raises concerns about Structural Funds investments. RC ZELDA notes that one activity under the ESF action programme (“Development of social rehabilitation services and social care services as alternatives to institutions in the region”) for 2007–2013 funded 97 projects. Only five of these were for supporting the development of “community-based social services” for people with intellectual and/or psychosocial disabilities. Furthermore, two of these projects, entitled “developing social rehabilitation programmes and improving existing services”, involved Structural Funds investments in two institutions at a total cost of €271,566. RC ZELDA notes that during the 2007–2013 financial period, European Regional Development Funds (“ERDF”) were invested in the renovation of institutions, with 5 such projects totalling €8,41 million, of which ERDF investment amounted to €7,1 million (this is not a final figure as investments will continue to be made during 2013). In addition, RC ZELDA comments that it is impossible to enumerate

the amount of Structural Funds invested in institutions compared to investments in community-based services, because the projects are combined, and because some projects implemented in institutions were categorised as ‘community-based care’ projects.²²

SOCIA (Slovakia) and IPP (Romania) report that no Structural Funds have been invested in the development of community-based services in their countries to date.²³

2.b Focusing on Poor Physical Conditions, Resulting in Renovation of Institutions

During the current programming period, significant amounts of money have been invested in long-stay institutions in Hungary, Latvia, Lithuania, Romania and Slovakia, either to renovate existing institutions or to build new ones.

Structural Funds investments in renovating institutions was highlighted as an issue of concern in the Ad Hoc Expert Group Report, noting that “this often makes it more difficult to close institutions in the medium term, as authorities are reluctant to close a service in which a great deal of money has been invested”.²⁴ Information from MHI/ENIL-ECCL partners demonstrates that despite such warnings, Structural Funds are still being used for this purpose:

- **Hungary:** HCLU provide the following examples:
 - €550.000 in Structural Funds for the renovation and extension of an institution for people with mental health problems (82 plus 20 residents in two buildings) in Símaság.
 - €436.487 in Structural Funds for the reconstruction of the Endre Piróth Social Care Home for Psychiatric Patients (350 residents) in Táplánypuszta.
- **Latvia:** RC ZELDA reports that Structural Funds investments were made in several long-term social care institutions for people with mental disabilities.²⁵ For example, the Social Care Centre Riga received €2,4 million from EU funding.²⁶
- **Lithuania:** LNF and MHP note that data published in 2011 by the Ministry of Social Security and Labour states that investments in social care institutions for people with disabilities received €17,46 million from the national budget’s Public Investment Programme for 2004–2011, and €12,45 million in Structural Funds. The Ministry announced in April 2012 that €42,86 million (out of which €36,49 million are Structural Funds – Operational Programme for the Promotion of Cohesion) will be used during 2011–15 to build new, or renovate social care institutions.

- **Romania:** on the basis of its extensive investigation, IPP concludes that €41,3 million (out of which €27,6 million were Structural Funds) has been targeted to renovate/expand institutions for people with disabilities.²⁷
- **Slovakia:** SOCIA report that a total of €209,36 million in Structural Funds was allocated to 136 projects in September 2010. Nearly half of this amount (€99,36 million) was allocated to 47 projects for building new large-scale social welfare institutions.²⁸

Governments often make arguments for the need to renovate institutions, namely that they are in a dilapidated state and renovation is necessary to improve the lives of the residents. The report *The European Union and the Right to Community Living* states that Structural Funds might be used to renovate institutions in *very limited* circumstances, such as to address life threatening risks to the residents, where Structural Funds were otherwise being invested as part of a wider programme to promote Community living.²⁹ The Toolkit considers that Structural Funds cannot be used to renovate institutions and that “investments in care infrastructure and services should prevent institutionalization of children and adults, and support the transition from institutional to community-based services”.³⁰

2.c Lack of Co-ordination of Different EU Funds

The source of funding for institutions requires investigation, as in some cases Structural Funds have been invested through Operational Programmes unrelated to reform in health and social care infrastructure, to meet other targets such as improving accessibility or energy efficiency.

In Hungary, Lithuania and Slovakia, Structural Funds have been invested in institutions to make them more energy efficient.

- **Hungary:** HCLU reports that in 2011 the Environment and Energy Operational Programme approved €168.000 in Structural Funds for a solar heating project in the Imre Takács Social Care Home for People with Disabilities, which has about 130 residents.
- **Lithuania:** LNF and MHP note that Structural Funds are being invested to renovate long stay institutions to enhance energy efficiency. The Operational Programme for the Promotion of Cohesion states that “investments in renovation and insulation of the public sector buildings...will result in at least twice less energy consumption needed for the heating”. In 2009, over €1 million in Structural Funds was spent on renovating one social care home. The overall goal of this project was to “increase the efficiency of energy resource use, and to reduce negative environmental impact” and the specific goal was “to reduce

the energetic resource use” in the buildings. It estimated that such work would lead to annual savings of €41,200, which could be utilised for “improvement of the patient care and personnel working conditions, performance of routine renovations, etc.” By focusing on an energy efficiency target, EU funding further perpetuates institutional care, rather than helping to dismantle it.

In **Hungary**, HCLU provide examples of two projects focused on improving the accessibility of institutions, namely “The Social Care Home for Psychiatric Patients” for 80 residents in Baja (€42.750) and “The Social Care Home for People with Disabilities” for 102 residents in Pásztori (€135.600). While the objective of making buildings accessible for people with disabilities is in itself laudable, to invest in this, rather than develop accessible housing and other services that are community-based, makes little sense. As in the case of energy efficiency enhancements, investments that increase accessibility in large institutions make it much more challenging to close them in the short to medium term.

2.d Systemic Barriers to Community Living

The Wasted Lives report identified a number of barriers to the development of community-based services. One is that current legal and financial frameworks, developed to support institutional systems, restrict, or entirely prevent, NGOs from providing community-based services. This is counter-productive as governments often do not have capacity to provide such services. Another barrier is the unwillingness of institution staff to engage in reform that they perceive as threatening. Information from MHI/ENIL-ECCL partners shows that these barriers continue and have a negative impact on Member States investing Structural Funds to promote Community living.

Exclusion of non-governmental organisations

Wasted Lives cited **Bulgaria** as an example of good practice on collaboration between the EC and government to develop community-based services for children. However, since this promising start, there have been significant problems in the development and in the implementation of the deinstitutionalisation strategy.³¹ One of the concerns highlighted by the NNC is that NGOs have been excluded from applying for Structural Funds projects despite the key role played by Bulgarian NGOs in the closure of four institutions:

“[f]rom 107 million euro provided from the European structural funds in the area of deinstitutionalization, there isn’t a single lev allocated to civil organizations that have closed homes and have taken children from the damaging institutions”.

Restrictions on how services are provided

CIL reports that there are significant restrictions placed on management of community-based services in **Bulgaria** that are funded with Structural Funds. For example, residents cannot do their own shopping and cooking. While where “thanks to the creativity and professional approach of the management and the staff, residents can engage in such daily activities, they have to be described as training activities and they remain unreported for obvious reasons”. This demonstrates that all of systems are still designed to support the archaic and inflexible institutional system.

Unintended incentives created by Structural Funds

SOCIA notes that in **Slovakia**, the management of Structural Funds “is judged primarily by their abilities to spend the highest possible amount of funds”, whereas there is no assessment of long-term benefits of the projects. Another factor giving rise to significant funds invested in a small number of institutions is that the “development of community-based services requires thousands of projects that are too demanding in terms of administration and too difficult to control from the perspective of funds’ managers”.³²

In the field of employment in **Romania**, IPP questions the enormous funding invested in employing people with disabilities on the open labour market through training, with very limited success (€43,7 million spent on employing 116 persons with disabilities).³³ This makes clear that the government has not assessed the needs of people with disabilities in the country, and highlights gaps in the planning, implementation and evaluation of Structural Funds projects.

3. 2014–2020: The Next Financing Period and Emerging Concerns

Plans for how Member States will invest Structural Funds to promote Community living will be set out in their Partnership Agreements and Operational Programmes.³⁴ In developing these, Member States must consult with various partners, including NGOs providing community-based services and/or advocating for the rights of people with disabilities.³⁵ In spite of this, there has been no direct consultation with NGOs on the preparation of these documents in Hungary or Lithuania:

- **Hungary:** HCLU states that there was an online public consultation³⁶ open for one month from mid October to mid November 2013, where anyone could post comments and propose recommendations on how to invest Structural Funds in 2014–2020.
- **Lithuania:** LNF and MHP report that they were involved in the development of the deinstitutionalisation strategy and action plan, but they were not involved in the drafting of the Partnership Agreement and the Operational Programmes.

In Bulgaria, Latvia, Romania and Slovakia, MHI/ENIL-ECCL partners report that they were involved in the consultation process. However, all report that they have concerns about some aspects of their government's approach:

- **Bulgaria:** CIL provides significant criticism of the draft Partnership Agreement, including that the situation analysis of Bulgaria does not reflect the situation of “people with disabilities who are victims of deep and long-lasting social exclusion, poverty and lack of opportunities for participation in the community”. In relation to promoting Community living, CIL states that “the analysis of the deinstitutionalisation process is superficial and incomplete” and comments that “the review of the so called ‘community services’ shows that they provide institutional type of care rather than support for Community living, as prescribed by the UN CRPD, Article 19”.
- **Latvia:** RC ZELDA reports that it was one of the few NGOs to be invited to be involved in the development of the *Social Services and Social Assistance Policy for*

2014–2020. This document prescribes how Latvia will fund its social care (whether investments will be for institutions or community services) and is the basis on which Structural Funds will be allocated for social care. But, as noted above, RC ZELDA is concerned that this policy allows for continued institutionalisation of people with intellectual disabilities and/or psychosocial disabilities who reside in such institutions.

- **Romania:** IPP reports that it has been involved in the preparation of the Operational Programme for Public Administration, as an observer in the Regional Development Consultative Committee and as a member of the working group for the new Strategy on Disability. However, it states “we cannot describe the process as being either transparent or substantive in terms of wider consultations with the Romanian civil society” and suggests that the extent of NGO involvement will depend on their determination to be involved. IPP’s main concern is how to ensure that the transition from institutions to community-based services will be achieved in the absence of a commitment to close the institutions.
- **Slovakia:** SOCIA reports that it has been directly involved in the preparation of the draft Operational Programme Human Resources. On the whole, however, the involvement of NGOs in the programming was rather limited, with one NGO representative per Operational Programme. SOCIA has welcomed that in both the Integral Regional Operational Programme and the Human Resources Operational Programme, deinstitutionalisation of large-scale institutions and the development of community-based services have been set as priorities. However, based on the implementation of the on-going deinstitutionalisation plan, which faces serious delays, SOCIA warns of possible problems in 2014–20. It also notes that deinstitutionalisation is not high on the political agenda, and much depends on changing priorities at regional and municipal levels.

Measuring the success of projects supported by Structural Funds

The Toolkit on the use of EU Funds suggests a number of output and result indicators for projects supported by ESF and ERDF. These indicators have been developed to help the Member States and the EC: (a) monitor and evaluate the results of the projects supported by Structural Funds, (b) establish whether Structural Funds have led to the improvement in the quality of life and social inclusion of project beneficiaries, (c) establish whether the Structural Funds contributed to the implementation of the deinstitutionalisation strategy. The indicators can be found on pages 30–33 of the Toolkit.

4. Recommendations

This briefing highlights some common and significant issues with Structural Funds investments in facilitating the transition from institutions to community-based services. It is essential that these are addressed now so they can be avoided in future. From the EC's perspective it makes little sense for Structural Funds to be used to maintain institutions. The purpose of Structural Funds is to support the goals of Europe 2020 by providing Member States with financial and technical support they need to replace their infrastructure with systems equipped to facilitate "smart, sustainable and inclusive growth". Structural Funds investments in institutions not only perpetuate a system that is not acceptable in the 21st Century, it also ties up money and resources in projects that undermine the EU 2020 goals, in particular combating poverty and social exclusion.

These recommendations aim to ensure that in the next programming period, Structural Funds are invested in promoting, not preventing, Community living. They focus on points that Member States and the EC should consider in drafting and negotiating Partnership Agreements and Operational Programmes. They can also be used by the EC to assess Member States' compliance with relevant *ex-ante* conditionalities, so that Structural Funds effectively promote Community living. The recommendations complement the comments and suggestions set out in the Common European Guidelines and the Toolkit.

Core Components for a Strategy on Using Structural Funds for Community Living

Recommendation 1: Clarity of Vision

The ultimate goal is for people with disabilities to be able to live and participate in society as equal citizens, as CRPD Article 19 mandates. Thus, the aims and objectives of Member States' strategies for the transition from institutions to community-based services cannot only focus on closing institutions – they must aim to effect systemic change so institutional care is not just unacceptable – it is redundant. To achieve this requires the development of "high quality, individualised services based in the community, including those aimed at preventing institutionalization" and "making mainstream services such as education and training, employment, housing, health and transport fully accessible and available to all children and adults with support needs".³⁷ Investing in human resource development, such as training staff members

who provide support (see the two examples below), and the careful preparation and consultation with individuals moving to new services, are of crucial importance to the success of deinstitutionalisation. These actions can be supported by the ESF.

Being clear about the vision ensures that monitoring and evaluation of projects funded by Structural Funds focus on assessing medium/long-term benefits to people who use services, rather than on short-term indicators such as the opening of a community-based program. There is also a need to ensure flexibility in the funding of community-based projects so services are person-centered and provided on the basis of individual needs. Some people require more support than others and most individual's needs change over time, including during the course of project implementation.³⁸ Developing "positive but realistic visions for the future lives of individual people"³⁹ requires the involvement of a wide range of individuals and organisations with an interest and role in the development of community-based services as alternatives to institutional care, such as central and local government, service users and their families and civil society, including NGOs that provide services and support to people with disabilities.⁴⁰

A crucial part of any deinstitutionalisation strategy is communicating its objectives and elements to all the stakeholders – including people with disabilities, their families, staff in institutions, media and the public. Awareness raising activities should be organised for the staff of institutions and members of the local community, with the active involvement of people with disabilities, focusing on the right to Community living and the value of inclusion. Such work should include engaging with the directors of institutions to help them understand their role within the new services. Such activities will help to prevent myths/misconceptions, which jeopardise the reform process.

Examples of workforce development for Community living

The **Centre for Adult Education VALIDUS**, in Croatia, provides state-certified training courses for direct support staff for people with disabilities living in the community, as well as professional development courses on providing person-centred services. The organisation is supporting the Ministry of Social Policy and Youth in implementing its deinstitutionalisation programme. Additional information is available at: <http://coovalidus.hr/en>

The **Eight Points** project in Hungary, supported by ESF, consists of mobile teams working with people with autism around the country. The project seeks to address the lack of professionals who can support children and adults with autism, and their families at home, in education, at work and in other areas of life. At the end of the project in 2015, the service will continue, funded from the national budget. Additional information is available in Hungarian at: <http://fszk.hu/ket-uj-szolgalatast-indit-a-nyolc-pont-projektiroda/>

Recommendation 2: Commitment to change

Strategies alone do not effect change. Their strength or weakness depends on whether they reflect a real commitment to implement change, understanding that it takes time, and that there will be obstacles, both known and unknown to ensuring that people with disabilities can live and participate in society as equal citizens. The transition from institutions to community-based services is complex, but it is possible. It requires vision, careful project management, leadership and shared commitment across various government entities (both central and local), and of health and social care, as well as education systems. It is especially important to advocate for inter-Ministerial co-operation, with key players such as the Ministry of Finance understanding the need to support the replacement of institutions with a range of community-based services in the long-term.⁴¹ Transition from institutional care to Community living should encompass both public and private providers, including services run by NGOs and religious organisations. The government must ensure that all the stakeholders are covered by the strategy and that the new vision is clearly communicated to them at the start of the process.

Recommendation 3: Needs assessment

To be effective, a strategy for deinstitutionalisation must be based on an assessment of the needs of the population and the available services in the country.⁴² This is clear in the provisions of Article 14 of the Structural Funds Common Provisions Regulation. The Toolkit notes that this “problem analysis” should include information about the available services provided in the community and the need to identify the causes of institutionalisation.⁴³

An assessment of each individual’s needs must accompany any deinstitutionalisation process. If this does not happen, the new services will use a “one size fits all” approach. In Hungary, HCLU noted that a complex needs assessment was carried out in one institution by independent experts, but its results were not considered in closing it, because the preferences of local authorities came before the needs and preferences of the residents.

Recommendation 4: Clear and precise definitions

As MHI/ENIL-ECCL’s partners have highlighted, too often Structural Funds have been invested in maintaining institutions rather than promoting alternatives due to a lack of understanding of key terms, in particular the meanings of “institution” and “community-based services”. The EC’s [draft] *Guidance on Ex-ante conditionalities* have adopted the following definitions:⁴⁴

- **“Institution”**: is defined as “residential care where: residents are isolated from the broader community and/or compelled to live together; residents do not have sufficient control over their lives and over decisions which affect them and the requirements of the organisation itself tend to take precedent over the residents’ individualised needs.”
- **“Community-based services”**: are defined as “...the spectrum of services that enable individuals to live in the community and, in the case of children, to grow up in a family environment as opposed to institutions. It encompasses mainstream services such as housing, healthcare, education, employment, culture and leisure, which should be accessible to everyone regardless of the nature of their impairment or the required level of support. It also refers to specialised services, such as personal assistance for persons with disabilities.”

Accordingly, the EC should ensure that Member States’ strategies clarify that Structural Funds will not be invested in settings that are “institutions” and that projects fund development of services that truly are “community-based” and promote social inclusion, as required by its guidance on ex-ante conditionalities.

Terms such as “independent living” or “personal assistance” should not be used by Member States to describe services that are institutional in nature or deny disabled people choice and control over their lives. ENIL has developed its own definitions⁴⁵, including:

- **“Independent living”**: “... includes the opportunity to make choices and decisions regarding where to live, with whom to live and how to live. Services must be accessible to all and provided on the basis of equal opportunity, allowing disabled people flexibility in our daily life [...] Independent Living is for all disabled persons, no matter the level of support need.”
- **“Personal assistance”**: “... is made possible through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of individual needs assessment depending on the life situation of each individual and in consistency with the domestic labour market. [...] Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance.”

Recommendation 5: Co-ordination of Operational Programmes

MHI/ENIL-ECCL partners have identified Structural Funds projects for people with disabilities that were entirely focused on improving the accessibility or energy efficiency of the buildings, not on improving the lives of residents. This lack of co-ordination between the Structural Funds Operational Programmes results in large amounts of money being invested in institutions for nonsensical reasons. To address this will require co-ordination within the relevant ministries in each member state. This also calls for close co-operation between the Directorate Generals of the EC (including DG Employment, Social Affairs and Inclusion, DG Regional Policy, DG Agriculture and Rural Development and DG Energy) so there is a consistent approach to ensuring that Structural Funds are not invested in long-stay institutions. The task of ensuring that none of the Operational Programmes invest in institutional care can also be assumed by inter-Ministerial or other working groups coordinating or overseeing the process of de-institutionalisation at the national level. Other donors should apply the same principles in their funding that apply to Structural Funds investments.

Additionally, the role of DG Justice, as part of the independent monitoring mechanism under Article 33 of the CRPD, must be strengthened to ensure that Structural Funds are invested in compliance with Article 19 of the CRPD.

Recommendation 6: Meaningful involvement of NGOs

As this briefing shows, NGOs are not always involved in programming and implementation of Structural Funds, though it is a legal requirement. When they are involved, their participation can be tokenistic. By excluding NGOs from the process of planning Structural Funds investments, the Member States are missing the opportunity of benefiting from their know-how, especially those who provide high quality community-based services. The EC should ensure that Member States comply with their partnership requirements in the planning, implementation and evaluation of Structural Funds projects. This should include NGO access to Structural Funds as service providers, and the involvement of service users in the process. In addition, deinstitutionalisation strategies should describe how goals and objectives have been developed and agreed upon, and how relevant individuals and their organisations have been consulted and their views taken into account.

Ten key elements of the transition from institutional care to Community living

Deinstitutionalisation is often understood by governments in the narrow sense of closing institutions and therefore results in replacing large institutions with smaller ones. The Common European Guidelines seek to provide practical advice on how to make a sustained transition from institutional care to Community living, helping to achieve the full inclusion and participation of people with disabilities in society. The ten components of the transition, presented below, can be used by governments when planning Structural Funds investments for 2014–2020.

1. Making the case for developing community-based alternatives to institutions
2. Assessment of the situation
3. Developing a strategy and an action plan
4. Establishing the legal framework for community-based services
5. Developing a range of services in the community
6. Allocating financial, material and human resources
7. Developing individual plans
8. Supporting individuals and communities during transition
9. Defining, monitoring and evaluating the quality of services
10. Developing the workforce

Annex 1

Partner Organisations

The Centre for Independent Living is a human rights organisation of disabled people in Bulgaria working for policy change in the area of disabilities and for creating conditions for equality and participation of people with disabilities in the life of the community. Website: www.cil.bg

The Hungarian Civil Liberties Union is a law reform and legal defense public interest NGO in Hungary, working independently of political parties, the state or any of its institutions. HCLU's aim is to promote the case of fundamental rights and principles laid down by the Hungarian Constitution and by international conventions. Generally, it has the goal of building and strengthening the civil society and rule of law in Hungary and the CEE region. Website: www.tasz.hu

The Institute for Public Policy is a think-tank whose aim is to support an increased quality of the processes related to the development of public policies in Romania. IPP is committed to advancing high quality policies in the following main areas: transparency of the legislative process, reform of the local government system, and promoting the rights of people with disabilities. Website: www.ipp.ro

The Lithuanian Forum for the Disabled is an umbrella organisation consisting of 15 national member organisations, representing about 280,000 people with disabilities and their families in Lithuania. LNF works to improve the situation and equal realisation of rights of people with disabilities, and to represent them in both national and European institutions. Website: www.lnf.lt

The Mental Health Perspectives (previously known as Global Initiative on Psychiatry – Vilnius) was founded in 2000 and for the last 10 years has been actively involved in reforming mental health care, and in promoting and protecting human rights of mental health care service users in Lithuania. Website: www.gip-vilnius.lt

The Resource Centre for People with Mental Disability "ZELDA" is based in Latvia and promotes de-institutionalisation and the development of community based mental health and social care services for people with mental disabilities (people with intellectual disabilities and people with psycho-social disabilities) through research,

monitoring of observance of human rights, legal advocacy and activities of informing and educating the public. Website: www.zelda.org.lv

SOCIA – Social Reform Foundation provides grants to non-profit organisations and schools to improve the quality of life of disadvantaged groups in Slovakia. SOCIA collaborate with NGOs and the public administration on forming policies and legislative proposals to reform the social system. Website: www.socia.sk

Annex 2

Relevant Reports

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

Bugarszki, Z., Eszik, O. & Kondor, Z., (unpublished), *Deinstitutionalisation in Hungary 2012–2013*. The report will be available in January 2014 at: www.tasz.hu

Centre for Disability Law and Policy, European Foundation Centre, Age Platform Europe, Lumos, The Equal Rights Trust and European Disability Forum, *Joint Memorandum on the need to provide clarity in Thematic Conditionality 10*, dated 16th October 2013. Available at: http://wearelumos.org/sites/default/files/research/2013%2010%2016%20_Joint%20MemoFinal.pdf

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

Puras D., Sumskiene, E. & Subaciene. I. (unpublished). Challenges of prolonged transition from totalitarian system to liberal democracy: A case of care for persons with mental disabilities. *Social Policy and Social Work in Transition*, Whiting and Birch.

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

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

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

INESS, 2013, *Monitoring of Absorption of Structural Funds in the Area of Social Services (2007–2011)*. Available at: <http://www.iness.sk/stranka/8362-Monitoring-of-Absorption-of-structural-funds.html>

Institute for Public Policy (IPP), October 2013, *Policy News – Results of structural funds investments during 2007–2013 – the lesson we have (not) learned for 2014–2020*. Available at: http://www.ipp.ro/library/IPP_National%20Report_Results%20of%20structural%20funds%20projects%20in%20Romania_2013.pdf and Appendix at http://www.ipp.ro/library/IPP_National%20Report%202013_Appendixes.pdf

Mansell, Jim et al. 2007, *Deinstitutionalisation and community living – outcomes and costs: report of a European Study*. Volume 2: Main Report. Available at: http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf

National Network for Children, April 2012, *Problem areas in the deinstitutionalization and development of social services for children and families policy and practice in Bulgaria*. Available at: <http://nmd.bg/en/Position/which-are-the-problem-areas-in-the-deinstitutionalization/>

Office of the High Commissioner for Human Rights (OHCHR), 2011, *Forgotten Europeans – Forgotten Rights: The Human Rights of Persons Placed in Institutions*. Available at: http://www.europe.ohchr.org/Documents/Publications/Forgotten_Europeans.pdf

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

Open Society Foundations (OSF), 2011, *A Community for All: Implementing Article 19, A Guide for Monitoring Progress on the Implementation of Article 19 of the Convention on the Rights of Persons with Disabilities*. Available at: <http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf>

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

ZELDA, 2013, *The Accessibility and Costs of mental health and social care community-based services compared to institutional care in Latvia (2004–2011)*. Available at: <http://zelda.org.lv/wp-content/uploads/Zelda-eng-Lab5.pdf>

Endnotes

- 1 Referred to as “European Structural and Investment Funds – ESI” in the Common Provisions Regulations.
- 2 These six countries have been included in the briefing thanks to the data on the use of Structural Funds provided by partner organisations. While the authors would have liked to have included other countries in Central and Eastern Europe and the Baltics, such as the Czech Republic, Poland, Slovenia and Estonia, this was not possible due to the lack of relevant information.
- 3 See the EC, Europe 2020 – A strategy for smart, sustainable and inclusive growth, COM(2010) 2020 final, available at: http://ec.europa.eu/europe2020/index_en.htm
- 4 Information about these organisations is provided in Annex 1.
- 5 A list of reports relevant to the issues raised in this briefing is set out in Annex 2.
- 6 The Toolkit, page 12.
- 7 See, for example, the list of reports in Annex 2 in European Coalition for Community Living, *Wasted Time, Wasted Money, Wasted Lives – A Wasted Opportunity?*, 2010.
- 8 The Common European Guidelines, page 50.
- 9 European Disability Strategy 2010–2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010) 636 final, page 5.
- 10 Towards Social Investment for Growth and Cohesion – including the implementing of European Social Fund 2014–2020, COM(2013) 83 final, page 17.
- 11 See for example, Open Society Foundations, *The European Union and the Right to Community living*, 2012 and the United Nation Office of the High Commissioner for Human Rights, *Getting a Life – Living Independently and Being Included in the Community*, 2012.
- 12 See Article 6, Common Provisions Regulations and the general ex-ante conditionalities, Annex V, Area 3 Disability.
- 13 See Open Society Foundations, *The European Union and the Right to Community Living*, 2012 and the United Nation Office of the High Commissioner for Human Rights, *Getting a Life – Living Independently and Being Included in the Community*, 2012.
- 14 See the Common Provisions Regulation on the European Regional Development Fund, the European Social Fund, the Cohesion Fund, the European Agricultural

- Fund for Rural Development and the European Maritime and Fisheries Fund, COM(2011) 615 final/2. The texts of the regulations which are part of the Cohesion Package 2014–2020 will be available at: http://ec.europa.eu/regional_policy/what/future/index_en.cfm
- 15 See the EC’s draft Guidance on Ex ante conditionalities, pages 252–257, available at: http://ec.europa.eu/regional_policy/what/future/pdf/preparation/20092013_guidance_part_2.pdf Given that the new Structural Funds regulations were approved on 20 November 2013, it is anticipated that the EC will issue the final version of this guidance very soon.
 - 16 These papers are available at: http://ec.europa.eu/regional_policy/what/future/program/index_en.cfm (accessed 27th October 2013)
 - 17 This was noted in the Joint Memorandum on the need to provide clarity in Thematic Conditionality 10, dated 16th October 2013 (further details are provided in Annex 2), page 23.
 - 18 Under Hungarian legislation, the newly established residential facilities can accommodate up to 12 persons. However, the same rule does not apply to the existing large institutions (with 50 plus residents), which may build new living centres for up to 50 people.
 - 19 See also ZELDA, *The Accessibility and Costs of mental health and social care community-based services compared to institutional care in Latvia (2004–2011)*, 2013, page 90, available at: <http://zelda.org.lv/wp-content/uploads/Zelda-eng-Lab5.pdf>
 - 20 See Case study 2 – Assistants for Disabled People Bulgaria (presentation by Elena Krastenova), available at: <http://www.eurofound.europa.eu/docs/events/2013/homecare/worksession1.pdf>
 - 21 Available at: <http://nmd.bg/en/Position/which-are-the-problem-areas-in-the-deinstitutionalization/>
 - 22 See ZELDA, *The Accessibility and Costs of mental health and social care community-based services compared to institutional care in Latvia (2004–2011)*, 2013, pages 84–90, available at: <http://zelda.org.lv/wp-content/uploads/Zelda-eng-Lab5.pdf>
 - 23 In Slovakia, ten projects have recently been submitted for funding under the ROP Call for proposals to support institutions involved in the national project for supporting deinstitutionalisation of social services and alternative care.
 - 24 EC, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, 2008, page 14.
 - 25 The term “mental disabilities” includes people with intellectual disabilities and people with psychosocial disabilities.
 - 26 The details of the other social care homes which received funding can be found (in Latvian only) at: <http://www.esfondi.lv/activities.php?id=867&pid=0&action=projects&identifier=5e6ab73f-6eaa-4633-bfe9-9aa300fd1236>
 - 27 IPP, Policy News – *Results of structural funds investments during 200–2013 – the lesson we have (not) learned for 2014–2020*, October 2013 available at http://www.ipp.ro/library/IPP_National%20Report_Results%20of%20structural%20

- funds%20projects%20in%20Romania_2013.pdf and the Appendix at http://www.ipp.ro/library/IPP_National%20Report%202013_Appendixes.pdf
- 28 See also INESS, *Monitoring of Absorption of Structural Funds in the Area of Social Services (2007–2011)*, 2013, available at: <http://www.iness.sk/stranka/8362-Monitoring-of-Absorption-of-structural-funds.html>
- 29 Open Society Foundations, *The European Union and the Right to Community living*, 2012, page 75.
- 30 The Toolkit, page 24.
- 31 Available at: <http://nmd.bg/en/Position/which-are-the-problem-areas-in-the-deinstitutionalization/>
- 32 INESS, *Monitoring of Absorption of Structural Funds in the Area of Social Services (2007–2011)*, 2013, page 40, available at: <http://www.iness.sk/stranka/8362-Monitoring-of-Absorption-of-structural-funds.html>
- 33 Available at: <http://www.ipp.ro/library/fse/IPPanalizafspcd.pdf>
- 34 Article 14 of the Common Provisions Regulation sets out what should be included in the Partnership Agreement and Article 87 sets out what should be included in the Operational Programmes. Chapter 2 of the Toolkit provides information on what should be included in these documents in relation to the promotion of community living. It should be noted that the Toolkit is based on the draft regulations. The Cohesion Package 2014–2020 was adopted on 20 November 2013 and will be available at: http://ec.europa.eu/regional_policy/what/future/index_en.cfm
- 35 The partnership principle is set out in Article 5 of the Common Provisions Regulation.
- 36 See: http://www.nfu.hu/forum_pate/29
- 37 The Toolkit, page 9.
- 38 The Toolkit provides information on how ESF and ERDF can be used to develop community-based services at pages 28–35.
- 39 Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J., (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report*. Canterbury: Tizard Centre, University of Kent (referred to as “the DECLOC report”), page 52.
- 40 Common European Guidelines, page 22.
- 41 One of the conclusions from the EEG meeting, *The Role of European Structural Funds in the Process of Transition from Institutional to Community-based Care*, Zagreb, Croatia, 24th October 2013.
- 42 See the Toolkit, page 23 and Chapter 2 of the Common European Guidelines.
- 43 The Toolkit, page 23.
- 44 These are similar to the definitions set out in the Common European Guidelines, pages 25–27.
- 45 See ENIL’s key definitions on Independent Living: <http://www.enil.eu/policy/>

Notes

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About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a Europe-wide network of people with disabilities. It represents a forum intended for all disabled people, Independent Living organisations and their non-disabled allies on the issues of independent living. ENIL's mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, deinstitutionalisation, provision of personal assistance support and adequate technical aids, together making full citizenship of disabled people possible.

About the European Coalition for Community Living

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

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

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

This briefing highlights key problems with Structural Funds investments for people with disabilities in six European Union Member States: Bulgaria, Hungary, Latvia, Lithuania, Romania and the Slovak Republic in the current programming period 2007–2013. It makes recommendations to the Member States and the European Commission on actions that need to be taken to ensure that such investments are not repeated in 2014–2020.

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**European Network on
Independent Living – European
Coalition for Community Living**

**www.enil.eu
www.community-living.info**

