

Briefing on the use of European Structural and Investment Funds to support the transition from institutional care to community living for people with disabilities

European Network on Independent Living – European Coalition for Community Living, April 2015

With the majority of Operational Programmes for the European Structural and Investment Funds ('Structural Funds') adopted, the European Network on Independent Living – European Coalition for Community Living (ENIL-ECCL) consider it important to highlight the significant on-going issues which may impede the transition from institutional care to community living for people with disabilities.

This briefing provides examples from five Member States: Hungary, Romania, Slovakia, Bulgaria and the Czech Republic¹. Nevertheless, the concerns highlighted in respect of the five countries covered are likely to be of some relevance to all the Member States in Central and Eastern Europe and the Baltics that are in the process of moving away from institutional care to living in the community.

Many of these concerns have been reflected in our response to the European Ombudsman's own-initiative inquiry concerning the respect for fundamental rights in the implementation of the EU cohesion policy, dated 25 February 2015 (see Annex). In the response, we expressed concerns related to the European Commission's (EC) ability to assess the Member States' compliance with the provisions on social inclusion, accessibility and non-discrimination in the Common Provisions Regulation,² and the existing monitoring and complaints mechanisms in the Member States and at EU level. Moreover, in relation to 'transition from institutional to community-based care', we noted inconsistencies between EC's position stated in the *Report on the implementation of the UN Convention on the*

¹ ENIL-ECCL are thankful to the following organisations which provided information for the briefing: the Hungarian Civil Liberties Union (TASZ), the Institute for Public Policy (IPP, Romania), SOCIA (Slovakia), the Centre for Independent Living Sofia (Bulgaria) and JDI – Jednota pro deinstitucionalizaci (the Czech Republic). Information regarding Latvia, Lithuania, Estonia, Slovenia and Croatia was not available at this stage. This may be due to the fact that many of the user-led organisations ENIL-ECCL work with have not been involved in the consultations on Partnership Agreements and Operational Programmes in their countries.

² Regulation (EU) No 1303/2013

Rights of Persons with Disabilities,³ which commits to no further investments into new or existing institutional infrastructure, apart from exceptional circumstances and provided the institution is earmarked for closure,⁴ and the *Draft guidance for EC desk officers on the transition from institutional to community-based care*⁵. According to the *Draft guidance*, such investments can still be made if “the persons concerned, given the seriousness of their condition, require constant medical supervision”. This goes against Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which provides for the right to live independently and to be included in the community for ALL people with disabilities.

1. The lack of adequate policies for the replacement of long-stay residential institutions with services that facilitate Independent Living

Although Partnership Agreements (PA) and Operational Programmes (OP) make reference to ‘transition from institutional to community-based care’, this objective is undermined by the absence of clear policies to implement deinstitutionalisation reforms. ENIL-ECCL are concerned that Member States lack the will and/or capacity to ensure the closure of long-stay residential institutions for people with disabilities, alongside the development of high quality support services in the community that facilitate Independent Living and access to mainstream services, such as housing, education, employment, health care, transport and others. For example:

- In **Romania**, both the PA and the two relevant OPs (the Regional Operational Programme - ROP⁶ and the Human Capital Operational Programme - HCOP⁷) contain measures to support ‘transition from institutional care (residential centres) to community services’. In the case of the ROP, this includes investment into family type homes, protected houses and adequate equipment, and in the case of HCOP soft measures such as hiring of staff to work in community-based services, supporting independent living skills of those in institutional care and any other actions to support the process of deinstitutionalisation. However, there is no national commitment to close all long-stay residential institutions for people with disabilities, nor is this commitment a condition for receipt of funding. ENIL-ECCL are therefore concerned that Structural Funds will not achieve a transition from institutional care to community-based support. Instead, these funds will help to establish a parallel system of community-based services, co-existing with long-stay residential institutions. To address this concern, **the outcome and output indicators for**

³ Commission Staff Working Document, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*, June 2014, available at:

http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf

⁴ According to this report, Structural Funds (specifically the European Regional Development Fund) should not be used for building new residential institutions or the renovation and modernisation of existing ones. The report adds that such investments could be justified in exceptional cases “where urgent and life-threatening risks to residents linked to poor material conditions need to be addressed” but “only as transitional measures within the context of a de-institutionalisation strategy”.

⁵ Draft Thematic Guidance Fiche for Desk Officers, *Transition from Institutional to Community-based Care (De-institutionalisation – DI)*, Version 2 – 27/01/2014. See:

http://ec.europa.eu/regional_policy/sources/docgener/informat/2014/guidance_deinstitutionalisation.pdf

⁶ See: http://www.inforegio.ro/images/programare2014-2020/POR_2014_2020_ian2015.pdf

⁷ See: http://www.fonduri-ue.ro/res/filepicker_users/cd25a597fd-62/2014-2020/po/VO.POCU.2014-2020.pdf

OPs and the criteria for project applicants in the *Guidelines for Beneficiaries* should also assess the number of institutions closed at the end of the programming period 2014 – 2020.⁸

- In **Bulgaria**, ENIL-ECCL are concerned that the Government's approach is likely to result in the continued institutionalisation of people with disabilities, albeit in settings where the physical conditions are better than in the large residential institutions. This is because there are plans to replace the large residential institutions with Small Group Homes (SGHs), with no indication that other (mainstream) housing options will be developed as well.⁹ Without the necessary support services for Independent Living, and due to the lack of quality standards and independent inspection mechanism, as well as problems in the way services are funded (with individuals losing funding should they leave residential care), it is unlikely that this approach will in any way facilitate social inclusion of people with disabilities in Bulgaria. Both ENIL-ECCL and the European Expert Group on the Transition from Institutional to Community-based Care (EEG), as well as the Council of Europe Human Rights Commissioner and the Committee on the Rights of Persons with Disabilities, have reiterated that **over-reliance on SGHs (also referred to as family-type homes and protected housing) leads to continued segregation of people with disabilities from the community and should not be used as the only alternative to institutional care. If at all, it should be used in exceptional circumstances only, alongside mainstream housing options (such as regular apartments of different sizes and already existing houses in the community).**
- Similarly, in **Romania**, the Regional Operational Programme refers only to investments into family-type homes and protected houses, rather than making mainstream housing available to people with disabilities (by, for example, purchasing existing apartments or houses in the community). As evidenced by countries in the process of moving away from institutional care to living in the community,¹⁰ **developing housing options does not have to be synonymous with building new infrastructure.**
- In the **Czech Republic**, the OPs neither make clear that community-based services are to be supported nor do they prohibit investments into institutional care. The **approach adopted by the Government is one of 'humanization' of institutional care. Not only does this not guarantee the closure of institutions and their replacement with services in the community, but allows the modernisation and renovation of existing institutions.** There has been a significant increase of places in the so-called 'homes with a special regime'

⁸ For more information, please see the statement by the Institute for Public Policy:

<http://www.ipp.ro/statement-on-the-use-of-european-structural-and-investment-funds-for-the-disability-sector-in-romania-in-2014-2020/>

⁹ This is similar to the previous programming period, when large residential institutions for children were replaced mainly with SGHs (accommodating up to 12 children).

¹⁰ For example, please see the Open Society Foundations briefing on the process of deinstitutionalisation in Croatia: <http://www.opensocietyfoundations.org/briefing-papers/deinstitutionalization-croatia>

and the majority of funding spent on 'care' for people with disabilities is still directed towards institutional care.

- In **Hungary**, despite the significant objections raised by civil society organisations to the Government's plan to allow Structural Funds to be invested in institutions for up to 25 persons, this has remained in the Human Resources Development Operational Programme 2014 – 2020. The OP states that "this size is only allowed for those who need 24-hour care, and whose needs are assessed by individualised assessments", which is in clear violation of Article 19 of the CRPD. This article applies without prejudice to all people with disabilities, regardless of their level of support needs. **Should the European Commission allow investments into such settings, it would be acting contrary to its own stated policy of not allowing investments into the building or renovation of long-stay residential institutions in 2014 – 2020, as well as its obligations as a State Party to the CRPD.**

2. Inadequacy of existing strategies in the Member States

Having an adequate strategy/ies in place which support the full social inclusion of people with disabilities and transition from institutional care to community-based services is key to ensuring that the measures supported by Structural Funds can both in the short-term and long-term ensure that people with disabilities are able to live and participate in the community. However, from the information received by ENIL-ECCL, several organisations have expressed concerns about the existing strategies in their countries. For example:

- In **Slovakia**, the formulations in the deinstitutionalisation strategy are considered too vague to be considered as adequate to facilitate the development of high quality alternatives to institutional care for people with different support needs.
- In the **Czech Republic** or **Romania**, to date no strategy for the transition from institutional to community-based services exists.
- In **Hungary**, we share the Committee on the Rights of Persons with Disabilities' concern¹¹ that the Government has set a 30-year timeframe to implement its deinstitutionalisation strategy.
- In **Bulgaria**, the adequacy of existing strategies relevant to people with disabilities for facilitating social inclusion is highly questionable. For example, the Government's strategy for supporting the employment of people with disabilities is focused on developing special workshops, rather than inclusion in the open labour market. This is despite the fact that most countries in Western Europe are moving away from this approach, which has shown not to be economically viable and results in the continued social exclusion of people with disabilities. Moreover, the recently issued call for proposals on personal assistance for people with disabilities provides for a

¹¹ See Concluding observations on Hungary, dated 22 October 2012: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fHUN%2fCO%2f1&Lang=en

limited number of hours, a very low hourly rate (inadequate to hire assistants on the open labour market), does not differentiate between places of provision (whether it is Sofia or other parts of the country) and is open only to the municipalities (rather than partnerships between NGOs and municipalities). ENIL's member - the Centre for Independent Living Sofia - which has been providing personal assistance to people with disabilities in Sofia for a number of years, has expressed disappointment that the Government has failed to build on the existing good practices in the country, instead opting for an approach which will leave many people with disabilities reliant on family members and unable to take up employment etc.

ENIL-ECCL question¹² the capacity of the EC to assess whether Member States are able to fulfil the relevant *ex ante* conditionalities (esp. thematic *ex ante* conditionalities under Thematic objective 9 of the Common Provisions Regulation). The mere existence of strategies is not enough, as such strategies must be directed at the closure of long-stay residential institutions and full inclusion and participation of people with disabilities in society, with adequate support. We have therefore urged the EC to involve people with disabilities and their representative organisations when assessing the fulfilment of relevant *ex ante* conditionalities.

3. Lack of coordination between the European Social Fund (ESF) and the European Regional Development Fund (ERDF) in relation to deinstitutionalisation

ENIL-ECCL welcome the EC's efforts to ensure that at least 20 per cent of the ESF allocation in the Member States goes towards supporting social inclusion of different groups, and is pleased that this target has been achieved during the programming stage. We also welcome the emphasis on the need to integrate ESF and ERDF funding; especially when it comes to deinstitutionalisation, the soft measures funded by ESF, such as staff costs, family support, early-intervention services etc., in combination with the needed infrastructure, are key to ensuring success of the process.

However, we are concerned whether the planned social inclusion measures will in fact be supported by ERDF investments, which are still geared towards supporting special (or 'parallel') services for people with disabilities (such as the already mentioned SGHs, family-type homes and protected housing, often situated in remote areas), rather than mainstream infrastructure. 'Accessibility' for people with disabilities is still interpreted in its narrow sense, as physical accessibility of the environment, including being able to enter schools, health facilities etc. While that is also of key importance, the fact is that housing options for people with disabilities in the community continue to be inadequate or absent; therefore, 'accessibility' should be interpreted as providing access of people with disabilities

¹² See, for example, *Realising the Right to Independent Living: Is the European Union Competent to Meet the Challenges?: ENIL-ECCL Shadow report on the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities in the European Union*, October 2014. Available at: <http://www.enil.eu/wp-content/uploads/2012/06/Shadow-Report-11-04-2014-final-WEB-1-1.pdf>

to mainstream housing, as well as to other services and facilities.¹³ Some concerns expressed in this regard are as follows:

- In **Slovakia**, the Coordination Working Group for Deinstitutionalisation, which should ensure that there is coordination between ESF and ERDF when such funds are used to support deinstitutionalisation, has still not been established. There are therefore concerns that once calls for proposals are published, the conditions for applicants will not be adequate to ensure that only those projects that facilitate living in the community are funded.
- In **Romania**, there is insufficient coordination between ESF and ERDF when they are funding projects aimed at supporting transition from institutional care to community-based services. The risk is that investments into infrastructure will not be combined with development of staff able to deliver quality services in the community, and vice versa.

4. Insufficient implementation of the partnership principle

Adoption of the Code of Conduct on Partnership has provided a real opportunity for Member States to more meaningfully involve organisations of people with disabilities, and people with disabilities themselves, in different stages of Structural Funds implementation. While there are noticeable improvements in comparison to the previous programming period – thanks to the fact that Member States have to report to the EC on how they are implementing the partnership principle – we are still concerned about the following issues:

- **Consultation often remains limited** to the National Disability Councils, larger umbrella organisations and service providers, which are not representative of a wide range of views among people with disabilities and may focus on the interests of one particular group. Furthermore, people with disabilities in institutional care (in the majority, these are people with intellectual disabilities and mental health problems) often remain without a voice in this process.
- It is not known whether Managing Authorities are using, or plan to use, funds for **technical assistance to build the capacity of user-led disabled persons' organisations** (DPOs), advocating for deinstitutionalisation, to meaningfully participate in Structural Funds implementation and monitoring. In the experience of ENIL-ECCL, which brings together mainly grassroots groups, most organisations lack the necessary expertise and influence to take part in the process.
- Where **coordination bodies** are being set up (with Structural Funds) to support the selection of projects and to provide training and other expertise, it is unclear whether there is scope for the involvement of people with disabilities able to provide peer support or in other ways ensure that those targeted by the projects are able to

¹³ This point has also been raised in the ENIL-ECCL *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013. Available at: <http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf>

make decisions about where, how and with whom they want to live, in line with Article 19 of the UN CRPD.

5. Conclusions

Although many OPs have by now been adopted, there is still an opportunity to **make modifications or to put in place measures** to ensure that the projects supported result in the development of high quality alternatives to institutional care and improved social inclusion of people with disabilities. Ensuring that the Member States have **adequate strategies** which support the process of deinstitutionalisation (in line with the relevant *ex ante* conditionalities and in consultation with organisations of people with disabilities), and closely monitoring the use of Structural Funds are of key importance to preventing the use of EU funds for services that perpetuate the segregation and social exclusion of people with disabilities. Furthermore, **increasing the capacity of a wider range of organisations, especially those with a track record in advocating for deinstitutionalisation, and service users themselves** to take part in the monitoring and implementation of Structural Funds can help to ensure that the projects funded respond to the requirements of people with different types and levels of support needs and build on the best practice in the country and Europe-wide/internationally.

Finally, **strong leadership** is required by the EC to ensure that Structural Funds will not be used to fund long-stay residential institutions for people with disabilities and the *Draft guidance for EC desk officers on the transition from institutional to community-based care* should be revised to clearly reflect this position.

This briefing was prepared with the support of the Open Society Foundations – Mental Health Initiative. For additional information, please contact Ines Bulic, Policy Officer and Coordinator of the European Coalition for Community Living, ines.bulic@enil.eu