

**List of Issues in relation to the initial report of the European Union
Comments on Article 19 (Living independently and being included
in the community) (Question 22) submitted by:**

**The European Network on Independent Living – the European
Coalition for Community Living (ENIL-ECCL)**

ENIL-ECCL welcomes the opportunity to comment on the List of Issues in relation to the initial report of the European Union (the EU report). This note focuses on Question 22 which concerns Article 19 (Living independently and being included in the community).

Information about ENIL-ECCL is provided below, together with an executive summary outlining our key concerns and recommendations. An executive summary of the ENIL-ECCL's report "Realising the Right to Independent Living: Is the European Union Competent to Meet the Challenges?" is included in the Annex to this report. The word version of the full report can be obtained at: <http://www.enil.eu/wp-content/uploads/2014/11/Article-19-Shadow-Report-Final-WORD-VERSION.doc>

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. ENIL has participatory status with the Council of Europe and is represented on the Advisory Panel to the EU Fundamental Rights Agency's Fundamental Rights Platform.

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.

Executive Summary of ENIL-ECCL's response

Potential of ESIFs to promote social inclusion not realised to date

Although European Structural and Investment Funds (ESIFs) have the potential to ensure, protect and promote social inclusion, in some cases they have helped to exacerbate the social exclusion of people with disabilities. ESIFs have been used to fund projects that maintain systems of institutionalised care, thereby segregating people with disabilities from their local communities, rather than supporting the reforms needed to promote the social inclusion of people with disabilities.

It is essential that the EU establishes effective systems to address these concerns and ensure that ESIFs facilitate the reforms needed to enable people with disabilities to live and participate in their local communities. In particular ESIFs have a crucial role in supporting the transition from institutional care to community-based services. To achieve the full potential of ESIFs, ENIL-ECCL recommend that the EU take a range of actions, which are summarised as follows:

1. Prohibit the use of ESIFs investments into institutional care.
2. Encourage Member States to use ESIFs to promote social inclusion, specifically to facilitate the transition from institutional care to community-based services.
3. Take action to avoid the misuse of ESIFs, e.g. insist on clear strategies for the transition from institutional care to community-based alternatives that promote social inclusion.
4. Establish monitoring systems to ensure the effective use of ESIFs.
5. Take action to prevent the inappropriate use of ESIFs.

Insufficient involvement of non-governmental organisations (NGOs) to date

Although the situation is much better than the previous financing period, there has been an insufficient involvement of non-governmental organisations (NGOs) in the programming and implementation of ESIFs in the financing period 2014 – 2020. This is a wasted opportunity given that many NGOs have valuable expertise, especially those who provide high quality community-based services. To address this concern, ENIL-ECCL recommend that the EU take a range of actions, including:

1. Work with Member States to increase greater awareness about the use of ESIFs, particularly amongst civil society and people with disabilities themselves.
2. Encourage the use of ESIFs to build the capacity of user-led disabled persons' organisations to meaningfully participate in ESIF implementation and monitoring.
3. Ensure that Member States comply with their partnership requirements in the planning, implementation and evaluation of ESIFs projects.
4. Require deinstitutionalisation strategies to describe how the 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 (including those of people with disabilities themselves).

A. Please explain how European funding, especially the European Structural and Investment Fund (ESIF), is used to ensure, protect and promote the inclusion of persons with disabilities in their local communities?

ESIFs have the potential to support a range of initiatives that seek to ensure, protect and promote the social inclusion of people with disabilities. However, significant problems with their implementation have undermined this goal and in some cases the use of ESIFs have exacerbated the social exclusion of people with disabilities. Of particular concern is that in the past, there has been a failure to use ESIFs to support the development of properly planned strategies for the transition from institutional care to community-based services. These points are considered further below.

A.1. Potential of ESIFs to promote social inclusion not realised to date

- *ESIFs can provide a significant resource to enable governments to address the social exclusion of people with disabilities.*

ESIFs have a particularly important role in addressing the prevalence of institutionalisation of people with disabilities in many parts of the European Union (EU). They can support the development of new services, including services that prevent institutionalisation and the provision of technical support for reforming legislative and financial frameworks to underpin and support community-based services that promote independent living.¹

The European Regional Development Fund (ERDF) can finance investments in health and social care infrastructure, and the European Social Fund (ESF) can support employment initiatives, such as the provision of training of staff working in community-based services or supporting personal assistance schemes.

- *ESIFs have a crucial role in the planning and implementation of the transition from institutional care to a system of community-based services and supports that enable people with disabilities to live and participate in their communities as equal citizens.* Such work is important because:
 - A study funded by the European Commission (EC) and published in 2007 estimated that 1.2 million people with disabilities across the EU² were living in institutions. As noted by the EU (paragraph 100, EU report), the study also found ‘that institutional care for disabled people in Europe fell short of acceptable standards’. Moreover, during the past decade, numerous reports have highlighted the severe and wide-ranging human rights abuses that form part of daily life in such institutional settings.³
 - Irrespective of any physical or other abuse perpetrated against residents, the segregation of people with disabilities in institutions is a human rights violation. In addition to being contrary to Article 19 of the CRPD and Article 26 (Integration of persons with disabilities) of the Charter of Fundamental Rights, the segregation of people with disabilities in long-stay residential institutions also runs against the provisions governing the use of ESIFs (see Article 7 of Regulation (EU) No 1303/2013 (‘Common Provisions Regulation - CPR’),

which requires the EC and EU Member States to take concrete steps to prevent any discrimination based on disability ‘during the preparation and implementation of programmes’.

- Although policies of the EU and Member States highlight the need for action to ensure the social inclusion of people with disabilities, progress towards alternatives has been slow and in many countries institutional care remains the predominant form of ‘care’. This is especially true for Central and Eastern Europe and the Baltic countries (which became EU members in 2004), which have a strong legacy of institutional care and very few community-based services in place.
- *Despite their potential for facilitating positive reforms that would enhance the social inclusion of people with disabilities, in many cases ESIFs have used to fund projects that have hindered rather than helped the realisation of the right to independent living.*

A.2. Past use of ESIFs: Key areas of concern

- *ESIFs investments into institutional care:* It is estimated that during the previous EU financing period (2007- 2013) a total of at least 150 million Euros were invested into the renovation or building of new institutions for disabled people in the countries of Bulgaria, Hungary, Latvia, Lithuania, Romania and the Slovak Republic.⁴ Additional information provided to ENIL-ECCL suggests that ESIFs have also been invested in institutional care in the Czech Republic, Estonia and Poland.⁵ The Council of Europe’s Commissioner for Human Rights, expressed his concern as follows:

“Unfortunately, Europe still has a long way to go even to eradicate the most obvious violations of this right; that is, the segregation of persons with disabilities in large institutions. The human rights violations such institutions engender are well documented, including in the case-law of the European Court of Human Rights and the reports of the Council of Europe anti-torture Committee (CPT), yet they continue to blight the European landscape. There are still European countries refurbishing existing institutions or even building new ones – sometimes, shamefully, with EU structural funds.”⁶

- *Resources diverted away from developing community services:* Using ESIFs to maintain institutional care means that funding is being diverted away from developing community-based services which would enable people with disabilities to live and participate in the community. As the Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (published by the EC in 2008) notes, such investment “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”.⁷
- *Services replicating institutional cultures:* ESIFs have supported the development of different residential settings (such as “small group homes”), which have replicated the institutional culture. Save for an improvement in the physical environment, little else has changed. Services referred to as “community-based”

or “independent living” are being supported, when in fact they remain institutional in character.⁸ This may be due to a number of factors, such as the number of residents living in one place, the fact that residents are not able to choose where, or with whom, they live, and the fact that the staff are not properly trained to work in the new services.

A.3. Future use of ESIFs: the need to avoid the past misuse of ESIFs

Largely thanks to the EC, a number of significant changes have been introduced to the provisions governing the use of ESIFs for the period 2014 – 2020.⁹ The emphasis on using ESIFs to support the “transition from institutional to community-based care”, as well as social inclusion, accessibility and non-discrimination, is very positive. These, together with the general *ex ante* conditionality to comply with the CRPD, has improved the EC’s ability to ensure that ESIFs are used to promote, rather than hinder, the social inclusion of people with disabilities. However, further work is required to ensure that the projects funded by ESIFs achieve these goals. Set out below are ENIL-ECCL’s recommendations on what action the EC needs to take, on behalf of the EU, in order to address the key concerns about the use of ESIFs, thereby helping to address the barriers to the social inclusion of people with disabilities.

Promoting Social Inclusion: Recommendations

1. Prohibit the use of ESIFs investments into institutional care

The EU report states (paragraph 98):

‘The ERDF should as a basic principle not be used for building new residential institutions or the renovation and modernisation of existing ones. Targeted investments in existing institutions can 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’.

Given that in the past ESIFs have been invested in institutions, it is crucial that this statement is set out clearly in EC guidance and other documents relevant to the use of ESIFs so that all those involved in the planning and implementation of projects funded by ESIFs are aware of this restriction.

2. Encourage Member States to use ESIFs to promote social inclusion

The EU must be more proactive in encouraging Member States to use ESIFs in order to promote the right to living independently and being included in the community. In particular:

- a) The EC should make clear that where it has identified transition from institutional care to community-based services as a priority area,¹⁰ those

Member States will be expected to invest a sufficient amount of ESIFs into genuine community-based alternatives to institutions (i.e. develop services and support that enable people with disabilities to engage in community life).

- b) The EC should provide leadership and guidance for Member States, for example ensuring that EC staff are familiar with, and promote the use of, materials developed to assist in facilitating the transition from institutional care to community based services. For example, the *Common European Guidelines on the Transition from Institutional to Community-based Care*¹¹ includes guidance on monitoring and evaluating the quality of services and how users of the services can be included in this work.
- c) The EC should promote personal assistance schemes as a measure to be supported by ESIFs. This is because personal assistance schemes are a crucial element of the range of community-based services that should be made available in accordance with Article 19 (they are specifically referred to by Article 19). Genuine personal assistance schemes should give disabled people choice and control over the recruitment, employment, and training of the assistants and the tasks they implement.¹²

Whereas the EU considers that “EU law does not directly address the issue of personal assistance schemes, which are a matter of national competence” (paragraph 103, EU Report), this view fails to take into account the EU’s role in promoting the use of personal assistance schemes through ESIFs investments. It is also at odds with the EU’s Disability Strategy which states that the EU will take action to support national activities in developing personal assistance schemes.¹³

3. Take action to avoid the misuse of ESIFs

To ensure that in the future ESIFs are used to promote, rather than hinder, independent living the EU needs to:

- *Insist on clear strategies for the transition from institutional care to community-based alternatives that promote social inclusion.*¹⁴ Guidelines endorsed by the EC, state that governments should prepare a strategy that sets out the overall framework for guiding the necessary reforms in three key areas, namely the closure of institutions, the development of community-based services (including prevention of institutionalisation) and inclusive mainstream services.¹⁵
- *Ensure that Member States’ strategies define terms such as “institution” and “community-based services” so that the services developed by projects supported by ESIFs are focused on enabling people to live and participate in the community, as required by Article 19, and do not fund services that replicate the regimes of the larger institutions they were intended to replace. Community-based services include accessible mainstream services, such as housing, healthcare, education, employment, culture and leisure, that eliminate the need for special or segregated institutions, as well as specialised services for persons with disabilities, such as personal assistance.*¹⁶

- *Facilitate greater co-operation between relevant Member State ministries and within the Directorate Generals of the EC so that no ESIFs are invested in institutions. In the past institutions have received funds to meet targets unrelated to reform in health and social care, such as improving accessibility or energy efficiency.¹⁷ While accessibility as such is a positive goal, making institutions accessible results in a waste of resources, which could have been invested in the development of community-based services, and delays the closure of the institution. This also highlights the need for an emphasis on social inclusion in the Member States' strategies.*

4. Establish monitoring systems to ensure compliance with EU law and policy (including the CRPD)

- a) The EU should acknowledge that it needs to take on a greater role in monitoring how ESIFs are applied by Member States.

This is needed because to date the EC has placed an overly restrictive interpretation of its role. In particular, the EU states (paragraph 99, EU report) and in its reply to the List of Issues (June 2015, paragraph 83) that while it has a responsibility for ensuring that Member States' Operational Programmes (OPs)¹⁸ comply with EU law and policies, implementation is the responsibility of Member States.

This statement requires clarification. It suggests that once OPs are agreed, the EC is not concerned with decisions on how ESIFs are applied (such as which activities are funded by ESIFs). However, as the EU Ombudsman notes, the EU should not allow itself to finance actions which are not in line with EU values.¹⁹

Whereas it is very positive that the EU has made clear that it will use its powers to suspend or withdraw payments if it finds that Member States have failed to comply with EU law and policy (paragraph 99 EU report), it is not clear how the EC can adhere to this commitment without monitoring the projects funded by ESIFs. Unless it does so, the EC will not be aware of cases in which ESIFs are funding activities that do not comply with EU law and policy. For example, using ESIFs to develop services that are institutional in character and/or located on the outskirts of towns would be contrary to the objective of promoting the transition from institutional to community-based care. However, without any means of monitoring such a project, the EC would be unaware of the problem and therefore not in a position to take remedial action.

- b) The EU should establish an effective mechanism for monitoring the implementation of the projects funded by the ESIFs.²⁰

This is necessary to ensure ESIFs, which are being provided by the EU, are not being invested in projects that conflict with the EU's obligations under the CRPD²¹

ENIL-ECCL is concerned that there are insufficient mechanisms in place to enable the EC to monitor the implementation of projects funded by ESIFs to ensure that such projects develop community-based services that promote social inclusion and are not used to create services that replicate institutional care.

In the light of these concerns, a key question for the EU is how the EC will assess Member States' compliance with the requirements set out under the revised provisions governing the use of ESIFs. ENIL-ECCL consider that in order to do so the EC will need to take the following steps:

- *Assess the adequacy of measures to promote independent living:* It is unclear how the EC will assess whether the measures for the shift from institutional to community-based services and support identified by Member States are sufficiently directed towards the closure of institutions and the development of services that fully support the right to independent living.²²
- *Assess the accessibility of mainstream services* (paragraph 95, EU report) it is not clear how compliance with these provisions will be monitored, or who would assess for compliance. As yet, there are no accessibility standards at the EU level, and Member States' standards vary. If this is to be monitored by civil society groups, additional funding will be required. Furthermore, it is not clear what would happen if projects supported by ESIFs are not accessible.
- *Assess the capacity to comply with the CRPD:* It is not clear how the EC intends to assess Member States' compliance with the general *ex ante* conditionality on disability (which requires the existence of "administrative capacity for the implementation and application of [the CRPD]"). The criteria for fulfilment refer to the involvement of "bodies in charge of protection of rights of persons with disabilities or representative organisations of people with disabilities and other relevant stakeholders" throughout the process of programmes funded by ESIFs, training of staff on disability law and policy and practical application of the CRPD and monitoring compliance with Article 9.
- *Engage with civil society organisations with an interest in this area:* The EU Ombudsman has recommended a number of actions that the EC could undertake to encourage civil society to contribute to the EC's work in monitoring the implementation of ESIFs, such as an on-line platform which would enable complaints and shadow reports to be submitted.²³

5. Investigate concerns about the inappropriate use of ESIFs

As noted above the EU's commitment to using its powers to suspend or withdraw payments if it finds that Member States have failed to comply with EU law and policy is very welcome. The EU should make clear that this commitment includes taking action to investigate cases where there are concerns that the ESIFs are being used for projects that do not comply with Article 19 and suspending/withdrawing funding in cases where the funds have been inappropriately used.

It should be noted that the EU Ombudsman's view is that the 'fact that the Commission is not directly responsible for managing ESI Funds should never be

used as a reason for not acting if fundamental rights have been, or risk being violated'.²⁴

B. How are representative organisations of persons with disabilities involved in the policy making, implementation, monitoring and evaluation of the use of that funding?

Insufficient involvement of non-governmental organisations (NGOs) to date

Although the situation is much better than the previous financing period, there has been an insufficient involvement of non-governmental organisations (NGOs) in the programming and implementation of ESIFs in the financing period 2014 - 2020, despite this being a legal requirement under the European Code of Conduct on Partnership.²⁵ This is a wasted opportunity given that many NGOs have valuable expertise, especially those who provide high quality community-based services.

Involving Civil Society: Recommendations

1. The EU (through the EC) should work with the Member States to ensure that there is greater awareness about the use of ESIFs, particularly amongst civil society (NGOs) and people with disabilities themselves.
2. The EU should encourage Managing Authorities to use of ESIFs to fund technical assistance to build the capacity of user-led disabled persons' organisations (DPOs) advocating for deinstitutionalisation to meaningfully participate in ESIFs 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.
3. The EU (through the EC) should ensure that Member States comply with their partnership requirements in the planning, implementation and evaluation of ESIFs projects. This should include ensuring that NGOs who are service providers know how to apply for EU funding, and taking steps to facilitate the involvement of service users.
4. The EC should require that Member States' deinstitutionalisation strategies describe how the 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 (including those of people with disabilities themselves). For example, a significant concern is that 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.

Annex

Realising the Right to Independent Living: Is the European Union Competent to Meet the Challenges? ENIL-ECCL Shadow report on the implementation of the UN Convention on the Rights of Persons with Disabilities in the European Union (October 2014)

Executive Summary

This report considers the action taken by the European Union (“EU”) to implement the rights of people with disabilities under Article 19 (living independently and being included in the community) of the UN Convention on the Rights of Persons with Disabilities (“CRPD”). It seeks to provide the Committee on the Rights of Persons with Disabilities with information that will be of assistance when assessing the extent to which the EU has complied with its obligations under Article 19. It does so by considering the initial EU report to the CRPD Committee, *Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union*²⁶ (“the EU report”) and providing comments under the following four broad areas:

1. Ascertaining the extent of the EU’s obligations under the CRPD
2. Understanding the current situation of people with disabilities living in the EU
3. Using Structural Funds to promote independent living
4. Promoting personal assistance as an essential element of independent living

Under each of these areas, key issues of concern are identified and discussed. They are followed by a set of proposed questions, which the CRPD Committee may wish to raise with the EU when considering the EU’s compliance with the CRPD. The two specific areas - the use of “Structural Funds” (European Structural and Investment Funds) to promote independent living and the promotion of personal assistance as an essential element of independent living are the focus of this report. This is because ENIL-ECCL consider these areas to be crucial elements of the work that must be undertaken by the EU to enable people with disabilities to exercise their right to independent living.

1. Ascertaining the extent of the EU’s obligations under the CRPD

Given that the CRPD is a “mixed agreement”, it is necessary to ascertain the extent of the EU’s responsibility to ensure compliance with the CRPD. The key issues of concern are as follows:

- Lack of clarity on the scope of the EU’s competence in relation to the CRPD
- Lack of clarity on action to be taken by the EU to ensure overall compliance with the CRPD
- Lack of clarity on EU’s competence and specific action to be taken in relation to Article 19 of the CRPD

The extent of the EU's obligations under the CRPD: Proposed questions

- **Question 1:** *In which areas of the CRPD does the EU have exclusive competence (i.e. areas for which it is solely responsible for meeting the obligations under the CRPD) and in which areas does it share competence with the Member States?*
- **Question 2:** *Has the EU undertaken a review of EU legislation and policies for compliance with the CRPD and, if such a review has been undertaken, what is the outcome of this review (i.e. what recommendations have been made and to what extent have they been implemented)?*
- **Question 3:** *Given that the EU shares competence with the Member States in relation to Article 19, what specific actions are being taken by the EU to promote Article 19, how does the EU work with Member States towards meeting the obligations under Article 19, and how is progress assessed?*

2. Understanding the current situation of people with disabilities living in the EU

People with disabilities living in the EU face significant barriers to independent living and being included in the community. For example, large numbers of people with disabilities continue to be placed in long-stay residential care - settings in which serious human rights abuses are known to occur. There is a disproportionate adverse impact on people with disabilities of governments' austerity measures and the progress towards achieving the transition from institutional care to community-based alternatives remains slow and uneven. Despite their relevance to the CRPD and the significant negative impact on the lives of people with disabilities, the EU report gives too little attention to these areas. This raises the following key issues of concern:

- Insufficient data on the situation of people with disabilities in the EU
- Insufficient information on people with disabilities living in institutions
- Adverse impact of austerity measures on people with disabilities
- Insufficient action to raise awareness about the institutionalisation of people with disabilities
- Slow progress in developing community-based alternatives to institutional care that ensure independent living for people with disabilities

The current situation of people with disabilities living in the EU: Proposed questions

- **Question 4:** *What action does the EU propose to take to address the lack of comprehensive and up to date information on the situation of people with disabilities in the EU, including people with disabilities living in long-stay residential care?*
- **Question 5:** *What action does the EU propose to take to ensure that Member States are aware of their obligations under the CRPD, including the obligation to promote independent living?*

- **Question 6:** *What action is being undertaken by the EU to encourage Member States to promptly identify and address the reasons for the continued institutionalisation of people with disabilities, including the increase in the institutionalisation of people with disabilities as a result of austerity measures?*

3. Using Structural Funds to promote independent living

Structural Funds can play a significant role in the promotion of the right to independent living. They have the potential for facilitating the systemic reforms that governments need to make, if they are to achieve the goal of moving from institutional care to a range of community-based services and supports that enable people with disabilities to live and participate in the community as equal citizens. Their use must comply with EU law, including the CRPD. However, in the past, there has been a failure to use Structural Funds to support the development of a properly planned strategy for the transition from institutional care to community-based services. The key issues of concern are as follows:

- Clear leadership required at EU level to ensure Structural Funds support deinstitutionalisation reforms in the Member States
- The use of Structural Funds to maintain institutional care should be prohibited
- If such failures are to be avoided in the future, the significant negative consequences of past failures to ensure that Structural Funds support the development of community-based must be acknowledged
- Concerted action is required to avoid any future misuse of Structural Funds
- Clear monitoring mechanisms are required to ensure the effective use of Structural Funds to promote the right to independent living

The use of Structural Funds: Proposed questions

- **Question 7:** *Where the need for “measures for the shift from institutional to community-based care” is identified as a funding priority by the EU, what action does the EU take to ensure that the Member State allocates a sufficient amount of Structural Funds for this purpose?*
- **Question 8:** *How will the EU ensure that all projects funded by Structural Funds accord with the CRPD, including the requirement under Article 19 that all people with disabilities have the right to “choose where and with whom they live”?*
- **Question 9:** *What action will the EU take if a Member State uses Structural Funds to support programmes that do not promote the right to independent living under Article 19, or otherwise do not comply with the EU or Member State’s obligations under the CRPD?*
- **Question 10:** *What monitoring mechanisms within the EU are in place to ensure the effective use of Structural Funds to promote the right to independent living and how does this involve people with disabilities and their representative organisations?*

4. Promoting personal assistance as an essential element of independent living

Personal assistance is one of the core elements of independent living. Article 19(b) requires State Parties to ensure that people with disabilities have access to “community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”. However, to date, too little attention has been given to the importance of ensuring that personal assistance schemes are available to all people with disabilities living in the EU. The key issues of concern are as follows:

- Lack of attention given to promoting personal assistance schemes
- Lack of portability of personal assistance schemes

Personal assistance as an essential element of independent living: Proposed questions

- **Question 11:** *What action will the EU take to ensure that personal assistance schemes are sufficiently supported by the Structural Funds, along with other community-based services?*
- **Question 12:** *What action will the EU take to ensure that people with disabilities have access to essential independent living services, including personal assistance, when taking up residence in another EU Member State?*
- **Question 13:** *How does the EU plan to use existing policy initiatives, such as those related to reaching Europe 2020 targets, to promote access to personal assistance for people with disabilities?*

Conclusion

The EU report gives insufficient attention to the problems and challenges faced by people with disabilities living in the EU, in relation to the right to independent living (Article 19). It fails to provide a realistic picture of the current situation of people with disabilities, with the corresponding problem that there is little discussion on how the continuing widespread and weighty barriers to achieving the goals set out in the EU Disability Strategy 2010 – 2020 might be addressed. In particular, while the action by the EC to highlight, in both policy and legislation, the need for Member States to ensure the shift from institutional care to community-based services is very welcome, more effective action is required to ensure that people with disabilities can exercise their right to independent living in accordance with Article 19.

ENIL-ECCL hopes that the range of comments and questions it has posed will assist the CRPD Committee in assessing the extent to which the EU has complied with its obligations under the CRPD, in particular Article 19, and to consider what further action the EU should take to address any areas in which it falls short in meeting its obligations.

Endnotes

¹ European Commission, *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes>

² 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”). See: http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf. Although this figure dates from 2007, there have been no further major studies aimed at establishing the number of people with disabilities living in institutions in the EU since then.

³ See, for example, Annex 2 (Selection of reports about institutionalisation of children and adults in countries accessing Structural Funds and IPA) of the *Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based care*, 2012: www.deinstitutionalisationguide.eu

⁴ See ENIL-ECCL, *Briefing on Structural Funds Investments for People with Disabilities: Achieving the Transition from Institutional Care to Community Living*, December 2013, (ENIL-ECCL Briefing 2013), pages 11 – 12: <http://www.enil.eu/wp-content/uploads/2013/11/Structural-Fund-Briefing-final-WEB.pdf>

⁵ Personal communication.

⁶ See: wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2503663&SecMode=1&DocId=2130702&Usage=2

⁷ *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, 2008, page 14 (see endnote 1)

⁸ ENIL-ECCL Briefing 2013 (endnote 4), pages 9 – 10.

⁹ Regulation (EU) No 1303/2013. See: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2013:347:0320:0469:EN:PDF>

¹⁰ See the European Commission Position papers on the development of Partnership agreements and programmes in 2014 – 2020, for Bulgaria, Czech Republic, Estonia, Greece, Hungary, Latvia, Lithuania, Poland, Romania, Slovenia, Slovakia and Croatia.

¹¹ 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*. See: <http://www.deinstitutionalisationguide.eu>

¹² ENIL-ECCL, *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, page 33. See: <http://www.enil.eu/wp-content/uploads/2012/06/Shadow-Report-11-04-2014-final-WEB-1-1.pdf>

¹³ COM(2010) 636 final European Disability Strategy 2010-2020: *A Renewed Commitment to a Barrier-Free Europe*, pages 5 - 6

¹⁴ See discussion on the lack of vision for developing community-based alternatives to institutional care, ECCL-ENIL Briefing 2013 (endnote 4), pages 8 – 11.

¹⁵ See endnote 11, available at: <http://www.deinstitutionalisationguide.eu>

¹⁶ ENIL-ECCL Briefing 2013 (endnote 4), page 19 and Chapter III of the *Common European Guidelines on the Transition from Institutional to Community-based Care* (endnote 11) provide definitions of key terms.

¹⁷ For examples of such investments, see ENIL-ECCL Briefing 2013 (endnote 4), page 12 -13.

¹⁸ Operational Programmes are plans in which Member States set out how funds from the ESIF will be spent for a specific thematic goal or country region.

¹⁹ Decision of the European Ombudsman closing her own-initiative inquiry OI/8/2014/AN concerning the European Commission, (European Ombudsman (2015) available at:

<http://www.ombudsman.europa.eu/et/cases/decision.faces/en/59836/html.bookmark>

²⁰ For ENIL-ECCL's comments on the European Commission's approach to complaints concerning Member States' monitoring and control mechanisms, see ENIL-ECCL's response to the European Ombudsman own-initiative inquiry OI/8/2014/AN concerning the European Commission; available at:

<http://www.ombudsman.europa.eu/en/cases/correspondence.faces/en/59845/html.bookmark>

²¹ For a detailed analysis of this issue, see Open Society Foundations, *The European Union and the Right to Community living*, 2012, page 70. Available at: <http://www.opensocietyfoundations.org/sites/default/files/europe-community-living-20120507.pdf>

²² This is discussed in more detail in ENIL-ECCL Shadow report (endnote 12)

²³ European Ombudsman (2015) (endnote 19)

²⁴ See endnote 19

²⁵ See, for example, ENIL-ECCL Briefing 2013 (see endnote 4), CEE-Bankwatch Network *Partners' involvement during EU funds programming: left out on crucial questions* (2014), available at: <http://bankwatch.org/publications/partners-involvement-during-eu-funds-programming-left-out-crucial-questions>,

²⁶ 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.