

Inclusion Europe's analysis of the EU Council conclusions on Independent living¹

In December 2017, the Council of the European Union issued conclusions on “Enhancing Community-Based Support and Care for Independent Living”. Inclusion Europe appreciates the focus of the Council on the critical issue of independent living. The lack of adequate and high-quality community support has a negative impact on the lives of millions of people with disabilities in institutions and psychiatric hospitals, and those relying on their families for support. It also makes a significant impact on their families who have to compensate for the lack of support from the State.

Inclusion Europe welcomes and would like to strengthen several statements made by the Council conclusions, in light of the Convention on the Rights of Persons with Disabilities (CRPD) and the recent General Comment issued by the CRPD Committee.¹

1. **It is of paramount importance to recognise the value of the European Structural Funds and their use towards the development of community-based support.**

In addition to continuing “to support the use of the funds in this way” as the conclusions state, it is **equally important to prevent the use of EU funds to create or refurbish institutional settings**. This is reinforced by the CRPD Committee’s clear declaration that *“investing money obtained within the framework of international cooperation in development of new institutions or places of confinement or institutional models of care is not acceptable, as it leads to the segregation and isolation of persons with disabilities”*.² The CRPD Committee also highlights the responsibility of State parties who *“should ensure that public or private funds are not spent on maintaining, renovating, establishing building or creating any form of institution or institutionalization. Furthermore, States parties must ensure that private institutions are not established under the guise of “community living”*.³

2. **It is essential to increase support for family carers.** Many States do not have sufficient and adequate community-based support, so families have to compensate for the inaction of the State. These families face many difficulties as a result. For example, as there is little

¹ CRPD Committee, [General Comment N°5 on article 19](#), adopted 31 August 2017

² Supra, para 96.

³ Supra, para 51

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social or financial recognition of informal care, family carers are very often isolated, without access to support services, including psychological support.⁴

3. **It is key for people with disabilities to be more involved in decision-making during the transition from institutional to community-based care.** This is crucial to help ensure the success of the transition and the quality of the newly created community-based support. **Their involvement is also critical to make sure that they do not return to institutions.** The CRPD clearly highlights the right to be involved in decision-making processes in article 4.3. The General Comment refers to this right several times, emphasising the need for *“full involvement of persons with disabilities in the decision-making process”*.⁵ Moreover, the CRPD Committee explains through the General Comment that *“decision makers at all levels must actively involve and consult the full range of persons with disabilities including organizations of women with disabilities, older persons with disabilities, children with disabilities, persons with psychosocial disabilities and persons with intellectual disabilities”*.⁶

4. **It is imperative, and not merely preferable as suggested in the Council’s conclusions, that individuals autonomously decide where to live.** In article 19(a), the CRPD underlines the right to choose the place of residence, where and with whom people want to live.⁷ The CRPD Committee further insists on this and recommends that Member States *“repeal all laws that prevent any person with disabilities, regardless of the type of impairment, to choose where and with whom and how to live”*.⁸ **By depriving people with disabilities of the right to make decisions, guardianships also prevent them from choosing where and with whom to live.**

5. **The scale and number of existing residential institutions must be reduced, hand-in-hand with developing affordable and high-quality community-based solutions.** These solutions will ensure that people who have been institutionalised are supported and are better included in society. However, **the lack of high-quality community based solutions should never constitute an excuse to rely on institutions or families.**⁹ Member States need to take immediate steps regarding deinstitutionalisation strategies. Support must be provided to people after they have left institutions, to help them cope with the segregation, and often violence or abuse, that they experienced there.¹⁰

⁴ Coface families Europe, [Making Europe’s invisible workforce visible: Results of the 2017 stocktaking study on the challenges and needs of family carers in Europe](#), 2017.

⁵ CRPD Committee, [General Comment N°5 on article 19](#), para 62

⁶ Supra, para 70

⁷ [Convention on the Right of Persons with Disabilities](#), article 19(a).

⁸ CRPD Committee, [General Comment N°5 on article 19](#), para 97

⁹ Supra, para 38(c)

¹⁰ [Inclusion Europe’s project Life after Violence](#), a study on how women with intellectual disabilities cope with institutionalised violence.

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Inclusion Europe notes with concern certain parts of the Conclusions, and comments on these in light of the CRPD.

1. Inclusion Europe is concerned with the following statement by the Council:

*“The remaining residential institutions should support residents' autonomy, provide high-quality personalised care and cater in particular for the needs of dependent persons for whom community care is not the preferred option. It is essential to ensure safety, dignity and a non-discriminatory environment in all care settings.”*¹¹

- a. **Residential institutions, as opposed to what is implied in the conclusions, can never be the “preferred option” for anyone**, let alone for people with complex support needs. The General Comment clearly states that article 19 “*extends the right to live independently and be included in the community to all persons with disabilities, regardless of their level of intellectual capacity, self-functioning or support requirements*”.¹² The CRPD Committee also underlines “*the right not to be confined on the basis of any kind of disability*”.¹³
- b. **It is important to acknowledge that it is not possible “to ensure safety, dignity and a non-discriminatory environment in all care settings”, nor to “support residents' autonomy, provide high-quality personalised care” in institutional setting.** Different reports and studies have shown that people are more vulnerable and exposed in institutions.¹⁴ Furthermore, people in institutions have no control over many aspects of their lives, which undermines their dignity.¹⁵ Finally, institutional environments are by nature discriminatory as they prevent children and adults from being included in the community and participating on an equal basis with others.

- ### 2. The transition from institutional to community-based services includes the closure of institutions.
- The European Council does not address this issue in its conclusions, maintaining that institutions are a relevant option in the range of services available to people. The CRPD Committee has made clear that “*deinstitutionalization also requires a*

¹¹ EU Council Conclusions, [Enhancing Community-Based Support and Care for Independent Living](#), 2017, para 9.

¹² CRPD Committee, [General Comment N°5 on article 19](#), para 21

¹³ Supra, para 91(a).

¹⁴ See WHO, [studies on Prevalence and risk of violence against children with disabilities and adults with disabilities](#); [World report on Disability](#), 2012.

Many examples of violence are provided by the EEG in its [Common European Guidelines on the Transition from Institutional to Community-based Care](#).

Look also [Inclusion Europe's project Life after Violence](#), a study on how women with intellectual disabilities cope with institutionalised violence.

¹⁵ EEG, [Common European Guidelines on the Transition from Institutional to Community-based Care](#).

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*systemic transformation, which includes the closure of institutions (...)*¹⁶ While it is obvious that the closure needs to be planned to ensure a successful transition to living in the community, the aim of closing institutions and abandoning this form of care as discriminatory and outdated should be already clearly specified in the relevant documents (policy documents, action plan etc..).

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¹⁶ CRPD Committee, [General Comment N°5 on article 19](#), adopted 31 August 2017, para 58.