



Draft General Comment on Article 19 (Living independently and being included in the community)

Joint submission by the European Disability Forum,
the European Network on Independent Living,
Inclusion Europe and Mental Health Europe

The European Disability Forum (EDF), the European Network on Independent Living (ENIL), Inclusion Europe (IE) and Mental Health Europe (MHE) welcome the draft General Comment (GC) on Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), which is key to clarifying States Parties' understanding of the right to live independently and to be included in the community and their obligations under Article 19. As is stated in the draft GC, Article 19 is 'a precondition for the implementation of the Convention across all articles' – without independent living, people with disabilities cannot access any of their other rights.

In Europe alone, more than 1,2 million people with disabilities live in institutions¹ and institutional placements are on the increase in a number of countries.² Furthermore, the Committee on the Rights of Persons with Disabilities (CRPD Committee) has raised concerns about the lack of community-based services³, the lack of progress towards deinstitutionalisation⁴ and the continued investments into institutional care, including of European Union funds.⁵ For this reason, a strong and clear GC is of crucial importance to people with disabilities, and their families, in Europe. In addition to drafting individual submissions, our organisations have decided to highlight the five key areas where the draft GC can be improved. These are: (1) more clarity is needed on alternatives to institutional care; (2) family support is key to independent living; (3) more emphasis is needed on funding and data collection; (4) deinstitutionalisation strategies must be time-bound

¹ This figure is taken from the last comprehensive report on institutionalisation of people with disabilities in the European Union (and Turkey), carried out in 2007. A more recent figure, which would include all people with disabilities, in the EU, or Europe, is not available. See: Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent, available at: https://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_2_Report_for_Web.pdf

² Directorate General for Internal Policies, Policy Department C: Citizens' Rights and Constitutional Affairs. (2016) *European Structural and Investment Funds and people with disabilities in the European Union*, p. 20, available at: [http://www.europarl.europa.eu/RegData/etudes/STUD/2016/571386/IPOL_STU\(2016\)571386_EN.pdf](http://www.europarl.europa.eu/RegData/etudes/STUD/2016/571386/IPOL_STU(2016)571386_EN.pdf).

³ *Ibid*, page 24.

⁴ *Ibid*, page 28.

⁵ *Ibid*, page 33.

and adequately resourced and (5) strengthening the focus on intersectional discrimination of persons with disabilities.

1. More clarity is needed on alternatives to institutional care

We are concerned that the draft GC **does not give States Parties clear guidance on the need to close institutions for people with disabilities and what the alternatives to institutionalisation are**. The most problematic statement is included in Paragraph 47, which gives States a green light to keep institutions open indefinitely by suggesting that the right to decide where, how and with whom to reside ‘embraces the decision to live in institutional care settings’. As noted in the draft GC (Paragraph 25), disabled people’s choices may be limited or influenced by a number of factors – including, but not limited to, lack of other options, long-term institutionalisation, lack of involvement during the process of deinstitutionalisation, lack of peer support, being under guardianship, negative attitudes and stigma. Therefore, to suggest that some people may choose institutionalisation, fails to take into account what leads to institutionalisation in the first place. We wish to remind the CRPD Committee that, as long as countries are allowed to keep institutions open, there will be incentives for people with disabilities to be institutionalised and there will be fewer resources to develop community-based services. It also puts into question the implementation of CRPD as a whole – given that the draft GC recognises independent living is a precondition for all the other rights.

Moreover, we are concerned about the **failure to distinguish well enough between institutional care settings and residential services**. Article 19(b) refers to ‘residential and other community support services’ among the range of services to be put in place by the States, on the condition that they ‘prevent isolation or segregation from the community.’ However, there are places in the draft GC where the distinction between ‘residential services’ and ‘institutional care settings’ is blurred. For example, Paragraph 28 refers to ‘residential services’ as transitional services and Paragraph 47 refers to ‘the right to choose a residential, institutional setting’. For these reasons, we are concerned about the implication that residential services are the same as institutional care services.

Recommendations:

- We suggest that **Paragraph 47** is deleted;
- We suggest that the definition of institutions in **Paragraph 15(c)** defines ‘institutional care’ as any residential care where: people with disabilities are isolated from the broader community and/or compelled to live together; they do not have sufficient control over their lives and over decisions which affect them; the requirements of the organisation itself tend to take precedence over their individualised needs.⁶ Rather

⁶ European Commission (2009) *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, p. 9, available at: <http://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=614&furtherNews=yes>

than referring only to group homes, the draft GC must make it clear that any residential setting – regardless of its size or the name - that has institutional care characteristics is in violation of Article 19. This would include different types of group homes (also called family-type homes, living centres etc.), but also individual apartments where people with disabilities have no control over their lives.

- We suggest that **Paragraph 21** is amended, in order to explain that living independently does not necessarily mean living on one's own. The following wording could be used: For some people, living independently may mean moving away from their family, for others – it may mean living with their family. The key issue is that it must be the person with disabilities who makes the decision and this must be the person's genuine choice; that is, the person's choice should not be restricted by environmental and attitudinal barriers and/or the lack of support.⁷
- We suggest that the sentence 'Residential services are services which offer ...' is deleted from **Paragraph 28**. Instead, it must be made clear that residential services may be necessary to ensure people with disabilities can live independently in the community. However, they must 'support living and inclusion in the community' and 'prevent isolation or segregation from the community', in order to be in line with Article 19. It follows that they exclude residential services with institutional care characteristics, or where the number of people does not resemble an average family size (as that would constitute 'segregation').
- We suggest adding to **Paragraph 29**: 'In addition to personal assistance, these services might include personal readers or sign language interpreters, peer to peer support from peers with disabilities'. Peer support is crucial in the context of Article 19, and can be especially beneficial for those who are leaving institutions. Peer support should be financed by the State as 'personalized service' and should include persons with disabilities as experts by experience.
- We suggest adding to **Paragraph 61**: 'When assessing persons with disabilities, the focus should be on the barriers that hinder the participation of the person with a disabilities in society, rather than on impairments. Prioritization on the basis of impairment could adversely affect persons with less visible disabilities, such as psychosocial or intellectual disabilities, who as a result may not receive the support they require.' These changes in wording are included to reflect the need to ensure that certain people with disabilities, including persons with psychosocial disabilities, are not excluded from seeking supports such as cash transfers, just because their support needs are different.
- We suggest that the sentence in **Paragraph 65** 'Misallocation of...' is revised to state: 'Misallocation of resources into institutional care services is a clear violation of Article 19.' Provided that the definition of institutions is made clear earlier in the draft GC, this will give clear

⁷ European Network on Independent Living (2017) *The Right to Live Independently and be Included in the Community – Addressing Barriers to Independent Living across the Globe*, p.12, available at: www.enil.eu

guidance to the States what type of services or settings should not be funded.

- We suggest changing **Paragraph 86**: ‘General health facilities and services (Article 25) should be accessible for persons with disabilities in their respective communities on an equal basis with others. ~~It is also important to distinguish support services as envisaged in article 19 of the Convention from health care according to article 25. The provision of nurses and physiotherapists, in hospitals as well as at home, is a part of health care and should not be seen as the fulfilment of a States parties obligation under article 19.~~ While some healthcare services, such as the provision of nurses and physiotherapists, in hospitals, as well as at home, are part of health care and should be distinguished from support services as envisaged under Article 19, other healthcare services, including community-based mental health supports (such as drop in-centres, clubhouses, mobile-crisis units providing psychosocial support), facilitate independent living and should be seen as a fulfilment of States Parties obligations under Articles 19 and 25.’ Paragraph 86, as it stands now, draws a distinct line between support services and healthcare. We do not consider the line between mental health support and support services to be as strict, when one applies the psychosocial model of mental health, which is not medicalised.
- We suggest that in **Paragraphs 33** and **51**, there is reference to ‘institutions’, rather than ‘residential institutions’ (‘the closure of ~~residential~~ institutions’ and ‘States parties should also prohibit that directors and/or managers of ~~residential~~ institutions become guardians of the residents’); this in order to avoid confusion between residential support services (referred to in Article 19(b) CRPD) and institutional care services.
- We suggest a stronger focus on employment services, among a range of services that should be put in place by States Parties. Therefore, we suggest adding to **Paragraph 7**: ‘Article 19 entails civil and political, as well as economic, social and cultural rights...’ and to **Paragraph 32**: ‘They cover a wide range of services, such as public libraries, hospitals, schools, workplaces and employment services, transport, shops, markets, museums and similar facilities and services.’

2. Family support is key to independent living

We welcome the recognition in the draft GC that the role of families of people with disabilities is not to replace the obligations of States Parties in providing for the right to live independently and being included in the community (Paragraph 53). However, we are concerned that the draft GC **does not sufficiently highlight the crucial role played by families** – immediate and extended - across the world. In many countries, families are the only support people with disabilities can rely on. Very often, families play a key role in preventing institutionalisation and in facilitating social inclusion of their family member – especially when they themselves have the necessary support. For example, families are especially important during the main transition periods in life – in childhood (such as starting school, going through puberty etc.) and from childhood to adulthood (such as going to university, finding employment,

starting a family etc.). From early on in life, families are essential in helping their family member develop independent living skills, facilitating their development and social inclusion. Therefore, we believe that families should not be considered as third parties, listed in Paragraph 50 alongside ‘service-providers, landlords or providers of general community services’, which people with disabilities deserve protection from. While recognising there is a case for more independence from families in adulthood, the current wording of the draft GC may be interpreted in a negative way towards families, enhancing some of the prejudices and discrimination they are subjected to. Instead, we would suggest a stronger focus in the draft GC on the obligation of States Parties to provide family carers with adequate support.

Recommendations:

- We suggest adding the following reference to **Paragraph 11**: Article 7 of the Convention on the Rights of the Child guarantees ‘the right to know and be cared for by his or her parents’. This right can only be truly realised if States respect their duty to provide parents of children with disabilities with support that will enable them to carry out their parental responsibilities, as enshrined in Article 18 of the same Convention.
- We suggest adding to **Paragraph 14(c)**: ‘as well as a lack of support for family carers’.
- We suggest adding a sub-paragraph to **Paragraph 40 (Core elements)**: To have family support services in place, so that families are able to support independent living and community living of their family member with disabilities.
- We suggest changing how families are referred to in **Paragraph 50** and adding a reference to guardianship among the duty to protect: ‘to prevent families and third parties’ and ‘families and third parties, such as families, service-providers (..)’. Add a specific reference to guardianship: [The duty to protect requires] a prohibition of all forms of guardianship by any party, as well as transition from substitute decision-making to supported decision-making (..)’.
- We suggest the following change to **Paragraph 53**: ~~‘Families can Many families contribute (..)~~ and ~~‘States parties should prevent and combat de facto guardianship of persons with disabilities by members of the family, as well as States parties should raise awareness and build capacity among families (...)~~’.
- We suggest a new paragraph is added in **Section C - Obligation to fulfil**’: ‘States parties should provide adequate support services to family carers, so they can in turn support their child or relative to live independently. This support includes respite care services, childcare services and other supportive parenting services. Financial support is also crucial for family carers who often live in situations of extreme poverty, without the possibility of accessing the labour market. States parties should also provide social support to families and foster the development of counselling services, circles of support and other adequate support options.’

3. More emphasis is needed on funding and data collection

We welcome the reference in Paragraph 65 of the draft GC to the misallocation of resources into institutionalised support services and the consequent recommendation to invest into independent living and community living programmes and deinstitutionalisation. **Funding is key to implementation of the right to independent living**, and reforming how services are funded, in order to implement Article 19, requires vision and commitment by States Parties. Therefore, we believe that additional paragraphs should be added in the draft GC, to be implemented both immediately and over time, in line with the principle of progressive realisation of economic, social and cultural rights. Importantly, States Parties which are donors, including the European Union, and which finance social and economic development in third countries, should not fund the renovation or building of new institutions, but invest in inclusive and accessible services.

In order to develop adequate services and to be able to allocate sufficient budgets, State Parties should have **comprehensive data about who will be using the services**. For this reason, they should collect consistent qualitative and quantitative data about people with disabilities, including those living in institutions.

Recommendations:

- We suggest adding two new sub-paragraphs to **Paragraph 40 (Core elements)**: firstly, 'To collect consistent quantitative and qualitative data on people with disabilities, including those living in institutions.';
- Secondly, 'To use any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services.'
- We suggest adding to **Paragraph 14** an additional barrier to implementation of Article 19: Misallocation of resources into institutional care services.

4. Deinstitutionalisation strategies must be time-bound and adequately resourced

We welcome various references to the need for a deinstitutionalisation strategy in the draft GC. In line with Article 4 CRPD, States Parties should take concrete action to establish **a clear, measurable and time-bound deinstitutionalisation strategy and action plans, adequately resourced** for achieving success. These strategies should include, among other: a target date for the closure of the institution(s); a measurable timetable, including progress that can be quantified; prohibition of new admissions into long-stay institutions; and a recognition of the need to develop clear standards for all community-based services, including that such standards will be developed in close collaboration with representative organisations of people with disabilities and their families. These commitments should go hand in hand with measures to increase the capacity of family and community-based care and/or support, in order to ensure that institutions do not close before appropriate services are

in place. The strategies and action plans should also be accompanied by a **budget**, setting out how the new services will be funded.⁸

The obligation to adopt and implement an effective strategy for the implementation of Article 19 is an immediate obligation, even if the full realisation of the right to live independently in the community will take time and resources to achieve. States Parties also need to demonstrate that progress has been achieved commensurate with available resources and other factors.⁹

Recommendations:

- We suggest adding to **Paragraph 14(e)**: ‘lack of deinstitutionalization strategies and plans, including a measurable timetable and adequate resources for its implementation’;
- In **Paragraph 40(d) and (e)**, we suggest clarifying what is meant by ‘basic’ personalised and mainstream services. There is a danger that States Parties will interpret ‘basic’ services in different ways, not necessarily preserving the right of people with disabilities to live in dignity and to participate in society. It is important that people with disabilities are able to receive the support services they need to live a life they want to live – and these will be different from one person to another.
- We suggest adding a new sub-paragraph to **Paragraph 40 (Core elements)**: ‘The development of a clear, measurable and time-bound strategy with allocation of adequate resources to realise Article 19 CRPD’.
- We suggest adding to **Paragraph 42**: ‘In this regard, States parties have the immediate obligation to enter into strategic planning and develop a clear, measurable and time-bound strategy with adequate resources, in close and respectful consultation with representative organisations or persons with disabilities...’.
- We suggest adding to **Paragraph 56**: ‘States parties should adopt a strategy of deinstitutionalisation, with a timetable and allocation of adequate resources.’
- We suggest adding in **Paragraph 56**: ‘It requires a systemic transformation which goes beyond the closure of institutional settings, which includes the closure of institutions, as part of a deinstitutionalisation strategy, and requires along with the establishment of a range of individualised support services as well as inclusive community services’.

⁸ 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*, p. 99, available at: <http://enil.eu/wp-content/uploads/2016/09/Guidelines-01-16-2013-printer.pdf>

⁹ United Nations Committee on Economic, Social and Cultural Rights, General Comment 3: The Nature of States Parties Obligations (art. 2, para. 1 of the Covenant), UNCESCROR, 5th Session, UN Doc E/1991/23, (1990).

5. Strengthening the focus on intersectional discrimination of persons with disabilities

The draft General Comment misses out on the chance to highlight the need to prevent and address discrimination experienced by persons with disabilities on the grounds of age, sex, sexual orientation, ethnicity, gender identity and other background.

Recommendation:

We suggest adding to **Paragraph 58**: ‘Disability support services must be available, accessible and acceptable to all persons with disabilities and be sensitive to different living and identity circumstances, such as sex, age, religion and ethnic, sexual and gender identity’. We consider gender identity and sex as separate concepts. This distinction is important for non-binary and trans people.

About our organisations

The **European Disability Forum** (EDF) is an independent NGO that represents the interests of 80 million Europeans with disabilities. EDF is a unique platform which brings together representative organisations of persons with disabilities from across Europe. EDF is run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

The **European Network on Independent Living** (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination.

Inclusion Europe, the European Association of Persons with Intellectual Disabilities and their families, represents the voice of more than seven million people. Our members include organisations of people with intellectual disabilities and their families at national, regional and local level. We fight for the recognition of equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of life. As a European association, we work in many different areas which our members have identified as important to them. The right to live independently and be included in the community has been recognised as one of the key areas to achieve inclusion and participation on an equal basis with others.

Mental Health Europe (MHE) is a European non-governmental network organisation committed to the promotion of positive mental health, the prevention of mental distress, the improvement of care, advocacy for social

inclusion and the protection of human rights for (ex)users of mental health services, their families and carers.