

Submission
to the UN Committee on the Convention on the Rights of Persons with Disabilities on
Key Issues for a General Comment on Article 19¹

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 is one of the most important areas to achieve participation on an equal basis with others.

Executive summary

In this submission, Inclusion Europe highlights some of the key issues for persons with intellectual disabilities to live independently and be included in the community. Following the provisions of the CRPD, current practices which put persons with disabilities in institutional settings must stop. Most importantly, the voice should be given back to persons by abolishing any forms of substituted decision-making regimes, in which persons are placed under guardianship and are denied to make their own decisions. A range of formal and informal support should be available in the community to ensure people can have choice and control over their lives and participate in society on an equal basis with others. Furthermore, persons with intellectual disabilities should be involved in a meaningful way in planning the transition from institutional to community-based care and in the development of support services. Mainstream support services must be accessible and available for all persons with disabilities, including those with severe intellectual disabilities, or complex needs.

Introduction

Inclusion Europe very much welcomes that the UN CRPD Committee is working on publishing a General Comment on Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (hereinafter UN CRPD, or Convention). In most European countries, persons with disabilities are living isolated in institutional settings, that violates their fundamental rights on an everyday basis. Furthermore, those living in institutional settings, do not receive adequate support, or do not have the opportunity to choose the services that they want to use in the community. Despite of the fact that 26 EU Member States and the EU itself have ratified the Convention, still a large number of persons with intellectual disabilities and complex needs are living in institutions.² Inclusion Europe fights for the full inclusion of persons with intellectual disabilities in society and we believe that the General Comment will help governments, policy makers and stakeholders to take

¹ This submission was prepared by the Working Group on Human Rights of Inclusion Europe.

² Children and adults with disabilities (including people with mental health problems). It covers the EU and Turkey from 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 (hereafter, “DECLOC Report”).

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appropriate measures in order to ensure the involvement of all persons with disabilities in the community.

Inclusion Europe's view on independent living

Article 19 of the CRPD states that

'States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community'.

Furthermore, Article 19 requires States Parties to ensure that

- a) Persons with disabilities can choose where and with whom they want to live without the obligation to live in a particular living arrangement.
- b) Persons with disabilities can access a range of in-home, residential and other community services, including personal assistance.
- c) Persons with disabilities can access mainstream community services on an equal basis with others.

While studies show, that nearly 1.2 million people are still living in institutions across Europe, for Inclusion Europe and its members, it is clear that Article 19 of the CRPD has a lot broader scope than deinstitutionalisation and it generally concerns the right to live independently and to be included in the community. Having this in mind and that deinstitutionalisation is an important prerequisite of independent living, we will focus on the process of planning transformation from institutionalised to community-based care and the development of a range of services that support people to live their lives independently.

Inclusion Europe is member in the European Expert Group on the Transition from Institution to Community-based Care, a broad coalition gathering stakeholders representing people with care or support needs including children, people with disabilities, people experiencing mental health problems, families; as well as service providers, public authorities and intergovernmental organisations.³ The Expert Group has developed the Common European Guidelines to provide practical advice about how to make a sustained transition from institutional to community-based care for those currently living in institutions and those living in the community, but without support.⁴ In this submission, we will use the terminology developed in this Guideline when we refer to institutions, deinstitutionalisation, independent living, or community-based services. This implies that we do not define institutions by their size, or the number or residents who are living there, but we consider any residential care 'an institution' where:

- Residents are isolated from the broader community and/or compelled to live together;
- Residents do not have sufficient control over their lives and over decisions which affect them;

³ See more about the European Expert Group on the Transition from Institution to Community-based Care at: <https://deinstitutionalisation.com/> (accessed 18 February 2016).

⁴ Common European Guidelines on the Transition from Institutional to Community-based Care (2012), available at: <http://deinstitutionalisationguide.eu/> (accessed 18 February 2016).

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- The requirements of the organisation tend to take precedence over the residents' individualized needs.⁵

Furthermore, in line with the guideline, we define 'independent living' as a life in which people can make choices and decisions as to where they live, with whom they live and how they organise their lives, including choosing the support and other social, or health services.⁶ Independent living requires:

- Accessibility of the built environment;
- Accessible transport;
- Availability of technical aids;
- Accessibility of information and communication;
- Access to personal assistance, as well as life and job coaching;
- Access to community-based services.

We think that Article 19 strongly interconnects with the following other provisions of the CRPD:

- Article 8 on awareness-raising that requires States Parties to adopt measures to raise awareness and combat stereotypes, prejudices and harmful practices;
- Article 9 on accessibility which requests that persons with disabilities are ensured access on an equal basis with others to enable them to live independently and participate fully in all aspects of life;
- Article 12 on equal recognition before the law, that states that persons with disabilities shall enjoy legal capacity on an equal basis with others in all aspects of life and get adequate support to make their own decisions;
- Article 14 on liberty and security of person that requests that persons with disabilities are not deprived of their liberty unlawfully or arbitrarily;
- Article 16 on freedom from exploitation, violence and abuse;
- Article 22 on respect for privacy;
- Article 23 on respect for home and the family states that children with disabilities have equal rights with respect to family life which require information, services, and support and which ensure that children are not removed from their families;
- Article 24 on education that recognises the right of all persons with disabilities to access inclusive education and lifelong learning;
- Article 25 on health that states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability;
- Article 26 on habilitation and rehabilitation that requires States Parties to take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.
- Article 27 on work and employment that guarantees that persons with disabilities have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
- Article 28 on adequate standard of living and social protection to recognise the right of persons with disabilities to an adequate standard of living for themselves and their families;
- Article 31 on statistics and data collection to inform policy makers for the development of community-based services.

⁵ Common European Guidelines on the Transition from Institutional to Community-based Care (2012), p.25.

⁶ Ibid. p.29.

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Current European situation based on research and experiences

It is particularly concerning in Europe, that European funding instruments, such as the European Structural and Investment Funds are still used to maintain institutional care instead of promoting the transition towards community-based care and to develop social and health infrastructures. While the new Structural Funds Regulations set ex-ante conditionality that include a measure to facilitate the use of EU money in line with the provisions of the UN CRPD, the European Commission should implement and monitor this provision in all EU Member States that receive European Funding.⁷ The ex-ante conditionality have a potential to ensure that no public money is used to keep persons with disabilities in institutions, instead of investing in frameworks and services that facilitate their participation in society.

Likewise, the European Union must find ways to ensure that the transpositions of its Directives in their Member States are respectful with Article 19 CRPD. For example, if Member States transpose the Public Procurement Directive incorrectly, this might result in using forms of social services, which promote institutionalisation.

Living in an institution is a human rights violation, as institutions deny the fundamental rights of people on citizenship, personal control, personal privacy, decision-making and inclusion. This includes possible physical and pharmacological restraints, psychiatric interventions, involuntary treatments and measures, such as sterilization, forced contraception, or abortion. Women with disabilities are particularly at risk due to multiple discrimination. While severe human rights violations can happen in community-based living too, we would like to note that the prevalence is a lot higher in institutional settings where people face a more vulnerable situation.⁸

Since 2008, the financial crisis and recession hit European countries and impacted economies by growing deficits, rising unemployment, and less public income. As a result of that, EU Member States took austerity measures to stimulate economic growth by reducing public spending. Unfortunately, those austerity measures had a disproportionately negative effect on benefits, provisions and support systems for persons with disabilities.⁹ Austerity measures have reduced the budgets of local and regional authorities with direct consequences on the availability of social services and benefits for individuals.¹⁰ It is important to note that there are far less budget cuts on institutional largescale provisions and support systems for people with disabilities such as residential institutions, or special schools. For instance, in the UK the Independent Living Fund was abolished and taxes were raised that affected people with disabilities living independently, whereas budgets and admissions in more costly residential institutions and assessment centers are suspected to grow.¹¹ In line with Article 19 of the CRPD, segregating measures must be tackled and investment should only target forms of care that contribute to the inclusion of all persons with disabilities in the community. It is especially concerning, that persons with complex needs and elder people with intellectual disabilities are considered unable to live outside of long-term institutional care.

⁷ European Disability Forum, Alternative Report to the UN Committee on the Rights of Persons with Disabilities (2015)

⁸ UNHCHR, Thematic study on the issue of violence against women and girls and disability, §15.

⁹ <http://www.enil.eu/category/news/austerity-measures/>

¹⁰ Opinion of the European Economic and Social Committee on Long Term social care and deinstitutionalization (27/05/2015) <http://www.eesc.europa.eu/?i=portal.en.soc-opinions.33311>

¹¹ See more at: <http://dpac.uk.net/tag/bedroom-tax/> or <https://www.mencap.org.uk/blog/update-winterbourne-view>.

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Recommendations

Inclusion Europe would like to see clear statements about the right to live independently and be included in the community in the General Comment on Article 19. We would appreciate if the Committee considered the following recommendations to be included in the General Comment:

To sub-paragraph a) of Article 19 related to **'Choice'**:

- States Parties must carry out legal reform to abolish any form of substituted decision-making and ensure that all persons with disabilities can enjoy supported decision-making;
- States Parties must carry out legal and funding reforms to eradicate obstacles to the deinstitutionalisation process;
- People with disabilities should be actively involved in planning, implementing and monitoring deinstitutionalisation projects and in the planning of community-based services;
- People should be able to choose and later change their residency after they moved out of the institution and should be provided with support and alternatives;
- It is very important to ensure the frequent monitoring of smaller residential settings, including group homes to avoid the reproduction of institutional culture and human rights violations in places where persons with disabilities live;
- The will and preferences of all persons with disabilities must be respected when making decisions about where, with whom and how they want to live, including persons with severe intellectual disabilities, or complex needs, and elder people with disabilities.

To sub-paragraph b) of Article 19 related to **'Support'**:

- The spending of public funding should be rigorously monitored to ensure it is only used to facilitate community-based care. Sanctions should be introduced to withdraw or suspend the payments if projects are breaching the provisions of the UN CRPD, with special regard to independent living and accessibility;
- Persons with disabilities should be involved in the planning of new social support services during the process of the deinstitutionalisation, including person-centred planning, direct payment, personal budget, development of personal assistant network, coordination of support, or the use of informal support system. Inclusive, informal support should be recognised as important as formal support, and flexibility should be possible in how to use personal budgets;
- The important role of peer-support in the transition period from institutionalised to community-based living and during independent living should be recognised and financially supported;
- Accessible victim support services should be available and affordable for persons with disabilities, who are moving out of the institutions to deal with trauma caused by institutionalisation;
- We know from experience that in some countries the staff who worked as caregivers will continue to work in the new residential facilities as support persons. It is essential that they undergo thorough training to understand the human rights model of disability and have a great understanding of the provisions of the UN CRPD. Such trainings and supervision should be provided at initial stages and then repeatedly to anyone who works as support person for persons with disabilities in residential facilities or with services.

To sub-paragraph c) of Article 19 on '**Access to mainstream services and infrastructure**':

- Accessibility must be guaranteed in the community, regarding the built environment, transport, technical aids, information and communication by considering the accessibility needs of persons with intellectual disabilities and complex needs, with special regard to easy-to-read information;
- Mainstream services should be available for all persons with disabilities and there should be coordination between specialised and mainstream services;
- In many countries the public procurement system should be revised to ensure involving the interest of persons with disabilities;
- Adequate housing, education and employment opportunities should be available to all persons with disabilities in the community to facilitate autonomy and independence. Without stable income inclusion is not possible as people will be unable to have real choices;
- Wide range awareness raising in the community is essential to fight against existing prejudices towards persons with disabilities. Persons with intellectual disabilities are often seen as 'children', or 'incapable' to make their own choices and decisions about their life, including private life or body integrity.

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