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Deinstitutionalisation of persons with disabilities

Report[1]
Committee on Social Affairs, Health and Sustainable Development
Rapporteur: Ms Reina de BRUIJN-WEZEMAN, Netherlands, Alliance of Liberals and Democrats for Europe

Summary

Placement in institutions affects the lives of more than a million Europeans. It is a pervasive violation of the right as laid down in Article 19 of United Nations Convention on the Rights of Persons with Disabilities (CRPD), which calls for firm commitment to deinstitutionalisation. Community-based support services and supportive living arrangements provide a better quality of life for persons with disabilities, as well as being more human rights compliant and cost-effective. A systemic approach to the process of deinstitutionalisation is needed in order to achieve good results.

The Parliamentary Assembly should thus recommend that Council of Europe member States develop, in co-operation with organisations of persons with disabilities, adequately funded, human-rights compliant strategies for deinstitutionalisation with clear time frames and benchmarks with a view to a genuine transition to independent living for persons with disabilities.

The Assembly should also call on parliaments to take the necessary steps to progressively repeal legislation authorising institutionalisation of persons with disabilities, as well as mental health legislation allowing for treatment without consent and detention based on impairment, with a view to ending coercion in mental health.

Finally, the Assembly should call on all stakeholders, including member States governments and parliaments, and the Committee of Ministers of the Council of Europe, not to support or endorse draft legal texts which would make successful and meaningful deinstitutionalisation more difficult, and which go against the spirit and the letter of the CRPD – such as the draft Additional Protocol to the Oviedo Convention concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services.

1. Reference to committee: Doc. 15106, Reference 4517 of 26 June 2020.

Contents **Page**

A. Draft resolution[2]

1. All human beings are born free and equal in dignity and rights. A precondition for anyone to enjoy their rights and fundamental freedoms is that they live in and are included in the community. For a long time however, persons with disabilities were viewed only as passive objects of care. A growing understanding of disability and movements pushing for equal rights have enabled a shift to a human rights-based approach in which society must accommodate human diversity and enable persons with disabilities to be an active part of it.

2. The rights of persons with disabilities to equality and inclusion are now recognised at the international level, in particular thanks to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, and ratified by all Council of Europe member States but one. This Convention represented an important milestone in the shift to a human rights-based approach to disability. Under the CRPD, State parties are obliged to take effective and appropriate measures with a view to achieving full inclusion and participation of persons with disabilities in the community.

3. The United Nations Committee on the Rights of Persons with Disabilities is currently working on "Guidelines on living independently and being included in the community: deinstitutionalization of persons with disabilities, including in emergency situations" with the support of the Global Coalition on Deinstitutionalization composed of representative organisations of persons with disabilities and civil society organisations advocating for the rights of persons with disabilities. The purpose of the guidelines is to supplement the Committee's General Comment No. 5 by providing concrete guidance to State parties and other actors on how to carry out deinstitutionalisation processes, including in emergency situations, in line with the CRPD. These guidelines, once adopted, should be implemented by Council of Europe member States as a matter of urgency.

4. Placement in institutions affects the lives of more than a million Europeans and is a pervasive violation of the right as laid down in Article 19 of the CRPD, which calls for firm commitment to deinstitutionalisation. Many are isolated in their own communities due to inaccessibility of facilities such as schools, health care and transportation, as well as lack of community-based support schemes. Community-based support services and supportive living arrangements provide a better quality of life for persons with disabilities, as well as being more human rights compliant and cost-effective.

5. However, persons with disabilities are often also presumed to be unable to live independently. This is rooted in widespread misconceptions, including that persons with disabilities lack the ability to make sound decisions for themselves and that they need "specialised care" provided for in institutions. In many cases, cultural and religious beliefs may also feed such stigma, as well as the historical influence of the eugenic movement. For too long, these arguments have been used to wrongfully deprive persons with disabilities of their liberty and segregate them from the rest of the community, by placing them in institutions. Measures must be taken to combat this culture of institutionalisation resulting in social isolation and segregation of persons with disabilities, including at home or in the family, preventing them from interacting in society and being included in the community.

6. A systemic approach to the process of deinstitutionalisation is needed in order to achieve good results, namely a genuine and successful transition to independent living in accordance with Article 19 of the CRPD. Concrete action must be taken towards ending the institutionalisation practice and ensuring that these persons and their families are met with appropriate support in the process of reintegrating into society.

7. The Parliamentary Assembly recommends that Council of Europe member States, in line with their obligations under international law, and inspired by the work of the United Nations Committee on the Rights of Persons with Disabilities:

> 7.1. develop, in co-operation with organisations of persons with disabilities, adequately funded, human-rights compliant strategies for deinstitutionalisation with clear time frames and benchmarks with a view to a genuine transition to independent living for persons with disabilities in accordance with Article 19 of the CRPD, in which:
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> > 7.1.1. the rights of the user groups are respected, the risk of harm is minimised, and positive outcomes for the persons concerned are ensured;

2. Draft resolution adopted unanimously by the committee on 17 March 2022.

7.1.2. the transformation of residential institutional services is only one element of a wider change in areas such as health care, rehabilitation, support services, education and employment, and in which the societal perception of disability and the social determinants of health, as well as gender and other stereotypes are adequately addressed;

7.1.3. institutions run by non-State actors are fully included;

7.1.4. independent mechanisms are empowered to properly monitor the process of deinstitutionalisation and contribute to its success;

7.2. make the child-centred, human-rights compliant deinstitutionalisation of children with disabilities a top priority.

8. The Assembly calls on parliaments to take the necessary steps to progressively repeal legislation authorising institutionalisation of persons with disabilities, as well as mental health legislation allowing for treatment without consent and detention based on impairment, with a view to ending coercion in mental health.

9. The Assembly welcomes the active role the Council of Europe Development Bank (CEB) has played in funding and underwriting the restructuring of institutional service provision and the building up of more inclusive, community-based services. It calls on the CEB, the World Bank and other social development funds such as the European Structural and Investment Funds to support member States to allocate adequate resources for support services that enable persons with disabilities to live in their communities, such as the strengthening, creating, and maintaining of community-based services. It is important that funds are directed towards sustaining systemic reforms that enable member States to fulfil their obligations under international law. In no way should funds be given to projects that involve maintaining, refurbishing or building new institutions, unless this is part of a clearly delineated transitional phase during which community-based services exist alongside institutions before these can be closed.

10. The Assembly welcomes the QualityRights initiative of the World Health Organization, which provides essential guidance on the implementation of mental health services and on community-based responses from a human rights perspective and offers a path towards ending institutionalisation and involuntary hospitalisation and treatment of persons with disabilities.

11. Finally, in line with its unanimously adopted Resolution 2291 (2019) and Recommendation 2158 (2019) “Ending coercion in mental health: the need for a human rights-based approach”, the Assembly calls on all stakeholders, including Council of Europe member States governments and parliaments, not to support or endorse draft legal texts which would make successful and meaningful deinstitutionalisation more difficult, and which go against the spirit and the letter of the CRPD – such as the draft Additional Protocol to the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, Oviedo Convention) concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services. Instead, it calls on them to embrace and apply the paradigm shift of the CRPD and fully guarantee the fundamental human rights of all persons with disabilities.

B. Draft recommendation[3]

1. The Parliamentary Assembly refers to its Resolution (2022) … "Deinstitutionalisation of persons with disabilities", its Resolution 2291 (2019) and Recommendation 2158 (2019) "Ending coercion in mental health: the need for a human rights-based approach", and its Recommendation 2091 (2016) "The case against a Council of Europe legal instrument on involuntary measures in psychiatry".

2. The Assembly reiterates the urgent need for the Council of Europe, as the leading regional human rights organisation, to fully integrate the paradigm shift initiated by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) into its work. It thus recommends that the Committee of Ministers:

2.1. support member States in their development, in co-operation with organisations of persons with disabilities, of adequately funded, human-rights compliant strategies for deinstitutionalisation with clear time frames and benchmarks with a view to a genuine transition to independent living for persons with disabilities in accordance with Article 19 of the CRPD;

2.2. prioritise support to member States to immediately start transitioning to the abolition of coercive practices in mental health settings, and to child-centred, human-rights compliant deinstitutionalisation of children with disabilities;

2.3. in line with the unanimously adopted Recommendation 2158 (2019), refrain from endorsing or adopting draft legal texts which would make successful and meaningful deinstitutionalisation, as well as the abolition of coercive practices in mental health settings more difficult, and which go against the spirit and the letter of the CRPD – such as the draft Additional Protocol to the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, Oviedo Convention) concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services.

3. Draft recommendation adopted unanimously by the committee on 17 March 2022.

C. Explanatory memorandum by Ms Reina de Bruijn-Wezeman, rapporteur

1. Introduction

1. On 20 May 2020, the Committee on Social Affairs, Health and Sustainable Development tabled a motion for a resolution on "Deinstitutionalisation of persons with disabilities".[4] Proper organisation and appropriate support in the process of deinstitutionalisation is vital in order to uphold the fundamental rights of persons with disabilities. Thus, the motion calls on the Parliamentary Assembly to study the process of deinstitutionalisation in line with relevant legal standards and calls on member States to ensure that autonomy, freedom of choice and full and effective participation in the life of society and the community are guaranteed to persons with disabilities. The motion was referred to our committee for report and I was appointed rapporteur on 6 July 2020.

2. On 16 March 2021, the Committee held a public hearing[5] composed of three sessions with the participation of:

– Ms Dunja Mijatović, Council of Europe Commissioner for Human Rights

– Mr Gerard Quinn, United Nations Special Rapporteur on the rights of persons with disabilities

– Mr Andreas Accardo, Head of Unit, Institutional Co-operation and Networks, European Union Agency for Fundamental Rights (FRA)

– Mr Luk Zelderloo, Secretary General, European Association of Service providers for Persons with Disabilities (EASPD)

– Ms Ritva Halila (Finland), Chairperson of the Council of Europe Committee on Bioethics (DH-BIO)

– Mr John Patrick Clarke, Vice President, European Disability Forum (EDF)

– Ms Jolijn Santegoeds, Board member, European Network for (ex)-Users and Survivors of Psychiatry (ENUSP)

– Ms Michelle Funk, Head of Unit, Policy, Law and Human Rights, Department of Mental Health & Substance Use, World Health Organization (WHO)

– Ms Stephanie Wooley, ENUSP

– Mr José María Solé Chavero, Board member, EASPD.

3. I would like to thank all colleagues and experts for the fruitful discussions and their valuable input, which I have incorporated into the text. I have further been informed by the process[6] which has developed in parallel to this report at the level of the United Nations (UN). This process is to lead to the adoption, by the end of 2022, of "Guidelines on deinstitutionalization of persons with disabilities, including in emergency situations" by the UN Committee on the Rights of Persons with Disabilities. The first annotated outline of the proposed guidelines, on living independently and being included in the community, were published end 2021, following a bottom-up process of seven regional consultations organised by the Committee's Working Group on Deinstitutionalization with the support of the Global Coalition on Deinstitutionalization composed of representative organisations of persons with disabilities and civil society organisations advocating for the rights of persons with disabilities.

4. Deinstitutionalisation is a key steppingstone to ending coercion in mental health. This report is thus also a follow-up to my report on "Ending coercion in mental health: the need for a human rights-based approach"[7], which led to the unanimous adoption of Resolution 2291 (2019) and Recommendation 2158 (2019), and which were also supported by the Council of Europe Commissioner for Human Rights.

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4. Motion for a resolution, Doc 15106, "Deinstitutionalisation of persons with disabilities".
5. "Would you call this home?", hearing on the deinstitutionalisation of people with disabilities", Minutes (session 2 devoted to the proposed draft Additional Protocol), March 2021.
6. The process had its origins in the human rights violations reported to the UN Committee on the Rights of Persons with Disabilities during the Covid-19 pandemic, "resulting in further isolation, marginalization, exclusion, and institutionalization" of persons with disabilities. See the draft outline and the annotated outline available here: www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx.
7. See Doc. 14895, report of the Committee on Social Affairs, Health and Sustainable Development and Doc. 14910, opinion of the Committee on Equality and Non-Discrimination.

5. The Council of Europe Committee on Bioethics (DH-BIO) took the procedural decision on 2 November 2021 to present the draft Additional Protocol to the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No. 164, Oviedo Convention) concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services to the Committee of Ministers with a view to a decision, despite me recalling the widespread opposition expressed with regard to the draft Additional Protocol at that meeting. The representatives of the EDF and of the EASPD also reiterated their position against the draft Additional Protocol at the meeting.

6. While this report is not the place to analyse the draft Additional Protocol in any depth, I believe it is my duty to recall that this Protocol, in the eyes of the Assembly,[8] the Council of Europe Commissioner for Human Rights,[9] the responsible UN mechanisms and bodies,[10] and representative organisations of persons with disabilities and civil society organisations advocating for the rights of persons with disabilities,[11] goes in the wrong direction. Its adoption would make the deinstitutionalisation of persons in mental health care services more difficult. This is why my report will touch upon this issue, and I will include a reference to the Assembly's position thereon in the draft recommendation.

7. The annotated outline of the guidelines on "Living independently and being included in the community" proposed by the UN Committee on the rights of persons with disabilities calls for both guardianship and institutionalisation to be recognised as forms of discrimination based on disability.[12] I briefly touched on the issue of guardianship in my last report on "Ending coercion in mental health: the need for a human rights-based approach", but did not go into detail, since this issue would merit its own report. I will concentrate on the issue of deinstitutionalisation in this report.

2. A human rights-based approach to disability

8. All human beings are born free and equal in dignity and rights. A precondition for anyone to enjoy their rights and fundamental freedoms is that they live in and are included in the community. For a long time however, persons with disabilities were viewed only as passive objects of care. A growing understanding of disability and movements pushing for equal rights have enabled a shift to a human rights-based approach in which society must accommodate human diversity and enable persons with disabilities to be an active part of it. Such an approach turns the focus away from a person's impairment and identifies social and attitudinal barriers that prevent people with disabilities from enjoying their fundamental rights.

9. The rights of persons with disabilities to equality and inclusion are now recognised at the international level, in particular thanks to the UN Convention on the Rights of Persons with Disabilities (CRPD). The adoption of this Convention in 2006 represented a milestone in recognising the fundamental rights of persons with disabilities and has enabled a shift to a social, and human rights-based approach on this issue. Under the CRPD, State parties are obliged to take effective and appropriate measures with a view to achieving full inclusion and participation of persons with disabilities in the community.

10. Persons with disabilities are often presumed to be unable to live independently. This is rooted in widespread misconceptions, including that persons with disabilities lack the ability to make sound decisions for themselves and that they need "specialised care" provided for in institutions. In many cases, cultural and religious beliefs may also feed such stigma, as well as the historical influence of the eugenic movement.[13] For

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8. See also Recommendation 2091 (2016) "The case against a Council of Europe legal instrument on involuntary measures in psychiatry".
9. Reform of mental health services: an urgent need and a human rights imperative – Human Rights Comments – Commissioner for Human Rights (coe.int).
10. Open letter to the Secretary General of the Council of Europe, the Committee of Ministers of the Council of Europe, the Committee on Bioethics of the Council of Europe, the Steering Committee for Human Rights, the Commissioner for Human Rights, the Parliamentary Assembly of the Council of Europe and other organizations and entities of the Council of Europe. Adopted by the [UN] Committee on the Rights of Persons with Disabilities and the Special Rapporteur on the Rights of Persons with Disabilities (June 2021).
11. Mental Health Europe (September 2021): MHE welcomes decision of the European Court of Human Rights on the Oviedo Convention and urges States to #WithdrawOviedo – Mental Health Europe, #WithdrawOviedo: Ending coercion in mental healthcare.
12. Annotated outline of the proposed CRPD guidelines on living independently and being included in the community, section B, paragraph II.8.5.
13. www.europeantimes.news/2021/10/the-european-convention-on-human-rights-designed-to-authorize-eugenics-caused-legislation/.

too long, these arguments have been used to wrongfully deprive persons with disabilities of their liberty and segregate them from the rest of the community, by placing them in institutions. Persons with psycho-social disabilities and/or mental health problems have been particularly badly affected.

11. Following the adoption of the CRPD, which since 2018 is finally ratified by all Council of Europe member States, States must ensure the equal right of persons with disabilities to live in the community, with choices equal to others. This involves ending their harmful practice of placing persons with disabilities in institutions, which is a violation of international human rights, and instead enable their full inclusion and participation in the community.

12. Placement in institutions affects the lives of more than a million Europeans[14] and is a pervasive violation of the right as laid down in Article 19 of CRPD, which calls for firm commitment to deinstitutionalisation. Many are isolated in their own communities due to inaccessibility of facilities such as schools, health care and transportation, as well as lack of community-based support schemes.

13. However, a key challenge is to ensure that the process of deinstitutionalisation itself is carried out in a way that is human rights compliant. This includes respecting the rights of the user groups, minimising risk of harm and ensuring positive outcomes for the persons concerned. Ensuring that there are proper community-based care services available for persons with disabilities, and thus a smooth transition, is pivotal for a successful deinstitutionalisation process. The aim is not mere deinstitutionalisation of the persons with disabilities, but genuine transition to independent living in accordance with Article 19 of the CRPD, General comment No. 5 (2017) of the UN Committee on the Rights of Persons with Disabilities on living independently and being included in the community,[15] and the upcoming Guidelines on deinstitutionalization of persons with disabilities, including in emergency situations.

3. Institutionalisation of persons with disabilities: lack of alternatives that lead to human rights violations

14. Institutions are defined by the European Expert Group on the Transition from Institutional to Community-based Care as any residential care 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; and the requirements of the organisation itself tend to take precedence over the residents' individual needs.[16]

15. Institutions may differ from one context to another. Yet, there are certain defining elements which characterises them and includes as follows: lack of control over day-to-day decisions; rigidity of routine irrespective of personal preferences or needs; identical activities in the same place for a group of persons under a central authority; a paternalistic approach in the provision of services; supervision of living arrangements without consent; obligatory sharing of assistants with others and no or limited influence over whom to accept assistance from; lack of choice over whom to live with and disproportion in the number of persons with disabilities living in the same environment.[17][18]

16. Institutional care provides a poorer outcome in terms of quality of life. The reason is that it is more challenging to ensure the person-centred approach and appropriate support needed in order to provide full inclusion of persons with disabilities.[19] Small environments, such as group homes, are not much better if the overall control remains with supervisors. For policy makers to have a thorough understanding of what it means to live in an institutional setting, it is important to avoid the introduction of newer forms of institutions that simply conceal the institutional reality by introducing superficial changes.

17. According to the Office of the United Nations High Commissioner for Human Rights (OHCHR), living arrangements should be assessed taking into account issues such as the choice of housemates, who decides when residents can enter or exit, who is allowed to enter a person's home, who decides the schedule of daily

14. Issue paper published by the Council of Europe Commissioner for Human Rights (2013): "The right of people with disabilities to live independently and be included in the community", page 5.
15. https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en.
16. Common European Guidelines on the Transition from Institutional to Community-based Care.
17. Report of the OHCHR (2014): "Thematic study on the right of persons with disabilities to live independently and be included in the community", A/HRC/28/37, page 7.
18. Report of the Special Rapporteur on the rights of persons with disabilities: "Rights of persons with disabilities" (2019), A/HRC/40/54, pages 5-6.
19. European Commission: "Guidance on Deinstitutionalisation".

activities, who decides what food is eaten and what is bought and who pays the expenses. Regardless of size and name, living arrangements that control those choices are inconsistent with the CRPD and constitute a deprivation of liberty.[20]

18. Persons with disabilities are some of the most vulnerable individuals in our society. Institutionalisation in and of itself should be recognised as a human rights violation.[21] But being placed in institutions further puts persons with disabilities at risk of systemic and individual human rights violations and many experience physical, mental, and sexual violence. They are also often subjected to neglect and severe forms of restraint and/or "therapy", including forced medication, prolonged isolation, and electroshocks.[22]

19. The interplay between disability and other identity traits, such as gender, age or belonging to a minority, produces further inequalities, as pointed out by the United Nations Special Rapporteur on the rights of persons with disabilities. For instance, women with disabilities are sometimes viewed as "burdens" and are at higher risk of being placed in institutions based on stereotypes and misconceptions that they are unable to fulfil the traditional role of mother and caregiver. Studies have also shown that minority populations are over-represented in psychiatric facilities.[23]

20. Children are particularly vulnerable to institutionalisation on the basis of impairment. In many cases, children are forcefully removed from their families and placed in institutions because of impairment. For example, in some countries, deaf and blind children are institutionalised for no other reason than "facilitating" access to education. Others are placed in institutions for the purpose of "treatment" and "rehabilitation". In a resolution adopted on 18 December 2019 on the rights of the child, the United Nations General Assembly stressed that no child or family should be forced to give up family connections in order to escape poverty, or to receive care, comprehensive, timely and quality health services, or education.[24]

21. Persons with disabilities who are placed in institutions are deprived of their liberty for long periods of time, and in some cases even for a lifetime. Most of them are institutionalised against their will or without their free and informed consent. Such practice along with the poor treatment that they receive in institutions affect their most fundamental rights, including the right to integrity and the right to liberty.

22. For residents in institutions, neglect and inadequate health care is too often a reality. The Covid-19 pandemic has highlighted the way that vulnerable persons are disproportionately affected in times of crisis. For persons with disabilities living in institutions this is shown in the way in which they are exposed to additional serious health risks in such settings, in addition to having particular, often unmet, support needs in this challenging period. Thus, in a statement on the impact of Covid-19 on persons with disabilities, the Commissioner for Human Rights of the Council of Europe called on member States to reduce the risks of Covid-19 for persons with disabilities, including by moving those who live in institutions out of these as much as possible.[25]

4. The right to live independently and be included in the community

23. The right to live independently and be included in the community is widely recognised in international and regional instruments as one of the most fundamental rights and is inevitably linked to the enjoyment of other human rights, including the right to personal liberty and security, freedom from ill-treatment or punishment, the right to integrity, the right to private and family life, the right to privacy, the right to health, the right to freedom of movement, and the right to freedom of assembly, association and expression.

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20. Report of the OHCHR (2014), A/HRC/28/37, op. cit., page 7.
21. Annotated outline of the proposed CRPD guidelines, op. cit., Section A, paragraph III.1.
22. European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), Public statement concerning Bulgaria, 4 November 2021.
23. Report of the Special Rapporteur on the rights of persons with disabilities, A/HRC/40/54, op. cit., page 9.
R. Gajwani and others, "Ethnicity and detention: are Black and minority ethnic (BME) groups disproportionately detained under the Mental Health Act 2007?", *Social Psychiatry and psychiatric Epidemiology*, vol. 51, No. 5 (2016), pp. 703-711.
24. United Nations General Assembly Resolution 74/133 adopted on 18 December 2019, Article 28.
25. Statement by the Council of Europe Commissioner for Human Rights, 2 April 2020: "Persons with disabilities must not be left behind in the response to the COVID-19 pandemic".

24. The most developed articulation for the right to live in the community of persons with disabilities is found in the UN Convention on the Rights of Persons with Disabilities. As laid down in Article 19, persons with disabilities, without exception, have the right to live independently and receive appropriate community-based services. This applies no matter how intensive the support needs. An important aspect of quality service provision is that persons with disabilities should be supported within their community.[26]

25. The overarching objective of Article 19 is full inclusion and participation in society. Its three key elements are: choice (sub-paragraph a); individualised supports that promote inclusion and prevent isolation (sub-paragraph b); and making services for the general public accessible to persons with disabilities (sub-paragraph c).

26. Article 19 is closely connected to provisions in other human rights treaties, including the International Covenant on Civil and Political Rights,[27] the International Covenant on Economic, Social and Cultural Rights[28] and the Convention on the Rights of the Child.[29] The right to live independently and to be included in the community is also recognised in regional instruments such as the Council of Europe European Social Charter (ETS No. 35)[30] and has strong connections to the right to liberty and security and the right to a private and family life as laid down in the European Convention on Human Rights (ETS No. 5).[31]

27. State parties to the CRPD have an obligation to comply with its Article 19 by putting an end to segregation of persons with disabilities and thus enabling them to have control over their lives. The Convention contains the most recent norms relating to the right to live independently and be included in the community. It should thus be considered the minimum standards when developing future human rights instruments at global and regional levels.

28. Fulfilment of the obligations under Article 19 of the Convention is a precondition for the implementation of the Convention across all articles - without independent living, persons with disabilities cannot access any of their other rights. For reasons mentioned above regarding the discrimination of persons with disabilities and their lack of ability to fully take part in their communities, and as a result of the adoption of the CPRD and other human rights instruments, institutionalisation is increasingly acknowledged as poor policy and a violation of human rights.

29. For cases concerning children, the best interests of the child, as laid down in Article 3 of the UN Convention on the Rights of the Child (CRC), must always be assessed and determined. State parties to the Convention also have an obligation to ensure that the child is heard and that his or her views are given due weight in accordance with the age and maturity of the child when it comes to living arrangements and the kind of support they need, in line with Article 12 of the CRC. The inclusion of children with disabilities in society is at the core of both Article 23 of the CRC and Article 7 of the CRPD.

30. Many persons with disabilities are wrongfully deprived of their legal capacity, making it difficult to contest the treatment they receive and their deprivation of liberty, as well as their living arrangements. Choice, the key element sub-paragraph a of Article 19, is upheld by recognising the legal capacity of the individual to make their own choices and have them respected, in line with Article 12 of the CRPD. Member States must therefore review their legislative and administrative measures, including guardianship and substitute decision-making, to ensure that persons with disabilities are able to exercise choice and control over their lives on an equal basis with others, with access to supported decision making when needed.[32]

5. Commitment to deinstitutionalisation in the Council of Europe member States

31. Existing studies show significant differences in the availability of community services across Europe to persons with disabilities, the provision of individualised support and the opportunities to choose services.

32. Unfortunately, several Council of Europe member States still hesitate to close down residential institutions and develop community-based services for persons with disabilities, arguing that institutional care is necessary for persons with multiple or “profound” disabilities, or for persons of “unsound mind” (as the

26. www.easpd.eu/en/content/europe-needs-better-monitor-quality-care-services-and-support-transition-community-living.
27. See for instance the International Covenant on Civil and Political Rights, Articles 9, 12, 16 and 17.
28. See for instance the International Covenant on Economic, Social and Cultural Rights, Articles 11 and 12.
29. See for instance the United Nations Convention on the Rights of the Child, Articles 2, 9, 16, 23, 25 and 27.
30. See the European Social Charter, Article 15.
31. See the European Convention on Human Rights, Articles 5 and 8.
32. Report of the OHCHR (2014), A/HRC/28/37, op. cit., page 17.

European Convention on Human Rights calls them) on the spurious grounds that they may pose a danger to public safety or that their own interests may necessitate their detention in an institution. It is also worrying that in a number of countries in the European region, institutionalisation is in fact increasing,[33] in spite of international obligations and long-standing calls from international human-rights bodies to end such practices.

33. Institutionalisation of persons with disabilities is especially prevalent in Eastern European countries. More should be done to support these member States in ending this practice and provide proper care and community-based services to persons with disabilities. For this, the Council of Europe Development Bank (CEB) has played an active role in funding and underwriting the restructuring of institutional service provision and the building up of more inclusive, community-based services.

34. During the 2021 autumn part-session of the Assembly, I had the pleasure of meeting Mr Pavlo Sushko (Ukraine, EC/DA) who wanted to tell me more about the deinstitutionalisation process in Ukraine. Ukraine unfortunately has one of the highest rates of institutionalised children in the world and the highest rate in Europe.[34] Following long standing calls from international human rights bodies and civil society, the Government of Ukraine has embarked on a process of reform and committed to transform its national care system through the adopted National Strategy on Reform of the Institutional Care System (2017-2026). I share Mr Sushko's concern over the fact that institutions are shut down without any proper community-based alternatives.

35. Member States must allocate adequate resources for support services that enable persons with disabilities to live in their communities. This requires amongst other things a redistribution of public funds from institutions to the strengthening, creating, and maintaining community-based services. Strong political engagement and commitment is needed on this matter, as pointed out during our hearing on 16 March 2021. This may require targeted investments, in particular in the initial phase, effective partnerships and prioritisation. The CEB, the World Bank and other social development funds such as the European Structural and Investment Funds can support such efforts. It is important however that funds are directed towards sustaining systemic reforms that enable member States to fulfil their obligations under international law. In no way should funds be given to projects that involve maintaining, refurbishing or building new institutions.

36. As illustrated in the deinstitutionalisation process of Ukraine, and as pointed out by the OHCHR, there may be a need for community-based services to exist alongside institutions during the transitional phase and this would thus need double funding.[35] Studies have demonstrated, however, that after the initial phase, community-based services are not necessarily more expensive than institutional services. In a report by the WHO and the World Bank, the transition from institutional care to community-based services is in fact found to be more cost-effective and to provide a higher quality of services.[36] Furthermore, the comparison of the costs of institutional care and those of community-based services should also take into account the long-term impact of deinstitutionalisation, including the fiscal implications of a higher number of persons with disabilities being part of the workforce and household income.

6. Ensuring a genuine transition to independent living and inclusion in the community

37. The United Nations Committee on the Rights of Persons with Disabilities, the WHO, persons with disabilities themselves and other human rights activists and stakeholders have repeatedly urged States to adopt adequately funded strategies for deinstitutionalisation with clear time frames and benchmarks, in co-operation with organisations of persons with disabilities. They should be actively involved in the implementation of Article 19, including in the development and implementation of legislation, policies and programmes, as stipulated in Article 4, paragraph 3 of the CRPD.

38. A systemic approach to the process of deinstitutionalisation is needed in order to achieve good results. Disability has been linked to homelessness and poverty in several studies.[37] If member States fail to secure income and housing assistance to persons with disabilities, they will have increased risk of ending up

33. Directorate General for Internal Policies of the European Parliament, Policy Department C: Citizens' Rights and Constitutional Affairs. (2016) European Structural and Investment Funds and people with disabilities in the European Union, page 20.
34. www.unicef.org/ukraine/en/press-releases/unicef-urges-government-ukraine-continue-deinstitutionalization-reform-line-approved.
35. Report of the OHCHR (2014), A/HRC/28/37, op. cit., page 9.
36. WHO and World Bank, World Report (2011) page 149 and Issue paper published by the Council of Europe Commissioner for Human Rights (2013), op. cit., page 32.
37. C. Mercier and S. Picard "Intellectual disability and homelessness", *Journal of Intellectual Disability Research*, vol. 55 (2011), pages 441-449.

involuntary committed or institutionalised. Following this, the transformation of residential institutional services is only one element of a wider change in areas such as health care, rehabilitation, support services, education and employment, as well as in the societal perception of disability and the social determinants of health.[38] Simply relocating individuals into smaller institutions, group homes or different congregated settings is insufficient and is not in accordance with international legal standards.

39. Support services are an indispensable element of the transition from institutions to community living and are essential to enable persons with disabilities to live independently and be included in the community. Article 19 b of the CRPD includes a reference to a range of services that can involve different providers. Services provided should be built around concepts of person-centeredness and individualisation, in order for them to be sensitive to the person's needs and wishes. Services must be flexible enough to support the individual's need and not the other way around. Universal design should be included in the service design and innovation in service provision should be fostered through structural involvement of persons with disabilities and their families.[39]

40. Support may include individualised assessment, information, counselling, auxiliary aid, support in finding a job, life planning, housing, and income assistance. Personal assistance is also an effective means to ensure the right to live independently and be included in the community in ways that respect the inherent dignity, individual autonomy, and independence of persons with disabilities.[40] This can include individually designed support for personal hygiene, meals, dressing, mobility and communication with others.[41]

41. Choice and control over the support needed to live and be included in the community are of paramount importance in the area of support services, in particular when it comes to personal assistance. As they know their own needs best, persons with disabilities must be the ones who hire, employ, supervise and dismiss their own assistants and should be able to choose between different service providers. This is seen as important to make services more accountable and at the same time reduce the risk of abuse within care.

42. For many years, institutions have contributed to the centralising of "care" for persons with disabilities. Thus, the process of deinstitutionalisation must naturally involve decentralising of services and building up infrastructure so that persons with disabilities are not discriminated against when it comes to the availability of services within the community. A necessary step in this relation is that mainstream community services and facilities must adapt to the needs of persons with disabilities, as was also pointed out by our colleague Ms Sevinj Fataliyeva (Azerbaijan, EC/DA) in her report entitled "Supporting people with autism and their families".[42]

43. Access to mainstream services is a good illustration of how costs may be reduced in the long-term by ensuring that community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs. More importantly, it is a human right and enables member States to fulfil their obligations under Article 19 c of the CRPD. Apart from health care, it can also include the right to attend school in the community, the use of the general transport system and to have access to work in the open job market, depending on individual aspirations and qualifications. Sheltered work is inconsistent with Article 27 of CRPD and, in effect, prevents inclusion and interaction with the community as pointed out by the OHCHR.[43] However, EASPD argue that innovative forms of sheltered work can be useful to provide a bridge between persons with disabilities and the labour market, as often it represents the only possibility for persons with disabilities to make a step into the world of work.[44] In the report on autism, Denmark and Austria were highlighted as member States with good practices in this regard, for example through the social enterprise Specialisterne that specialised in preparing people from the autism spectrum for suitable jobs, using a mixture of training, coaching, and support measures.[45]

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38. Report of the OHCHR (2014), A/HRC/28/37, op. cit., page 8.
39. Written submission by EASPD to the Draft General Comment No. 5 (2017), Article 19 of CRPD: Living independently and being included in the community.
40. Issue paper published by the Council of Europe Commissioner for Human Rights (2013), op. cit., pages 7 and 13.
41. Report of the OHCHR (2014), A/HRC/28/37, op. cit., pages 10-11.
42. Doc. 15177 "Supporting people with autism and their families".
43. Report of the OHCHR (2014), A/HRC/28/37, op. cit., page 14.
44. Written submission by EASPD to the Draft General Comment No. 5 (2017), op. cit.
45. Specialisterne has a success rate of 90%, as it recognises and helps develop the strengths of a particular group of people with disabilities (those with ASD) that struggle in the labour market. It takes targeted and personalised measures to make these individuals job-ready, and coaches firms to implement inclusive structures and processes within their organisation. It connects individuals and firms, utilising a long-term follow-up strategy to ensure that both parties are a good match for each other. It caters to candidates with different needs, offering gainful employment in an alternative setting with extra flexibility. It represents a highly cost-effective measure to empower long-term unemployed people with ASD to (re)enter the labour market.

44. Training is also essential in order to ensure that support is in conformity with the standards of the CRPD, responds to needs and respects the individual's will. The WHO QualityRights initiative can provide essential guidance on the implementation of mental health services and on community-based responses from a human rights perspective. The recommendations are accompanied by seven technical packages, each encompassing a specific category of service required for a fully responsive mental health system (crisis services, hospital-based services, networks of services, and others). At the end of each package, examples of practical actions are included, to facilitate implementation. QualityRights offers a path towards ending institutionalisation and involuntary hospitalisation and treatment of persons with disabilities. The initiative can be a useful tool for care givers in health as it complies with the CRPD and the 2030 Agenda for Sustainable Development frameworks.[46] DH-BIO has published a compendium with examples of good practices to promote voluntary measures in the field of mental healthcare.[47]

45. If the process of deinstitutionalisation is not managed properly, and without due consideration of the special needs of each individual and his or her family, this can have severe and unfortunate consequences, such as the person concerned not being able to fully integrate into the community and thus having to be re-institutionalised, the person ending up homeless, or even in prison.[48] Community living arrangements should not be established and monitored by the institution itself. Consequently, appropriate monitoring mechanisms in member States must be put in place to ensure that the support given in the deinstitutionalisation process is adequate. The ombudsperson of each member State could play an important role in this.

46. The annotated outline of the proposed CRPD guidelines on living independently and being included in the community, includes a requirement for States parties to "Recognise that institutionalization also occurs in the private sphere, in urban or rural areas, through institutions run and controlled by non-State actors, including charities and church-run organisations. Recognise also that States have duties in ending these type[s] of institutions."[49] It is indeed important that institutions run by non-State actors are fully included in any deinstitutionalisation strategies.

7. Deinstitutionalisation of children

47. Deinstitutionalisation of children must be a top priority. Scientific research into children's early development shows that even a relatively short institutional placement can negatively affect brain development and have life-long consequences on emotional well-being and behaviour.[50] Institutionalisation of children with disabilities is clearly not in the best interests of the child, but in many cases, parents feel they have no choice but to put their children in institutions due to poverty and lack of support, or a false belief that children with disabilities are better protected by placing them in institutions. As reiterated by UNICEF, no child or family should be forced to give up family connections in order to escape poverty, or to receive care, comprehensive, timely and quality health services, or education whether that is special or inclusive.[51] Children do not belong in institutions.

48. Member States must ensure adequate support services and necessary information are provided to children with disabilities and their families. As the upcoming CRPD Guidelines on deinstitutionalization of persons with disabilities point out,[52] States must ensure support for children with disability in the family, and when the family is unable to care for a child with a disability, provide alternative care within the wider family and, failing that, within the community in a family. Building up family support, respite care services, the provision of child services within the community, different child protection strategies, inclusive education, and the development of disability-inclusive family-based alternative care are all important measures that would contribute to a successful transition from institutional care to community living for children with disabilities. Moreover, providing assistance and learning to families to understand disability in a positive way may help

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46. www.who.int/publications-detail-redirect/who-qualityrights-guidance-and-training-tools.
47. Compendium report: Good practices in the Council of Europe to promote Voluntary Measures in Mental Health Services. However, the relevant NGOs pulled out of this exercise because of the inclusion of examples which were not considered good practice by them, and because of a lack of sustained co-operation, as well as in protest to DH-BIO's continued work on the draft Additional Protocol to the Oviedo Convention, despite strong opposition from PACE, UN experts and civil society.
48. "Innovation in deinstitutionalization": a WHO Expert Study.
49. Annotated outline of the proposed CRPD guidelines, op. cit., Section A, paragraph II.3.
50. G. Mulheir, "Deinstitutionalisation – A Human Rights Priority for Children with Disabilities", *The Equal Rights Review*, Vol. Nine (2012), pages 119-121.
51. www.unicef.org/ukraine/en/press-releases/unicef-urges-government-ukraine-continue-deinstitutionalization-reform-line-approved.
52. Annotated outline of the proposed CRPD guidelines, op. cit., Section B, paragraph III.15.3.

them understand how to support their children in accordance with their age and maturity.[53] Conversely, listening to children with disabilities and their families will make it easier for the State to adapt services to actual needs. After all, persons with disabilities and their families know best what their needs are, as pointed out by our colleague Ms Fataliyeva in her report on autism.[54]

49. Recognising their important role in supporting persons with disabilities, families are sometimes given compensation. In many countries this is given in the form of social security benefits, allowances and pension schemes. However, exclusive reliance on support from the family can have adverse consequences and lead to the endorsement of gender stereotypes of women as caregivers. Mothers are often exposed to higher levels of stress and fatigue in these situations. Likewise, it may affect other siblings in a negative way. Family support may also affect the choice and control that persons with disabilities exercise over the type of support required. In situations where families do not receive sufficient support from the State, this often results in a reduction of the number of working members in the family and thus a lower household income, and a possible slip into poverty – with further negative effects on all family members. Sometimes families are simply not able to provide full support to persons with disabilities as needed. More resources should be allocated to provide viable options to these families in order to alleviate their burdens without resorting to institutionalisation.

8. Conclusions and recommendations

50. In institutions, persons with disabilities have limited capacity and possibilities of taking part fully in society because of the physical separation from their families and the rest of the community they live in. Institutionalisation of persons with disabilities is ripe with serious human rights violations. The human rights violations are compounded further if institutionalisation is resorted to in childhood.

51. As an alternative to institutionalisation, scholars, practitioners, and persons with disabilities alike have found that community-based support services and supportive living arrangements provide a better quality of life for persons with disabilities, as well as being more human rights compliant and cost-effective.

52. As “proper” deinstitutionalisation (a genuine transition to independent living in accordance with Article 19 of the CRPD) is vital in order to uphold the rights of persons with disabilities. Concrete action must be taken towards ending the institutionalisation practice and ensuring that these persons and their families are met with appropriate support in the process of reintegrating into society. At the same time, measures must be taken to combat the “culture of institutionalisation resulting in social isolation and segregation of persons with disabilities, including at home or in family, preventing them from interacting in society and being included in the community”,[55] a culture which also persists in many of our member States.

53. We need to move on from the outdated paternalistic and medical models of disability and the widespread use of coercion against persons with disabilities, in particular in mental health settings, and embrace the paradigm shift to a human rights model of disability. Indeed, the CRPD Committee is looking to strengthen the role of regional international organisations in promoting deinstitutionalisation processes in line with the CRPD.[56] This means refraining from adopting the draft Additional Protocol to the Oviedo Convention concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services, which is anchored in the outdated medical model, incompatible with the CRPD, incapable of protecting persons with mental health conditions or psychosocial disabilities from violations of their human rights – and quite frankly, not worthy of a human rights organisation like the Council of Europe.

54. The Council of Europe and its member States should follow the provisions of the UN Convention on the Rights of Persons with Disabilities, the UN Convention on the Rights of the Child, the European Social Charter, the European Convention on Human Rights, and other international legal standards implement measures reinforcing the transition from institutional to community-based services. Parliaments need to take the necessary steps to progressively repeal legislation authorising institutionalisation of persons with disabilities, as well as mental health legislation allowing for treatment without consent and detention based on impairment.

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53. Report of the OHCHR (2014), A/HRC/28/37, op. cit., page 10.
54. Doc. 15177, op. cit.
55. Annotated outline of the proposed CRPD guidelines, op. cit., Section A, paragraph II.4.
56. Ibid, Section B, paragraph II.11.5.

55. The process of deinstitutionalisation requires a long-term strategy that ensures that good quality care is available in community settings.[57] As institutionalised persons are being reintegrated into society, there is need for comprehensive social services and individualised support in the deinstitutionalisation process in order to support these persons and their families. Support must be timely and sustainable, accompanied by specific access to services outside institutions to enable people to obtain, *inter alia,* care, work, social assistance and housing. Thus, it is vital that the social determinants of health are also addressed.

56. Persons with disabilities have different needs. This entails the need for a holistic approach between all relevant stakeholders so as to ensure that they are guaranteed their right to full and effective participation in the life of society and the community. An individualised approach is key to providing preparedness for those who have been or are still living in or growing up in institutions to participate fully in their community and wider society. Gender and other stereotypes also need to be addressed.

57. For cases concerning children with disabilities, the deinstitutionalisation process must be child centred. Resources must be mobilised so as to ensure that children with disabilities can live with their families while at the same time having their needs met and their human rights realised, such as the right to education. Family caregivers also need to be given adequate support.

58. Above all, member States must actively include persons with disabilities and their representative organisations in the implementation of Article 19 and when considering policies, legislation, and development of programmes in the deinstitutionalisation process. Persons with disabilities know their own needs best. Member States must listen to them and act according to their needs.

59. Independent mechanisms are needed in order to properly monitor the process of deinstitutionalisation and ensure its success. Funding must be directed towards sustaining systemic reforms that enable member States to fulfil their obligations under international law. It is of paramount importance that member States commit to refraining from projects that involve maintaining or building new institutions.

60. Neither member States, nor the Committee of Ministers, should support or endorse draft legal texts which would make successful and meaningful deinstitutionalisation more difficult, and which go against the spirit and the letter of the CRPD – such as the draft Additional Protocol to the Oviedo Convention concerning the protection of human rights and dignity of persons with regard to involuntary placement and involuntary treatment within mental health care services. Instead, the Council of Europe and its member States need to embrace and apply the paradigm shift of the CRPD[58] and fully guarantee the fundamental human rights of all persons with disabilities.

57. Doc. 15177, op. cit.
58. As exemplified by UN bodies such as WHO.