



Declassified¹

AS/Soc (2020) 47

1 December 2020

Asocdoc47_2020

Committee on Social Affairs, Health and Sustainable Development

Deinstitutionalisation of persons with disabilities

Rapporteur: Ms Reina de Bruijn-Wezeman, The Netherlands (ALDE)

Introductory memorandum

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”. 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 call 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. Deinstitutionalisation is a key steppingstone to ending coercion in mental health. This report is a follow-up to my last report on “Ending coercion in mental health: the need for a human rights-based approach”, which led to the unanimous adoption of Resolution 2291² and Recommendation 2158 last year, and which were also supported by the Council of Europe Commissioner for Human Rights.

2. Aim and scope of the report

3. Deinstitutionalisation is the transition from institutional to community-based services. For centuries, persons with disabilities have been housed in institutions. Such institutions were once seen as the best way of taking care of and treating persons with additional support needs, and the intention was to provide care, food and shelter for them, while also keeping them out of the public eye.³ This approach was changed however in the latter part of the 20th century together with the growing understanding of the harm caused by institutionalisation and new movements pushing for equal rights for persons with disabilities.⁴ Following this, most European countries have begun to reform their systems of care over the past fifty years.⁵

4. 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

¹ Introductory memorandum declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting held by videoconference on 1 December 2020.

² Resolution 2291 (2019) and Recommendation 2158 (2019), (see Doc. 14895, report of the Committee on Social Affairs, Health and Sustainable Development, rapporteur: Ms Reina de Bruijn-Wezeman; and Doc. 14910, opinion of the Committee on Equality and Non-Discrimination, rapporteur: Ms Sahiba Gafarova). Text adopted by the Assembly on 26 June 2019 (23rd Sitting).

³ “Once You Enter, You Never Leave” Deinstitutionalization of Persons with Intellectual or Mental Disabilities in Croatia: <https://www.hrw.org/report/2010/09/23/once-you-enter-you-never-leave/deinstitutionalization-persons-intellectual-or>

⁴ Ibid.

⁵ Mulheir, Georgette: Deinstitutionalisation – A Human Rights Priority for Children with Disabilities: https://www.equalrightstrust.org/ertdocumentbank/err9_mulheir.pdf

which affect them; and the requirements of the organisation itself tend to take precedence over the residents' individual needs.⁶

5. Institutional care provides 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.⁷ Persons with disabilities are some of the most vulnerable individuals in our society. Being placed in institutions further puts them 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.

6. 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 affects their most fundamental rights, including the right to integrity and the right to liberty.

7. As an alternative to institutionalisation, scholars have found that community-based support services and supportive living arrangements provide a better quality of life for persons with disabilities.⁸ An individualised approach is key to providing preparedness for those living in or growing up in institutions to participate fully in their community and wider society. In institutions, persons with disabilities have limited capacity and possibilities of taking fully part of society because of the physical separation from their families and the rest of the community they live in.

8. 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) which has enabled a shift to a human-rights based approach on this issue. As laid down in Article 19 of the Convention, persons with disabilities have the right to live independently and receive appropriate community-based services. An important aspect of quality service provision is that persons with disabilities should be supported within their community.⁹

9. As is stated in an NGO submission on the Convention, Article 19 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.¹⁰ 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.

10. For cases concerning children, the best interest of the child, as laid down in Article 3 of the UN Convention on the Rights of the Child (UNCRC), must always be assessed and determined. 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. Institutionalisation of children with disabilities is clearly not in the best interest of the child. For this reason, a chapter of my report will be dedicated to the deinstitutionalisation of children and their special needs in the process of reintegration into the community.

11. 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. It is also worrying that in a number of countries in the European region, institutionalisation is in fact increasing,¹¹ in spite of international obligations and long-standing calls from international human-rights bodies to end such practices.

⁶ Common European Guidelines on the Transition from Institutional to Community-based Care: <https://deinstitutionalisationdotcom.files.wordpress.com/2017/07/guidelines-final-english.pdf>

⁷ European Commission: Guidance on Deinstitutionalisation: https://ec.europa.eu/regional_policy/sources/docgener/informat/2014/guidance_deinstitutionalisation.pdf

⁸ Ericsson and Mansell, “Introduction: towards deinstitutionalization,” in Mansell and Ericsson, eds., *Deinstitutionalization and community living: intellectual disability services in Scandinavia, Britain, and the USA*, <http://www.kent.ac.uk/tizard/staff/documents/Mansell1996DeinstitutionalisationandCommunityLiving.pdf>

⁹ <https://www.easpd.eu/en/content/europe-needs-better-monitor-quality-care-services-and-support-transition-community-living>

¹⁰ 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

¹¹ 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)

12. 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 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.

13. 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 crises. 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 support needs in this challenging period. Thus, in a statement by the Council of Europe Human Rights Commissioner on the impact of Covid-19 on persons with disabilities, the Commissioner calls 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.¹²

14. The process of deinstitutionalisation requires a long-term strategy that ensures that good quality care is available in community settings.¹³ 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. For cases concerning children with disabilities, the deinstitutionalisation process must be child centred. 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.

15. Persons with disabilities have different needs. This entails the need for a holistic approach between all relevant stakeholders so as to ensure that persons with disabilities are guaranteed their right to full and effective participation in the life of society and the community. 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.¹⁴ 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.

3. Working methods and planning

16. As deinstitutionalisation is vital in order to uphold the rights of persons with disabilities, concrete action must be taken towards ending this practice and ensuring that these persons and their families are met with appropriate support in the process of reintegrating into society.

17. In order to get a better understanding of the sometimes inhumane living conditions of persons with disabilities and to propose recommendations to member States on how to provide appropriate community-based services, I will engage in communication with relevant organisations representing persons with disabilities and their families to better understand their needs. I would be interested in conducting two fact-finding visits to member States, one that has already had success with deinstitutionalisation and another one that is still in the process of ending the harmful practice of placing persons with disabilities in institutions. I would also like to explore the possibility of further supporting member States who need it through the Council of Europe Development Bank in their processes of deinstitutionalisation.

¹² 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": <https://www.coe.int/en/web/commissioner/-/persons-with-disabilities-must-not-be-left-behind-in-the-response-to-the-covid-19-pandemic>

¹³ Innovation in deinstitutionalization: A WHO Expert Study: https://apps.who.int/iris/bitstream/handle/10665/112829/9789241506816_eng.pdf?sequence=1

¹⁴ Innovation in deinstitutionalization: A WHO Expert Study: https://apps.who.int/iris/bitstream/handle/10665/112829/9789241506816_eng.pdf?sequence=1

4. Work programme envisaged

Date	Action
<i>1 December 2020 Committee meeting</i>	Consideration of an introductory memorandum
<i>Spring 2021</i>	Fact-finding visits (subject to Committee authorisation)
<i>Summer- Autumn 2021</i>	Consideration of a preliminary draft report Hearing with experts
<i>Autumn 2021</i>	Consideration of a draft report and adoption of a draft resolution and a draft recommendation

The formal deadline for the adoption of this report in committee is 26 December 2022.