

Comments on the Draft Guidelines on Deinstitutionalization, including in emergencies Committee on the Rights of Persons with Disabilities

Submitted by Centre for Mental Health Law & Policy, ILS, Pune, India

Executive Summary

This submission is in response to the call for comments on the ‘*Draft Guidelines on Deinstitutionalization, including in Emergencies*’ drafted by the Committee on the Rights of Persons with Disabilities. The comments contained in this document are submitted by the **Centre for Mental Health Law & Policy** (hereafter referred to as ‘the Centre’), at the Indian Law Society, Pune, India.¹

These comments have been drafted considering the geographic focus of the Centre’s work in low- and middle-income countries (LMICs) that are usually characterised as low resource settings. Low resource settings are defined as those with limited availability of material, infrastructural and human resources, resulting in limited access to and poor quality of mental healthcare treatment and services.² The Centre specifically focuses on vulnerable and marginalised communities and has extensive experience of working with persons with psychosocial disabilities in low resource settings.

The Centre’s approach to policy change is rooted in the experiences of individuals living with psychosocial disabilities within low-resource communities. These community-centred interventions include *Atmiyata* that has been recognized by the World Health Organization as one of the 25 good practices for community outreach mental health services around the world.³

The Centre provided technical assistance to the Ministry of Health & Family Welfare, Government of India, for the drafting of India’s Mental Healthcare Act, 2017 (hereafter ‘MHCA’). The MHCA came into force in 2018 and was introduced in compliance with India’s international obligations as a signatory of the CRPD; the MHCA replaced the erstwhile Mental Health Act, 1987 which drew upon colonial era legislations.

¹ The Centre for Mental Health Law & Policy works towards strengthening and transforming the mental health care and services to be holistic and responsive in addressing individual and collective well-being. Using a rights-based approach and guided by the principles of the UN Convention of the Rights of Persons with Disabilities, the Centre works in collaboration with multiple stakeholders, including policymakers, mental health professionals, researchers, civil society organisations, persons with lived experience and the media.

More details: <https://cmhlp.org/about-us/>

² Jordans MJD, Luitel NP, Kohrt BA, Rathod SD, Garman EC, De Silva M, et al. (2019) Community-, facility-, and individual-level outcomes of a district mental healthcare plan in a low-resource setting in Nepal: A population-based evaluation. *PLoS Med* 16(2): e1002748. <https://doi.org/10.1371/journal.pmed.1002748>

³ *Atmiyata* is an innovative & evidence-based community-led intervention to reduce the mental health and social care gap in rural communities. <https://cmhlp.org/projects/atmiyata/>

In India, the MHCA under section 19 reaffirms the right to community living, stating that persons with psychosocial disabilities have the right to be a part of society and have access to community-based facilities even in circumstances where they cannot remain with families or relatives. The MHCA is complemented by the National Mental Health Policy, 2014 which recognizes the spectrum of support needs that persons with psychosocial disabilities may require and calls for appropriate transitional services to be made available in communities to facilitate their holistic recovery.

However, the availability, accessibility, and quality of mental healthcare in general in the country is severely compromised. Therefore, the comments take into consideration these ground realities and the implications of deinstitutionalisation in impeding the psychosocial recovery of individuals and violating their rights to healthcare in certain circumstances drawing on key principles of capacity and supported decision-making.

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Detailed Submission

The '*Draft Guidelines on Deinstitutionalization, including in Emergencies*' drafted by the Committee on the Rights of Persons with Disabilities (hereafter 'the Committee'), are a welcome development and vital to the realisation of Article 19 on the right to living independently and Article 14 on the right to liberty and security of persons with disabilities, under the Convention on the Rights of Persons with Disabilities (hereafter 'CRPD'). Further, these guidelines substantially complement the observations made by the Committee in General Comment 5 on Article 19 of the CRPD.

However, there are concerns with the draft guidelines, which must be addressed in order for them to be actualised not just in letter but also in spirit. The draft guidelines adopt an abolitionist approach towards deinstitutionalisation in demanding immediate closure and de-funding of institutions for persons with disabilities (Clauses 9, 14, 15, 43). The guidelines do not take into account the diversity of contexts, particularly the challenges faced in low- and middle-income countries (LMIC), where institutions play an important role in making mental healthcare treatment and services accessible to not just marginalised and vulnerable groups, but also the general population. Recognising the nature of challenges faced in low resource settings, the guidelines must adopt a more balanced approach. The guidelines also place much emphasis on the role of families and communities for the realisation of Article 19 of the Convention. However, this is problematic as it operates upon the assumption that all families and communities are safe spaces, without acknowledging that often even the most basic human rights are denied to persons with disabilities within these spaces, owing to stigma, social discrimination, violence, poverty and financial insecurity, poor awareness, and limited access to mental healthcare treatment and support.

Based on our experience in India during the pandemic, we do not agree that there is a need for urgent deinstitutionalisation in the absence of community living facilities established and maintained by the State. Rather we feel it is important to establish the infrastructure to support community living for persons with psychosocial disabilities in low resource settings before any precipitous closure of institutional facilities. During the first nation-wide lockdown announced in India in March 2020, several persons with psychosocial disabilities residing in institutions were forcefully sent back home, resulting in gaps in treatment and rehabilitation, and denial of care.⁴

⁴ <https://covid-19-constitution.in/analyses/analysis-of-the-governments-response-to-mental-health-concerns-due-to-the-covid-19-pandemic-in-context-of-the-right-to-health>

1. Need for a balanced approach

Section II of the guidelines, call for a complete end to the practice of institutionalisation, recognising it as 'discriminatory' and 'denial of legal capacity'. While supporting this in principle, we believe that this should not happen until community living facilities and community support is established. The focus therefore should be on encouraging States to establish these community living facilities and community support immediately. We are in complete agreement with Clause 9 of the draft guidelines which state that "There is no justification to perpetuate institutionalization. States Parties should not use lack of support and services in the community, poverty, or stigma to justify ongoing maintenance of institutions, or delay their closure." However, it fails to recognize the ground reality in low resource settings, where not just persons with disabilities, but also a large proportion of the general population is unable to access the required support (social, cultural, economic) and care. Thus, in order to facilitate deinstitutionalisation processes, it is important to recognise that the process would also require structural and systemic reform, which cannot be ushered in overnight.

2. Challenges in Deinstitutionalisation in LMIC settings

The guidelines, in seeking complete and immediate deinstitutionalisation, overlook multiple and diverse realities and the role of the larger ecosystem in facilitating reform.

With regard to provisions pertaining to individualised assistance, income support and access to mainstream services in the guidelines, the Committee must revisit these taking into account the various systemic and infrastructural deficiencies and disparities in LMICs. In low resource settings where such support systems and social security nets are not available to the general population it is unlikely that they will be made available to persons with disabilities in the immediate future. Clause 86 and 87 states all persons must be independently in-charge of their own expenses and spending. This is based on the assumption that all persons have basic financial literacy, however, in a majority of the LMICs that is not the case, given the limited access to education.

The guidelines under Section VI on support services and systems must be revised keeping in mind the range of challenges that present themselves in low resource settings, and their magnitude. In India approximately 150 million people live with some form of psychosocial disabilities, yet 70-92% of persons are unable to access appropriate treatment and care for the same.⁵ This care gap can be attributed to poor budgetary allocations and a serious deficiency of human resources, at all levels of the mental health system. It is also important to note that in low resources settings, given the lack of infrastructure for support, economic disparities and the absence of financial security nets, families and communities are often unable to provide the required support to persons with disabilities. Under such circumstances and without larger systemic reform required to facilitate complete deinstitutionalisation, services such as personal assistance and personalised support services are nearly impossible to provide.

In several LMIC, persons with disabilities are still fighting for their right to equal recognition before the law; in countries where the right has been recognised access to justice remains a challenge. Thus, to suggest that immediate compensation and reparations be provided is not

⁵ Murthy RS. National Mental Health Survey of India 2015-2016. *Indian J Psychiatry*. 2017 Jan-Mar;59(1):21-26. doi: 10.4103/psychiatry.IndianJPsychiatry_102_17. PMID: 28529357; PMCID: PMC5419008.

practical (Clause 117 & 118). Measures such as these could also lead to early discharge of persons with psychosocial disabilities from institutions before they have fully recovered and in some cases may also lead to denial of care and treatment.

We strongly recommend the Committee hold more consultations with stakeholders located in low resource settings to understand the role of institutions in enabling persons with disabilities to exercise their rights and ensure their right to security.

3. Role of Family and Communities⁶

The guidelines place too much responsibility and onus on families and communities, not taking into considerations that family and communities are also spaces where rights violations occur, further it is based upon the assumption that everyone has a family or a community, this may not always be the case. For example, during a conflict or natural disasters families may get displaced, separated, or die – in such situations persons with psychosocial disabilities are unlikely to find family or community support. Institutions could provide them with the required support under such circumstances; the complete absence of institutions would make persons more vulnerable to rights violation and more importantly hamper their recovery and rehabilitation.

Particularly, with regard to children, the guidelines adopt a paternalistic approach, by not acknowledging the autonomy and right to self-determination of children, as recognised by the UN Convention of the Rights of the child. In low resource settings, children with psychosocial disabilities are often denied basic rights and face discrimination and rights violations within families and communities, which are not always 'safe' spaces.

Further, while the Committee under Section X on Disaggregated data recognises the importance of collecting data from institutions to enhance the deinstitutionalisation process, it must with equal measure acknowledge the need for empirical evidence on the lived experiences of persons with psychosocial disabilities within their families and communities. Such evidence must inform the process and approach to deinstitutionalisation and identify safe and enabling environments that promote an individual's social recovery.

The call for State parties to immediately stop funding for institutions, could lead to variety of other challenges, such as early discharge of persons from institutions while they are yet to fully recovery, making them vulnerable to relapses. It would also lead to a complete lack of support for persons with psychosocial disabilities who do not have family or have been abandoned by their family and community. It is common for persons with disabilities to face abandonment in low resource settings, owing to poor financial and social security nets available to them and their families.

Alongside considering the abovementioned recommendations and comments submitted, we strongly urge the Committee to study India's Mental Healthcare Act to revise the guidelines on deinstitutionalisation to be more balance, as opposed to their current abolitionist nature. For persons with psychosocial disabilities, specifically those living in low resource setting, complete and immediate deinstitutionalisation would result in and create circumstances for

⁶ <https://www.indiatoday.in/mail-today/story/mental-health-supreme-court-mental-hospitals-homeless-349880-2016-11-03>

the complete violation of the individual's right, particularly the right to access justice and security. The Committee must hold more consultations with stakeholders in LMICs and most importantly with persons residing in institutions in these settings. Not all persons with disabilities would want to return to living with their family or community, as these may be spaces of various forms of violence, exclusion, and discrimination. Lastly, the Committee must work with State parties to develop a roadmap and national policy for deinstitutionalisation, tailored to suit their socio-cultural, political, and economic context.