# Transforming lives: Deinstitutionalisation for people with disabilities

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## Background

Central to the disability rights movement, culminating in the development of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), was protesting 'against the service systems, medical professionals and social institutions that keep people with disabilities "captives of care"'.[4] Progress towards universal deinstitutionalisation has been slow. Many people with disabilities are continually denied the right to live independently in the community. They are segregated in health or social care institutions or held captive in homes where they are deprived of basic liberties such as being able to make decisions about their lives and participate in the community on an equal basis with others.[5,6]

The UN Committee on the Rights of Persons with Disabilities' Guidelines on Deinstitutionalisation calls on Member States to 'recognise institutionalisation as a form of violence'.[7] The Guidelines, together with the Committee's General Comment No. 5 on living independently and being included in the community, emphasise that institutionalisation is a discriminatory practice, involves de facto denial of legal capacity, constitutes detention and deprivation of liberty, and exposes people with disabilities to the administration of drugs and other interventions without free and informed consent.[8] As such, all disability-based institutionalisation is prohibited under the CRPD.

People with mental health issues and psychosocial disabilities, people with intellectual disabilities, and those with complex support needs make up the largest institutionalised groups. In the European

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[4] Kayess R and Sands T. 2020. Research report: Convention on the Rights of Persons with Disabilities, shining a light on social transformation. https://disability.royalcommission.gov.au/system/files/2020-09/Research%20Report%20-%20Convention%20on%20the%20Rights%20of%20Persons%20with%20Disabilities%20Shining%20a%20light%20on%20Social%20Transformation.pdf

[5] Human Rights Council. 2019. Report on the deprivation of liberty of persons with disabilities. https://www.ohchr.org/en/calls-for-input/report-deprivation-liberty-persons-disabilities

[6] Human Rights Watch. 2020. Living in Chains: Shackling of People with Psychosocial Disabilities Worldwide. https://www.hrw.org/report/2020/10/06/living-chains-shackling-people-psychosocial-disabilities-worldwide

[7] Committee on the Rights of Persons with Disabilities. 2022. Guidelines on deinstitutionalization, including in emergencies. https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including, para.22

[8] Committee on the Rights of Persons with Disabilities. 2017. General comment No. 5 (2017) on living independently and being included in the community. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/87/PDF/G1732887.pdf?OpenElement

Union alone there are an estimated 1.4 million people living in institutions.[9] The UN estimates that of 8 million children who live in institutions, 1 in 3 are children with disabilities.[10] People in institutions, particularly women and girls, experience greater rates of sexual and physical violence, forced sterilisation, neglect, substance abuse, suicide, human trafficking, and other forms of torture and violence.[11] The COVID-19 pandemic brought institutionalisation back into the public eye with higher rates of infection and morbidity than the wider population. Representative organisations of people with psychosocial and intellectual disabilities indicate that disability-based institutionalisation is one of the gravest issues affecting their constituents in Asia and the Pacific.[12]

## Challenges and opportunities

Despite many states being in a process of deinstitutionalisation for over 50 years, processes are often not CRPD-compliant or are overdue and, in some contexts, institutionalisation may be increasing.[13] While a global issue, quantification of the problem is challenged by poor data collection and reporting, including a lack of reporting by privately run institutions and exclusion from mainstream surveys and censuses.[14] Several factors, often complex and interrelated, contribute to the persistence of institutionalisation of people with disabilities.

High levels of stigma, stereotyping and prejudice toward people with cognitive and psychosocial disabilities and lack of respect for their dignity and autonomy is common. People with disabilities are often treated as though they are objects of charity, unable to make decisions, or potential criminals. A lack of understanding of the rights of people with disabilities to live in the community persists.[15] Pervasive historical, colonial, legal, and attitudinal barriers fuel ongoing justifications and practices of institutionalisation. For example, the persistence of a medical model of disability which sees psychosocial disability as the purview of medical professions and as an individual and tragic problem to be lamented and 'treated'. The marketisation of mental health by the mental health industry and psychopharmacology curtails both will and preferences and is underpinned by colonial mindsets.[16]

Discriminatory laws and policies supporting institutionalisation are based on actual or perceived impairment. Some countries have adopted CRPD Article 19 into their disability or amended mental health legislations (e.g. India) without explaining the provisions through case or constitutional law. Such new laws also allow traditional coercive methods of disability-based institutionalisation. Within national human rights institutions (NHRIs) and women's rights commissions, the issue of 'mini-institutions', shackling practices, and human rights violations have been sporadically addressed by higher order courts. However, more is needed to find legal solutions and create legislation to free

[9] Mansell J, Knapp M, Beadle-Brown J, and Beecham, J. 2007. Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Tizard Centre, University of Kent. https://research.kent.ac.uk/tizard/wp-content/uploads/sites/2302/2019/01/DECLOC_Volume_2_Report.pdf

[10] Committee on the Rights of the Child. 2019. United Nations Global study on Children Deprived of Liberty. https://www.ohchr.org/en/treaty-bodies/crc/united-nations-global-study-children-deprived-liberty

[11] Human Rights Council. 2019. Report on the deprivation of liberty of persons with disabilities. https://www.ohchr.org/en/calls-for-input/report-deprivation-liberty-persons-disabilities

[12] Transforming Communities for Inclusion. 2018. Bali Declaration. https://tci-global.org/bali-declaration/

[13] Committee on the Rights of Persons with Disabilities. CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies. 2022. https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including, para.22

[14] Economic and Social Commission for Western Asia. 2019. Barriers to Implementing Article 19: A Study on the Institutionalization of Persons with Disabilities in Select Arab Countries. https://e-inclusion.unescwa.org/sites/default/files/resources/barriers-implementing-article19-institutionalization-persons-disabilities1-en.pdf

[15] Kayess R and Sands T. 2020. Research report: Convention on the Rights of Persons with Disabilities: Shining a light on social transformation. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities. https://disability.royalcommission.gov.au/publications/convention-rights-persons-disabilities-shining-light-social-transformation

[16] Clarke J. 2014. Medicalization of global health 2: the medicalization of global mental health. Global Health Action, 7(10) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4028926/

people bound under incapacity, guardianship, and commitment laws. There is a lack of awareness in judicial systems, law faculties and other technical agencies worldwide of the need to transform legal systems towards inclusion.

Mental health legislation continues to be a barrier to living independently in the community. Discriminative legislation is continually promoted and increasingly taken up in new contexts. In Peru, where good practice disability legislation exists, independent living is under threat by new mental health legislation developed without consultation with people with disabilities.

Confusion persists around what deinstitutionalisation entails and ineffective strategies for implementation. Efforts to deinstitutionalise without a comprehensive human rights foundation and commitment of public funds have resulted in different forms of institutionalised living arrangements in the community (trans-institutionalisation), such as 'small-scale' residential care facilities. These 'group homes' accommodate large groups of people making individualised attention and inclusion in the community difficult. This perpetuates segregation and lack of choice instead of promoting genuine community-based alternatives.[17, 18] Funding plans for deinstitutionalisation that do not consider the needs of institutionalised children with complex disabilities or behaviours have seen children with disabilities left behind in institutions while other children returned to the community.

Market trends and competing interests have seen private psychiatric hospitals replacing state-run institutions. Private insurance systems have contributed to increased hospitalisation and discourage psychosocial interventions and alternative treatments. The dependence of psychiatric research and development on multinational pharmaceutical companies means it is difficult to generate evidence around 'competitive' alternatives and establish a balanced knowledge base for policymakers to draw on. Further, the low cost of hospitalisation in some areas does not provide an economic incentive to push for deinstitutionalisation.[19]

Many institutionalised people remain there indefinitely due to the absence of mainstream opportunities, support networks, and community-based services. The ongoing provision and funding of medical care through institutions, rather than in the community, means individuals and families are compelled to give up children or admit themselves to institutions to receive support. With the shift towards decentralisation in many states, there is risk transferring responsibility for deinstitutionalisation from national to local governments will result in reduced funding and issues with service coordination, consistency, and competence. A lack of reparations and redress mechanisms for those affected by institutionalisation to support people immediately following deinstitutionalisation also negatively impacts people with disabilities.

Donor funding can perpetuate the maintenance of institutional approaches. For example, donor funds are used to renovate and 'prop up' institutions in the short term, with the unintended impact of perpetuating their existence. There is also evidence of perception by states that deinstitutionalisation is a 'donor-led' project, thereby risking the sustainability of changes.

Despite the challenges, there are growing models of rights-based alternatives to institutionalisation supported by key human rights and legal frameworks. These include the CRPD, the Sustainable

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[17] Siska J and Beadle-Brown J. 2020. Report on the transition from institutional care to community-based services in 27 EU States. https://www.researchgate.net/publication/341902653_Report_on_the_Transition_from_Institutional_Care_to_Community-Based_Services_in_27_EU_Member_States

[18] Committee on the Rights of Persons with Disabilities. N.d. Outcome of Regional Consultations for Eastern Europe and Central Asia on Deinstitutionalization. https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx

[19] Cortes C, Moller J, Dominguez I, Thomas F, and Ortiz, J. 2023. Moving psychiatric deinstitutionalisation forward: A scoping review of barriers and facilitators. Cambridge Prisms, Global Mental Health, 10. https://doi.org/10.1101/2023.03.28.23287810

Development Goals, the UN General Assembly Resolution on the Promotion and Protection of the Rights of Children, and recently released UN Guidelines on Deinstitutionalisation, including in emergencies. These Guidelines detail the aspirational as well as immediately achievable actions to ensure the rights-based inclusion of people with disabilities and effective deinstitutionalisation. There is an opportunity to use the COVID-19 recovery process and the introduction of the new Guidelines to highlight the need to address deinstitutionalisation as a matter of urgency.

## Looking ahead to 2030

Underpinning key actions for the full realisation of the rights of people with disabilities is a commitment to transformative development. This means engaging with and challenging prevailing structures and systems that maintain the status quo and shifting decision-making power to those most marginalised and most affected by institutionalisation. For deinstitutionalisation to succeed, states, development partners, and communities must urgently address these key issues:

- establish a supportive legal environment and repeal discriminatory legal incapacity, mental health, and other disability-based detention laws and provide supported decision-making mechanisms
- foster enabling environments within communities to better support all persons with disabilities
- address entrenched negative attitudes and social norms about the capacities of people with disabilities
- mobilise public funds to mainstream inclusion and provide personal supports and community-based services.

Community-based programs led by people with disabilities, created within a human rights and integrated development framework in the Global South, demonstrate deinstitutionalisation is achievable now. Lessons from these programs and recent CRPD committee consultations suggest the following actions to support successful deinstitutionalisation.

Build capacity of DFAT staff and partners on deinstitutionalisation, including how to identify and prevent institutionalisation, with technical guidance for staff engaging in National reform. This includes an intersectional approach with attention to children, women, LGBTQIA+ people, culturally and linguistically diverse communities, people affected by leprosy, older people, people with dementia, and unhoused people. Provision of clear guidance and standards for programs and embedding expectations into contract negotiations and guidance would support communication of expectations to downstream partners. Enhanced safeguards, such as the European Checklist for EU-Funded measures, would help prevent funds being used to create or renovate new institutions .[20]

Support states to chart a clear vision and policy for deinstitutionalisation with the effective participation of people with disabilities in the design, implementation, and review of deinstitutionalisation efforts and decision-making processes.[21] For example, via funding situational analyses and needs assessments sensitive to contextual factors and with mapping of existing services, gaps and opportunities, and supporting the review, repeal, and reform of harmful legislation.

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[20] European Expert Group on the transition from institutional to community-based care. 2020. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community-based services. https://enil.eu/wp-content/uploads/2022/03/EEG_Checklist.pdf
[21] Committee on the Rights of Persons with Disabilities. N.d. Outcome of Regional Consultations for Asia Pacific on Deinstitutionalization. https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/OutcomeRegionalConsultationAsiaPacific.docx

**Prioritise investment in high-quality, individualised support and inclusive mainstream services** in the community without delay. Support services should include personal assistance, peer support, caregivers for children in family settings, crisis support, communication, and mobility support, including provision of assistive technology, support in securing housing and household help, and other community-based services. Support should be available to access and use mainstream services, including in education, employment, social protection, justice, and health. People with disabilities, particularly people with psychosocial and cognitive disabilities in development, should be included in implementation and monitoring of mental health services and psychosocial supports. Investment in reparations and redress mechanisms, such as compensation packages, to support people immediately following deinstitutionalisation to live with adequate standard of living in open settings without fear of insecurity is essential.

**Ensure social protection programs account for the additional costs of disabilities and include end of program outcomes for people with disabilities.** People with disabilities should have access to disability allowances on an equal basis with others and information about housing and unemployment allowances, personal assistance, health care, vocational training, and social protection. Additionally, child protection and welfare systems should prioritise and address the needs of children with disabilities, including those with high support needs.

**Raise national and community awareness** on community inclusion of people with psychosocial and cognitive disabilities. Core funding for emerging representative organisations will amplify the voices of people with psychosocial and cognitive (particularly intellectual) disabilities by supporting their collective action.

**Improve data collection and engagement of civil society.** Establishing national monitoring frameworks for institutions, including indicators on children in alternative care, is crucial. Developing and publishing official statistics on this population group and monitoring progress is important, for example around implementation of child protection system reforms. Civil society can improve inclusion of people with psychosocial and cognitive disabilities and those with high support needs in programming and advocacy by developing and testing person-centred, community-based mental health and psychosocial services and offering choices as per the will and preference of people with disabilities. Incorporating action research will contribute to the evidence base in the Global South.