**Written submission by**

**the Global Coalition on Deinstitutionalization**

**for the CRPD Committee’s Day of General Discussion on persons with disabilities in situations of risk and humanitarian emergencies**

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**Introduction**

1. The Global Coalition on Deinstitutionalization (GC-DI)[[1]](#footnote-1) welcomes the initiative by the Committee on the Rights of Persons with Disabilities to hold a Day of General Discussion on persons with disabilities in situations of risk and humanitarian emergencies.
2. The GC-DI focuses this submission on recommendations in relation to deinstitutionalization.
3. The global report on findings of the COVID-19 Disability Rights Monitor (COVID-DRM)[[2]](#footnote-2) showed the shocking impact of the COVID-19 pandemic for persons with disabilities living in various types of institutions around the world, with hundreds of testimonies describing mass fatalities, a lack of preparedness to prevent virus transmission, and shocking accounts about the implications of total lockdowns on residents who were often denied even basic information about how to keep themselves safe. The findings highlight the inherently dangerous nature of congregate settings at all times and point to a reckless disregard on the part of policymakers and duty-bearers to take protective measures.
4. Institutionalisation itself is a human rights violation, and while all States which have ratified the CRPD are under an obligation to end this practice and promote independent living, the lack of progress in many countries prior to the pandemic inevitably subjected residents with disabilities to extreme risks and serious consequences.
5. During its twenty-seventh session, the United Nations Committee on the Rights of Persons with Disabilities adopted the ‘Guidelines on Deinstitutionalization, including in emergencies’, which draw on the experiences of persons with disabilities before and during the pandemic. The Guidelines provide concrete guidance to States on ending widespread institutionalization of persons with disabilities, highlighting a wide variety of violations consequent on policies of institutionalization for the lives of persons with disabilities. They call for concrete action to tackle the causes and consequences of institutionalization and the violence, neglect, abuse, ill-treatment and torture, including chemical, mechanical and physical restraints, that persons with disabilities experience in institutions.[[3]](#footnote-3)
6. It is the submission of members of the GC-DI that there is a need for greater awareness of the Guidelines and action by States Parties.
7. The Guidelines were developed with a high level of participation of national Organizations of Persons with Disabilities and civil society organizations through online regional consultations. They represent an exemplary evidence-base for practical measures to be taken by States Parties, towards independent living and inclusion of all persons with disabilities. The GC-DI and all the organisations partnering herein, have worked hard to raise awareness of the Guidelines, integrating them within our various advocacy initiatives, and circulating the call for inputs into a General Comment on Article 11.
8. This written submission provides recommendations to the Committee on the Rights of Persons with Disabilities regarding proposals to strengthen the action of States Parties. These recommendations draw on the findings of the COVID-DRM and the Guidelines on Deinstitutionalization, including in Emergencies. We hope that these proposals will generate discussions during the Day of General Discussion on persons with disabilities in situations of risk and humanitarian emergencies.

**Recommendations on the basis of the ‘Guidelines on deinstitutionalization, including in emergencies’**

1. Institutionalization should never be considered by States Parties as a proactive measure for “protecting” persons with disabilities or an acceptable “building back better” strategy. States parties must accelerate efforts to close institutions [Guidelines, para. 107] during emergency situations, such as pandemics, natural disasters or conflicts. States Parties must, inter alia, prevent institutionalization, place a moratorium on new placements, the maintenance, construction of expansion of wards and buildings, and should not prioritise renovation of old structures. Deinstitutionalization should be prioritized within emergency preparedness and response plans, with identified human and financial resources, protocols and accountabilities clearly established.
2. During emergencies, immediate efforts are necessary to identify people with disabilities in institutions [Guidelines, para 107], and those at risk for institutionalization. Fast-tracking mechanisms should be built into disaster risk reduction and response plans under the Sendai Framework and in accordance with the Guidelines. State machinery deployed in humanitarian or disaster mitigation actions must identify groups at risk, such as internally displaced persons with disabilities, unaccompanied and separated children with disabilities, migrants,and refugees with disabilities in order to prevent their institutionalization.
3. In accordance with the Guidelines on Deinstitutionalization, States Parties should ensure high level leadership on developing and implementing deinstitutionalization strategies and plans. Such leadership is key to ensuring that the Guidelines are integrated into all policies, plans and programs concerning disaster risk reduction and response. There should be better alignment of national instruments with the Convention, and its jurisprudence, including the Guidelines on Deinstitutionalization.
4. As a part of “building back better” States Parties must ensure the availability and accessibility of community support systems that are grounded in human rights standards. States Parties are reminded that: “*Support systems and networks include the relationships that an individual develops with family members, friends, neighbours or other trusted persons who provide the support that a person requires for decision-making or daily activities, in order that the person can exercise the right to live independently and to be included in the community, which for children means to live in a family*” [Guidelines, para 69].
5. Examples of such support systems and networks must include, “*peer support, self-advocacy, circles of support and other support networks – including organizations of persons with disabilities and centres for independent living*” [Guidelines, para 70]. Culturally appropriate approaches to community development and building support systems must be financed and supported by States Parties, after consulting with Organisations of Persons with Disabilities and survivors or institutionalization.
6. “States parties should maintain internationally agreed minimum core standards, preventing isolation, ill-treatment, disability-based discrimination and bias in triage protocols and avoiding preventable injury, illness and death. The prohibition of disability-based detention and the right to legal capacity should be upheld including during emergencies” [Guidelines, para 108].

**Recommendations on the basis of the findings of the COVID-DRM**

*Provide adequate measures to protect persons with disabilities in institutions during emergencies*

1. Develop an emergency deinstitutionalization plan in line with Article 19 of the CRPD, General Comment No. 5: Right to independent living (2017), and the Guidelines on deinstitutionalization, including in emergencies (2022) of the CRPD Committee.
2. Implement an immediate no-admissions policy to large- and small-scale institutions.
3. Closely monitor the situation in institutions and release meaningful disaggregated data and information, including on age, sex, gender, type of disability, location and the number of fatalities in institutions.
4. Guarantee immediate, unfettered access to independent national human rights authorities, including NHRIs, NPMs, and non-governmental human rights organizations to all institutions, ensuring safety protocols and procedures are in place to enable independent monitoring and direct communication between monitors and residents.
5. Provide immediate access to food, personal protective equipment, and appropriately trained staff.
6. Provide accessible information in easy to read, pictorial and multiple formats about the state of emergency.
7. Ensure full access to healthcare on an equal basis with other citizens.
8. Implement immediate measures to ensure that residents can contact law enforcement and complaints mechanisms, and ensure contact with family and friends.
9. Ensure that persons within institutions have access to mental health specific psychosocial supports and services, trauma informed counselling, use of arts and activity-based expression for those not being able to freely express themselves using words, group support services, fitness and recreational activities suitable to persons emerging from trauma, etc. Any available mainstream measures based on coercive treatments escalating to ‘forced hospitalization’ must be prohibited.
10. Prevent family separation and institutionalization of children (or parents) due to emergency situations and create family-based alternatives to avoid detention in residential institutions.
11. Actively involve persons with disabilities and their representative organisations, and civil society, in planning the recovery process and emergency deinstitutionalization plans.
12. Allocate adequate financial and human resources to support the transition from institutions to the community. Particular assistance should be provided for persons with mobility impairments, older persons, women and children, persons with high support needs, and those on psychiatric drugs to move to higher ground or be evacuated. Some medications produce mobility impairment, sedation and other adverse effects that do not allow people to move quickly.

*Prevent significant or fatal breakdown of community support during emergencies*

1. Guarantee full participation and meaningful involvement of persons with disabilities and their representative organisations at every stage of emergency response. Reasonable accommodations must be guaranteed to all persons with disabilities, regardless of location or access needs, to ensure effective participation.
2. Safeguard community-based services including personal assistance, home supports, and assistive technology, and the requisite training to use it.
3. Provide information about the state of emergency in multiple, accessible formats.
4. Enact emergency measures to ensure adequate and affordable food and medication distribution throughout the country, including rural and remote areas.
5. Provide immediate financial assistance, social protection and cash transfers to persons with disabilities to cover the additional costs of living, including extra costs associated with disability, and the rising costs of food, medications, phone plans and other essential supplies and services during periods of emergency.
6. Work with private sector companies such as supermarkets to ensure that food is delivered to the homes of persons with disabilities who are unable to go out of their homes, and encourage them to allocate dedicated time for those who require, including persons with disabilities.
7. Investigate and hold accountable police and other security services who abuse, injure, or kill persons with disabilities.
8. Put in place necessary measures to protect persons with disabilities who are in situations of risk, especially during curfews, lockdowns, shielding orders, or shelter-at-home orders related to emergency situations. Ensure that persons and children with disabilities who may be wandering or lost are brought to safety, and reunited with their own community, if not family.
9. Ensure all security briefings and reports consider the perspectives and rights of persons with disabilities during emergency situations.
10. Ensure police officers and security forces are trained to consider the needs of persons with disabilities during emergency situations.

*Prevent disproportionate impact of emergencies on underrepresented groups of persons with disabilities*

1. Guarantee full participation and meaningful involvement of underrepresented persons with disabilities and their representative organisations in decision and policy-making processes. These include women and girls with disabilities, homeless persons with disabilities, children with disabilities, LGBTQI persons with disabilities, those with disabilities living in tribal, mountainous, conflict affected, rural and remote areas present residents of institutions and survivors of institutionalization.
2. Ensure that legislation and policies are disability-sensitive and recognise diversity among persons with disabilities and the universality and interrelatedness of human rights. No legal barriers must exist that impinge on the right of persons with disabilities to exercise their full legal capacity.
3. Closely monitor the situation of underrepresented groups of persons with disabilities and collect data and information on their needs.
4. Ensure that the implementation of legislation and policies, especially emergency response, is sensitive to the specific, overlapping needs of persons with disabilities.
5. Provide persons with disabilities access to justice, women’s shelters, social workers, trauma counselling, and other supports for survivors of domestic violence and sexual abuse.
6. Ensure that children with disabilities have equal access to healthcare, education, food and medicine, and other community services on an equal basis with all children.
7. Guarantee that essential services, such as healthcare and mental health services, are age-appropriate, gender-sensitive and compliant with the Convention on the Rights of Persons with Disabilities.
8. Provide accessible, community-based accommodation for homeless persons with disabilities.
9. Guarantee long-term housing and community inclusion support services for homeless persons with disabilities.
10. Establish a coordination mechanism within the government to ensure equal access to support services throughout the country, including remote and rural areas.

*Prevent denial of access to healthcare during emergencies*

1. Guarantee full participation and meaningful involvement of persons with disabilities and their representative organisations at every stage of health policy making.
2. Prohibit denial of health information, health care, or health services on the basis of disability. Provide access to justice for those who have been denied access to healthcare.
3. Ensure that persons with disabilities, including persons still living in institutions, enjoy the highest attainable standard of health without discrimination on the basis of disability.
4. Require health professionals to provide healthcare and health information to persons with disabilities on an equal basis with other citizens, including persons still in institutions.
5. Raise awareness of the rights of persons with disabilities among health professionals, including the right to access information and give free and informed consent to medical treatment.
6. Ensure access to specialized health services including rehabilitation.
7. Guarantee free or affordable healthcare, food and medicine, and prohibit discrimination against persons with disabilities in the provision of health insurance.
8. Provide health information and services as close as possible to people’s own communities, including in remote and rural areas.
9. Provide information about healthcare in multiple, accessible formats.

*Provide immediate actions during emergencies*

1. Ensure that all recovery efforts protect the rights to life, health, liberty, freedom from torture, ill-treatment, exploitation, violence and abuse, the rights to independent living and inclusion in the community, and to inclusive education, among others, for persons with disabilities without any discrimination on the basis of disability. Ensure that medical emergency services do not violate the right to the highest attainable standard of health and wellbeing, and prohibit cruel, inhuman degrading and tortuous ‘treatments’.
2. Ensure that all persons with disabilities have immediate access to food, fluids, medicine, and other essential supplies.
3. Ensure that persons with disabilities have equal access to basic, general, specialist, and emergency health care and that triage policies never discriminate on the basis of disability or impairment.
4. Enact emergency deinstitutionalisation plans, as informed by persons with disabilities and their representative organisations, including adopting an immediate ban on institutional admissions during and beyond emergencies, and the transfer of funding from institutions into community supports and services. Ensure that transinstitutionalization from big to small institutions, other institutions or any aggregate living arrangements is prevented.
5. Allocate adequate financial and human resources to ensure that persons with disabilities are not left behind in emergency response and in the recovery process.
6. Provide economic, financial, and social support to ensure that persons with disabilities can enjoy their right to fully participate in the community on an equal basis with others, including having access to personal assistance at all times.
7. Guarantee full participation, meaningful involvement, and leadership of persons with disabilities and their representative organisations at every stage of planning and decision-making processes in emergency responses. Take steps to meaningfully involve children and young people with disabilities and their families and caregivers in the design and implementation of all policies in response to emergencies.
8. Ensure that emergency responses are disability-inclusive and take into account the diverse and individual needs of persons with disabilities, in particular those experiencing intersectional forms of discrimination and marginalisation such as women and girls with disabilities, persons living in rural or remote areas, deaf and hard of hearing persons, persons with deafblindness, persons with intellectual or psychosocial disabilities, and autistic persons.
9. Ensure inclusive education for children and young people with disabilities, especially children and young people living in congregate care. Ensure education provision is accessible and provides individual education plans tailored to each child and young person with disabilities, and provide reasonable accommodation when required, to guarantee their right to education.
10. Prioritise the dissemination of comprehensive and accessible information in a variety of formats for persons with disabilities concerning the pandemic, response efforts, and public health information and guidance.
11. Provide disability-awareness training for police and law enforcement authorities, and accountability for disproportionate enforcement of public health-related restrictions. Ensure access to justice for persons with disabilities who have experienced or are at risk of experiencing abuse, violence, or exploitation as a result of emergency measures.

1. The Global Coalition on Deinstitutionalization (GC-DI) is a network comprised of the following organisations: International Disability Alliance (IDA), Inclusion International (II), Transforming Communities for Inclusion (TCI), European Network on Independent Living (ENIL), Disability Rights International (DRI), Disability Rights Fund/Disability Rights Advocacy Fund (DRF/DRAF), Disability Unit at the Centre for Human Rights at the University of Pretoria, and the Validity Foundation. [↑](#footnote-ref-1)
2. Brennan C. S. et al. (2020). *Disability rights during the pandemic: A global report on findings of the COVID-19 Disability Rights Monitor.* <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>. [↑](#footnote-ref-2)
3. UN CRPD Committee (2022). *Guidelines on deinstitutionalization, including in emergencies*. CRPD/C/5, para 2. [↑](#footnote-ref-3)