***Annotated outline***

# **Living independently and being included in the community: Guidelines on deinstitutionalization of persons with disabilities, including in emergency situations.**

# Origin, process and purpose of the Guidelines

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| This section describes how the draft Guidelines originated, the process leading to the guidelines, and their main purpose.  |

1. **Origin and purpose of the Guidelines**
2. Origin of the Guidelines:
	1. Human rights violations reported to the Committee during the COVID 19 pandemic resulting in further isolation, marginalization, exclusion, and institutionalization.
	2. Process leading to the guidelines
3. Briefing of the COVID-19 Disability Rights Monitoring[[1]](#footnote-1) to the Committee about worldwide survey on human rights violations during the COVID 19 pandemic.
4. Committee’s decision to establish a Working Group on Deinstitutionalization (23th session).
5. Seven regional consultations addressed to persons with disabilities and their organizations.
6. Outcomes of regional consultations prepared by the Secretariat of the Committee.
7. Annotated outline of the Guidelines prepared by the Committee’s Working group with the support of a consultant. The Working Group received inputs from the Global Coalition on Deinstitutionalization[[2]](#footnote-2).
	1. Limited understanding by State parties and other actors about the right of persons with disabilities to [live independently and be included in the community (article 19](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19)).
8. Purpose:
	1. Supplement the [Committee’s General Comment No. 5](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en) by providing concrete guidance to State parties and other actors on how to carry out deinstitutionalization processes, including in emergency situations, in line with the [Convention on the Rights of Persons with Disabilities](https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx)

# Areas of action and concrete recommendations

# Section A

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| Section A addresses State authorities and provide them with concrete guidance on how to recognize in practice what constitutes institutions, the culture of institutionalization, and de-institutionalization processes in line with the Convention. It also provides guidance to State parties that institutionalization can never be considered as a measure of protecting persons with disabilities, about their duty to end institutionalization and to address and eliminate root causes that lead to institutionalization. This section will be developed in manner consistent with general comment No. 5 of the Committee on the right of persons with disabilities to live independently and be included in the community, without duplicating the latter content. |

# States parties shall[[3]](#footnote-3):

1. **Recognise the extent of the concept of institution and institutionalization**
2. Recognise that an institution is any setting in which persons with disabilities cannot exercise their choice concerning living arrangements, and where persons with disabilities lack control and autonomy about their daily lives, irrespective of their size or the kind of services that are provided therein to persons with disabilities[[4]](#footnote-4).
3. Recognise and identify that institutions may have different forms, including psychiatric institutions, rehabilitation centres, half way homes, group homes, sheltered or protected living homes, transit homes, nursing homes and other congregated living settings, including small sized institutions. Recognise also that institutions also comprise practices that deprive persons with disabilities of their liberty such as leprosy colonies, camps for persons with albinism hostels, social care institutions, children’s shelters, special boarding schools, refugee camps, prayer camps. Different forms of institutions may vary from country to country.
4. 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 organization. Recognise also that States have duties in ending these type of institutions.
5. Recognise the persistence of a culture of institutionalization 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.
6. Recognise that confinement and lockdown in institutions, particularly during emergency situations, is an aggravated form of institutionalization.
7. Incorporate a concept of deinstitutionalization in line with the Convention, which is
	1. Connected to realising human rights of persons with disabilities and therefore, human dignity
	2. Focused at restoring the rights of persons with disabilities curtailed by institutionalization, and at providing persons with disabilities with genuine choices lo live independently and be included in the community.
	3. Focused at: a) restoring legal capacity of persons with disabilities, and provide them with supported decision-making concerning all decisions, including living arrangements, b) establishing individualized support to live in the community, and c) ensuring access to accessible services in the community.
	4. Recognize that moving persons from large scale institutions to small group homes that perpetuate control of third parties over daily routines and choices of persons with disabilities do not constitute de-institutionalization
8. **End institutionalization in law and practice and restore the dignity of persons with disabilities**
9. Recognise institutionalization as a human rights violation of multiple rights in the Convention and that it constitutes:
	1. Disability-based discrimination;
	2. Deprivation of liberty[[5]](#footnote-5);
	3. A harmful practice that entails different forms of violence, coercion, ill treatment and torture against persons with disabilities with profound impacts on their physical and mental integrity
	4. A violation of the right of persons with disabilities to live independently and to be included in the community (article 19) of the Convention[[6]](#footnote-6).
10. Recognise that institutionalization is not a form of protection of persons with disabilities, or as a “solution” for persons with disabilities or as an adequate form of support or the provision of services, such as health, education or rehabilitation.
11. **Identify, address and eliminate the root causes of institutionalization as framework for a successful deinstitutionalization**
12. In parallel to designing and implementing deinstitutionalization processes, States parties should address and eliminate the underlying and root causes of institutionalization, which include: a) widespread poverty, extreme poverty, and homelessness of persons with disabilities; b) reliance of persons with disabilities on informal economy, exacerbated in emergency situations, including the covid-19 pandemic; c) lack of development of support in the community for persons with disabilities; d) lack of support to families of persons with disabilities, exacerbated during emergency situations; e) lack of alternatives to institutions; f) lack of coverage for the extra-costs of living with impairment; g) prevalence of the medical model of disability, and related practices such as bio-medical determination of disability, the widespread use of coercion against persons with disabilities, particularly in mental health settings, and widespread medicalization and judicialization of situations of crisis and mental distress experienced by persons with disabilities; h) prejudices, and disability stereotypes in the family and in society, including false beliefs that there are persons with disabilities who are unable to live independently, that children with disabilities are better protected by placing them in institutions and deep rooted cultural and social misunderstanding about the worth and value of persons with disabilities; i) Lack of meaningful participation of persons with disabilities, including in the management and response to situations of emergency., and j)the teaching and training of disciplines that inculcate the practice of coercion and institutionalization, such as “defectology” and “abnormal psychology”.

# Section B

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| Section B addresses State authorities and provide them with concrete guidance to carry out deinstitutionalization processes, in line with the Convention. It guides States authorities on the main principles which should be respected in DI processes, the structural issues which required to be addressed and concrete implementation measures of DI processes |

# Deinstitutionalization processes (DI) should

1. **Be guided in the following principles**

**1. Be inclusive of all persons with disabilities regardless of impairment, age, sex, gender, ethnic origin or any other grounds**

* 1. Include all persons with disabilities regardless type of impairment or level of support required to live independently and in the community. All persons with disabilities are eligible for DI

**2. Effectively shift from the outdated charity, paternalistic and medical models of disability to the human rights model of disability.**

* 1. Ensure that persons with disabilities are not excluded from DI process on the basis of bio-medical assessments of severity of impairment, and that bio-medical assessments are not used to evaluate the provision of support in the community
	2. Ensure freedom of persons with disabilities instead of control over their lives, equality instead of segregation, dignity instead of capacity-devaluation, personal support instead of institutional care, and active participation instead of passive recipient role.
	3. Respect the dignity of persons with disabilities throughout the whole DI process
1. **Incorporate an approach centred on persons with disabilities, and focus on empowering persons with disabilities to live independently and in the community**
	1. Focus on persons with disabilities, and not on reforming institutions.
	2. Avoid one fit for all solutions, recognize the diversity of persons with disabilities,
	3. Develop individualized plans, based on will and preferences of persons with disabilities
	4. Raise awareness of persons with disabilities about their rights in the Convention,
2. **Enable full and effective participation of persons with disabilities, and allow for their independent participation;**
	1. Ensure participation of persons with disabilities through their representatives organizations in all steps and decision-making processes concerning the DI
	* Information sharing through public website does not exhaust the duty to ensure participation.
	1. Ensure that decision-making processes throughout the DI are fully accessible to all persons with disabilities, including for persons with intellectual disabilities, including by using information and communication technologies.
	2. Provide reasonable accommodation when requested, to enable full participation of person with disabilities on an equal basis.
	3. Foster an environment respectful of the independent participation of persons with disabilities and their representative organizations
3. **Ensure gender equality and gender diversity throughout the whole DI process.**
	1. Recognise gender-based discrimination, including gender-based violence to which women and girls with disabilities have been exposed in institutions and take it into account in the design and implementation of individualized support plans during transition from institutions to live independently.
	2. Recognise discrimination based on sexual orientation, gender identity, gender expression and variations of sex characteristics to which persons with disabilities have been exposed in institutions and take it into account in the design and implementation of individualized support plans during transition from institutions to live independently.
4. **Address multiple and intersecting forms of discrimination affecting persons with disabilities.**
	1. Pay particular attention to the situation of persons with disabilities affected by multiple and intersecting forms of discrimination while in institutions.
5. **Combat disability prejudices, stigma and stereotypes in the family and in society and recognize and restore the dignity and the worth of persons with disabilities in society.**
	1. Develop and implement sustainable awareness-raising plans of action on the rights of persons with disabilities addressed to all society, at the national, regional and local levels, and particularly to communities where persons with disabilities choose to be resettled.
	2. Include in the curriculum the content of the Convention at all levels of the education system.
	3. Ensure widespread dissemination of the content of the right to live independently and be included in the community.
	4. Develop and carry out sustainable training and awareness-raising programmes addressed to the general public and all officials in all sectors.
	5. Prevent violence and abuse, including sexual violence and abuse and bullying, against persons with disabilities, and effectively investigate cases and incidents of all forms of violence and sanction perpetrators.
6. **Address structural issues, including through the reform of legal and policy frameworks, and practices perpetuating institutionalization**
7. **Be framed in legislation aligned with the Convention, which includes the following components**
	1. Repeal all forms of institutionalization in legislation, policies and in practice. Establish in law a moratorium of establishing new institutions
	2. Review and repeal in mental health legislation any provision allowing for medical treatment without consent and detention based on impairment. [[7]](#footnote-7)
	3. Recognise in law the right to live independently and be included in the community and all its components as described in General Comment No5
	4. Repeal legislation allowing for guardianship and establish supported-decision making [[8]](#footnote-8)(check below sub chapter 14),
	5. Ensure that anti-discrimination legislative frameworks recognise guardianship and institutionalization as forms of discrimination based on disability[[9]](#footnote-9).
8. **Address the situation of specific groups of persons with disabilities who have been disproportionally affected by institutionalization and have faced compounded forms of segregation**: children with disabilities, older persons with disabilities, persons with disabilities requiring high levels of support, persons facing multiple discrimination, women with disabilities, persons with intellectual disabilities, persons with psychosocial disabilities, people with disabilities belonging to indigenous or minority communities, persons facing multiple discrimination, persons with albinism and persons with disabilities experiencing crisis.
9. **Foster accessibility and inclusion in the community**
	1. Ensure mainstream services in the community are available, acceptable, affordable, accessible, adaptable, sustainable and inclusive, and of appropriate quality, to all persons with disabilities.
	2. Ensure reinsertion and return-to-work, away from sheltered employment or any segregated employment; including by ensuring access to employment opportunities in the open labour market.
	3. Invest in accessible public housing programmes in the community, not in group homes
	4. Ensure access to inclusive and quality education systems in the community, at all levels of education and particularly in rural and remote areas
	5. Develop inclusive quality education as a main driver of inclusion
	6. Accelerate the transformation of special education into a quality inclusive education system and abolish special education, special schools, boarding schools or any other models of segregated education
	7. Train teachers and education professionals on inclusive and quality education, using general comment No 4
	8. Provide individualized support and reasonable accommodation in the educational system.
	9. Ensure restoration and inclusion in community life, through social networks, family ties when applicable, friends, peers, associations, etc.

1. Foster development and maintenance of friendships and relationships

* 1. Ensure that access and provision of services in the community is respectful of the right to privacy of persons with disabilities.
	2. Develop accessible health services in the community
1. Ensure sexual and reproductive rights are respected;
2. Ensure all medical treatments are provided on the basis of free and informed consent and that quality mental health services are offered by personnel trained in human rights;
3. End the use of coercion, particularly in mental health settings;
4. End the use of long-term psychiatric medication.
	1. Ensure access of persons with disabilities, and particularly those living in poverty and extreme poverty to mainstream social protection programmes on an equal basis with other;
	2. Ensure disability-specific programmes are available to all persons with disabilities, and that they cover disability-related costs.
5. **Ensure that international cooperation is used in DI process in line with the Convention**
	1. Explicitly include the goal of deinstitutionalization in international development cooperation programmes and funds.
	2. Ensure the use of funding through international cooperation in line with the human rights based approach to disability, including the following aspects: transparent processes for implementing international cooperation and accountability mechanisms
	3. Ensure an open and direct consultative process with persons with the disabilities and organizations of persons with disabilities on the design and implementation of development projects funded by international cooperation.
	4. Link deinstitutionalization to all actions and measures to implement the 2030 Agenda and the Sustainable Development Goal; mainstream the rights of persons with disabilities in all international cooperation efforts
	5. Strengthen the role of regional international organizations in promoting DI processes in line with the Convention.
6. ***Ensure Implementation in line with the Convention***

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| This segment will provide concrete and practical examples on the implementation of DI processes.It will strive to provide practical elements, nuanced and specific to particular institutional settings (Such as residential facilities which requires development of community accessible housing, and community based support services; mental health facilities which require law reform and development of alternatives to forced and coercive mental health care; and specific actions regarding the culture of institutionalisation of persons with disabilities segregated in family settings or at home)It will also strive to refer to practical elements related to specific population groups, such as children with disabilities, Indigenous individual with disabilities and migrants, and asylum seekers with disabilities |

1. **Adopt a well-planned and structured deinstitutionalization process**, including a comprehensive strategy and plan of actions, with reasonable timelines, benchmarks, human, technical and financial resources, and in the meantime establish a moratorium on new institutionalizations and re-institutionalizations. Strategies and plan of actions should:
	1. Ensure full respect of persons with disabilities’ autonomy, will and preferences, and genuine choices to live in the community
	2. Ensure incorporation of individualized support, respectful of the will and preferences of persons with disabilities
	3. Include measures to support persons with disabilities during the transition from institutions to live independently in the community
		1. Pay attention to the need of supporting families of children and adults with disabilities, including siblings, in transition from institutions to life in the community, and prevent recourse to re-institutionalization.
		2. Establish a short defined time frame for the transition
		3. Set up a period for the discharge of persons with disabilities from institutions, without delay.
		4. Ensure that support continues to be provided after the release from institutions.
	4. Ensure DI process are prioritized and carried out timely
2. Adopt short, medium and long term goals
3. Avoid delays in the implementation of the DI process based on alleged lack of resources
4. Ensure expeditious implementation of emergency DI
5. Introduce a deadline for the closure of all institutions, including mental health facilities.
	1. Ensure sustainable resource allocation
6. Ensure maximum available resources
7. Allocate appropriate human, technical and financial resources
8. Reorient and transfer financial resources, from institutions to individualized forms of support to live in the community, in particular at the local level.
9. Establish earmarked budgets for individualized forms of support: personal assistance, peer-to-peer networks of support, personal budgets.
10. Ensure no retrogression, including preventing the use of resources in the construction or refurbishing of institutions.
	1. Ensure appropriate governance of De-institutionalization process
11. DI is a State-led process, should include all relevant government departments and ensure comprehensive and inter-sectoral commitment throughout the government
12. Establish a leading authority
13. Establish a coordination mechanism, and division of responsibilities
14. Ensure the participation of persons with disabilities in the process, and their representative organizations; their views should be given due weight, and be prioritized over the views of families, service providers, caregivers, and charity and religious organizations, - persons with disabilities should be the majority people in any governance group or meeting.
15. Ensure coordination and cooperation between public authorities and non-state actors involved in the process;
16. Exclude institutions and service providers from the governance of the DI process; ensure that any former staff of any institutions wanting to join the DI process undergo vetting to prevent any person who has been involved in human rights violations participating in the DI process.
17. Ensure regular and accessible communication between different stakeholders (persons with disabilities, State officials, civil society organizations)
18. Ensure coherent implementation of deinstitutionalization between central and local governments and bodies
19. Clearly identify roles of state and non-state actors in the process
20. Ensure coordination with strategies, policies and actions plans in all areas of development (education, health, employment, social security, gender equality, etc.) and concerning different population groups (young, older, migrant persons with disabilities).
21. Prevent the emergence of new forms of institutionalization.
22. Implement the recommendations of subsequent chapters of these guidelines
23. DI strategies and action plans should be applicable and implementable during emergencies
24. **Ensure the free choice of persons with disabilities, and respect their will and preferences**
	1. Ensure the availability of a wide range of options of non-congregated living arrangements and prevent persons with disabilities to be constrained to choose only among available support and services. (Disguised “false choice” around what is available).
	2. Clarify that ‘choice’ over where and with whom to live does not extend to the choice to live in an institution; nor the obligation of States to create/maintain institutions.
	3. Develop skills in open and inclusive environments;
25. Develop skills of persons with disabilities for independent living, including through support by peers
	* 1. Ensure that young people are adequately prepared before exit from institutions psychologically and emotionally because it is often the only living environment they know;
26. Develop skills and ensure that persons with disability access modern information and communication technologies and devices
27. Enable persons with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential, through their participation in cultural activities, arts, leisure activities, sports, music, etc.
	1. Develop awareness raising activities targeting persons with disabilities, their families, services providers and staff working with or for persons with disabilities, including staff of institutions, and society in general including during periods of transition.

1. **Restore legal capacity**
	1. Recognise, ensure and restore the legal capacity of persons with disabilities who are institutionalized (both the capacity to be holder of rights and the capacity to act under the law)
	2. End *De facto* deprivation of legal capacity of persons with disabilities who are institutionalized
	3. Develop supported decision-making regimes based on the will and preferences, and on consent of person with disabilities.
2. Supported decision-making should be available for all persons with disabilities regardless level of impairment.
3. Supporters should be chosen by persons with disabilities, and not by third parties, including judicial authorities, family members, etc.
4. Supporters should respect the will and preferences of persons with disabilities.
5. Support should be available at nominal or no-cost for persons with disabilities
	1. Repeal legislation allowing for the disenfranchisement of persons on the basis of impairment, and restore political rights of all persons with disabilities affected by institutionalization.
6. **Ensure the provision of individualized support, respectful of the will and preferences of persons with disabilities**
	1. Develop personal and individualized support, including personal assistance, respectful of will and preferences
	2. Raise awareness of persons with disabilities about the availability and forms of individualized support.
	3. Develop a wide-range of disability support, including by recognizing different types of support (peer-to-peer, support networks, etc.),
7. Ensure affordability, availability and accessibility of individualize support, including for persons with disabilities in rural and remote areas
8. 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.
9. Ensure access to assistive technology to promote autonomy.
10. Allocate sustainable and personalized financing mechanisms.
11. Develop forms of support culturally appropriate for persons with disabilities belonging to minorities, and maintain an intersectional approach, including children, women, LGBTI+, etc.
	1. Ensure that the provision of personal assistance includes
12. Choice of personal assistance or any other support for independent living by the user
13. Provision of proper training to personal assistants that includes persons with disabilities as trainers, for ensuring respectful and professional assistance.
14. End of dependence on family members.
15. Personalised budgets for support, including budget for personal assistants are controlled by persons with disabilities with appropriate supported decision-making.
	1. Develop specific inclusion strategies (country and culture specific): community dialogue for inclusion, open dialogue. How to use existing support (and social capital) in the community to develop inclusive communities.
	2. Prevent disability specific supports that do not contribute to inclusion: such as day care centres, respite care and other so-called community-based services that do nothing to support inclusion
	3. Separate support from institutions
	4. Recognize the role of informal support, including the one provided by families, and ensure is in line with the Convention
	5. Provide non-coercive crisis support, including peer support and respect the provisions previously made by the individual through advance directives.
16. Ensure De-medicalization of support during crisis
17. Ensure de-judicialization of support provided during crisis
	1. Ensure income replacement and supplementation to cover disability related costs.
	2. Ensure the availability and continuation of all support services during emergency context.
18. **Be transparent and provide regular access to information in accessible formats and technologies**
	1. Ensure regular access to information about the DI process
	2. Develop and use accessible communication formats for mass media and public information.
	3. Provide persons with disabilities with accessible information about services and support available.
	4. Involve persons with disabilities in the preparation of documents in accessible formats, related to the DI process, including in emergencies.
	5. Train staff working for and with persons with disabilities to communicate effectively and understand the varying communication requirements and forms of communication.
19. **Address trauma and provide redress to survivors of human rights violations in the context of institutionalization**
	1. Adopt measures to restore the rights and dignity of persons with disabilities who are in institutions or have faced institutionalization.
	2. End *De facto* deprivation of legal capacity of persons with disabilities who are institutionalized and prevent directors or administrators of institutions from becoming guardians of persons with disabilities.
	3. Adopt measures to end violence and ill-treatment in institutions
	4. Stop over-medicalization, including any treatment without consent.
	5. Address gender-based violence, including institutional forms forced sterilisation, forced abortion, forced contraception
	6. Address the impact of permanent deprivation of liberty in institutions, including in mental health facilities.
	7. Provide human rights-based support, which includes accessible emergency shelter, legal aid, medical, psychological , social and peer-to-peer support
	8. Provide individual and collective redress and reparations, including adequate compensation, to persons with disabilities affected by institutionalization, and persons that have suffered direct harm.
	9. Acknowledge re-institutionalization as a form of re-victimization, and end re-institutionalization
	10. Include a disability perspective in restorative and transitional justice processes.
20. **Ensure accountability, end impunity, and bring to justice perpetrators of human rights violations in the context of institutionalization**
	1. Identify all forms of violence against persons with disabilities, particularly against children with disabilities.
	2. Reinforce mechanisms of reporting incidents of deaths, violence, ill-treatment, exploitation and abuse
	3. Ensure that persons reporting abuses are not further subjected to mental health treatments of coercive and punitive nature and that they are given protection and safeguards against backlash, punishment, intimidation, reprisals and threats.
	4. Provide access to justice to victims, by ensuring gender and age-sensitive procedural accommodations, and the provision of legal aid, independent of institutions
	5. Combat stigma and prejudices against victims and witnesses of gender-based violence, and ensure safe environments for reporting cases and incident of gender-based violence to independent authorities.
	6. Provide particular attention incidents of abuse against persons with disabilities by their family members, and abuses that took place in the private sphere by service providers.
	7. Establish vetting processes for perpetrators
	8. Investigate and impose administrative and/or penal sanctions authors of human rights violations in institutions, irrespective of their placement in the hierarchy of the institutions.
21. **Overhaul DI in situations of risk, disasters and humanitarian emergencies, including in situations armed conflict.**
	1. Acknowledge that during emergency situations lockdown disproportionately affect persons with disabilities in institutions.
	2. Prevent isolation, ill-treatment, disability-based discrimination and bias in triage protocols, avoiding preventable death
	3. Ensure the collection of disaggregated data on persons with disabilities affected by emergency situations
	4. Prevent homelessness of persons with disabilities released from institutions
	5. Develop and implement inclusive emergency protocols
	6. Ensure inclusion of persons with disabilities in the community as a priority during emergencies
	7. Provide support in the community to families of persons with disabilities in emergency situations
	8. Include accessibility and reasonable accommodation in emergency protocols
22. Pay particular attention to specific groups of persons with disabilities, for example, persons with intellectual disabilities affected by isolation and confinement measures; deaf persons affected by the use of masks that do not allow for lip-reading;
23. Avoid standardized solutions, which infringe upon the inclusion of persons with disabilities, for instance, those who use augmentative and alternative means and modes of communication.
24. Develop accessible information about emergency protocols
	1. Acknowledge that the congregate nature of institutions makes these places inherently dangerous, particularly during any type of health/natural disaster/humanitarian emergency
	2. Ensure safety of persons with disabilities during emergency, through inclusion in the community
25. Acknowledge that health is compromised due to long-term use of psychiatric medication in institutions, which increase the risk of infection, sickness and death, during emergencies.
26. Acknowledge that improving conditions/modernising/investment in staff is not the answer, and that safety through inclusion in the community is the only safe environment.
27. Prevent homelessness and impoverishment of persons with disabilities during emergencies.
28. Ensure equal access of persons with disabilities to vaccination programmes and ensure access to information about available vaccines in accessible formats.
	1. Ensure the continuation of disability support services during crises and prevent regression.
	2. Ensure access of persons with disabilities affected by armed conflict to humanitarian assistance and relief on an equal basis with other, ensuring also that information about assistance and relief is provided in accessible formats.
	3. Ensure effective participation of persons with disabilities in the design and implementation of emergency response, relief and recovery.
	4. Ensure effective implementation of accountability mechanisms to address human rights violations in situations of emergency.
29. **Collect disaggregated data**
	1. Collect appropriate disaggregated data to understand the context in which persons with disabilities are living and to design policies, plans and programmes for DI and to measure implementation
	2. Involve organizations of persons with disabilities in relevant decision-making processes including defining data collection priorities
	3. Guarantee the privacy of personal data
	4. Address the uncertainty about numbers and percentages of persons with disabilities affected about institutionalization, by compiling disaggregated statistics in a sustainable manner.
30. **Ensure DI processes are monitored by independent authorities and by organizations of persons with disabilities**
	1. Ensure independent monitoring mechanisms, National Human Rights Institutions, ombudspersons, and equality bodies and monitor the implementation of DI process; ensure they have unrestrictive access to institutions, documents and relevant information;
	2. Implement recommendations issued by independent monitoring bodies.
	3. Ensure monitoring by organizations of persons with disabilities; ensure they have unrestrictive access to institutions, documents and relevant information.
	4. Ensure that independent monitoring bodies, National Human Rights Institutions and National preventive mechanisms (NPMs) have a role in identifying violations of human rights of persons still living in institutions, address and implement their recommendations and protect persons with disabilities undergoing deinstitutionalization.
	5. Ensure monitoring during emergencies.

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1. Membership in the COVID-19 DRM to be explained in this footnote [↑](#footnote-ref-1)
2. Membership of the Global Coalition on Deinstitutionalization and consultants [↑](#footnote-ref-2)
3. Reference to Committee’s General comment No 5 (2017) to be inserted here, particularly paragraphs explaining State parties’ duties, including vis-à-vis non-state actors [↑](#footnote-ref-3)
4. Reference to Committee’s General comment No. 5 (2017), particularly paragraphs related to obligations of states parties. [↑](#footnote-ref-4)
5. General comment No. 1 (2014) see para. 40 [↑](#footnote-ref-5)
6. Committee’s General comment No. 5 and inquiry reports. [↑](#footnote-ref-6)
7. Reference to Guidelines on article 14 to be included. [↑](#footnote-ref-7)
8. Reference to GC No1 to be included here [↑](#footnote-ref-8)
9. Reference to GC No6 to be included here [↑](#footnote-ref-9)