

**Comments submitted to the Committee on the Rights of Persons with Disabilities on its draft Guidelines on Deinstitutionalization, including in Emergencies**

June 30, 2022

Introduction

The Center of the Human Rights of Users and Survivors of Psychiatry (CHRUSP) is a non-membership DPO taking a survivor of psychiatry perspective, with board members in the United States and in Singapore and networks reaching throughout the world in our Absolute Prohibition Campaign. CHRUSP board members all identify as survivors of institutionalization.

CHRUSP and its individual board members regularly contribute to the work of the Committee on the Rights of Persons with Disabilities and other UN human rights mechanisms, advise DPOs, NGOs, individual rights holders, researchers and state entities regarding the application of the CRPD, and collaborate with other organizations in our human rights work. CHRUSP promotes a reparations approach to deinstitutionalization and organized a side event on ‘Remedy and Reparation for Institutionalization’ at the most recent Conference of States Parties, in cooperation with Transforming Communities for Inclusion – TCI and Validity Foundation.

These comments address four primary areas of concern: I. Position of persons with disabilities vis a vis families and family members; II. Ensuring independent living support as a primary service; III. Short-term disability-based detention (a clarification); IV. Deinstitutionalization process to be reparative; followed by V. Additional comments for consistency with the Convention and good practice on a) Respect for legal capacity and privacy; b) Representation; and c) Additional clarifications.

**Comments on draft Guidelines on Deinstitutionalization**

1. Position of persons with disabilities vis a vis families and family members
2. Persons with disabilities, not family units or non-disabled family members, are rights holders and protagonists under the Convention. They may occupy any family role or relationship, including those of spouse and parent. DPOs in regional consultations identification the control exercised by families over persons with disabilities as a barrier to inclusion, calling for de-familizarization along with deinstitutionalization. Furthermore, in a vast proportion of instances, family members of persons with disabilities are directly implicated in institutionalization. These premises are not adequately reflected in the Draft Guidelines.
	1. Family members of persons with disabilities should not be addressed in the Guidelines as direct rights holders unless justifiable under Article 2 (non-discrimination based on association with a disabled person).
		1. The last sentence of paragraph 92 is unjustifiably broad, is repetitive of narrower provisions elsewhere in the draft Guidelines, and should be deleted. See in addition comments below on deinstitutionalization process (point 4).
	2. The noun ‘the family’ or ‘families’ should not be used in the document to refer to family members, inclusive or exclusive of persons with disabilities, as a unit. Instead, **‘***family members*,’‘*family members of persons with disabilities*,’ or ‘*their family members*’ should be used as appropriate, to maintain the centrality of disabled persons as rights holders and their inclusion in any family unit they are part of. This applies to paragraphs 37, 44, 50, 69, 72 (see additional comments), 87 (second instance), 92 (see additional comments), 98 (as it refers contextually to family members of disabled persons rather than all families in the society).
	3. The scope of family roles and relationships of persons with disabilities, as well as the diversity among families, should be acknowledged to include those relevant to persons with disabilities at all ages. Language could be included in paragraph 37 (following the first sentence), to the effect that: ‘*The concept of family for adults with disabilities may include spouse or partner, children, family of origin, extended family, and chosen family.*’
	4. Paragraph 69, second sentence, should be amended as follows: ‘*Persons with disabilities must have access to a wide range of options to create support systems and networks, not limited to their family members*.’
	5. Support is a right held by persons with disabilities who may use it. This includes the right to have backup support when their usual supporters are unavailable. It cannot be claimed derivatively as a right of their usual supporters to have backup support provided so that they can take breaks, whether the usual supporters are family members or otherwise. The content of paragraph 72 should be deleted following the first two sentences (after modifying to ‘*family members*’ as per above). A separate paragraph appropriately placed should provide that ‘*Persons using support, including support by family members, must be informed about the likely need for backup support arrangements when their regular supporters may not be available, and supported, if necessary, to create such arrangements*.’
		1. The concept of ‘respite’ under Article 28(2)(c) of the Convention cannot be interpreted to mean a derivative right for the benefit of supporters. An alternative meaning for ‘respite’ is as a direct service to persons with disabilities who need to take breaks from their usual support or living arrangements. This can be a form of crisis support, as organized by people with psychosocial disabilities using peer respite.[[1]](#footnote-1) WNUSP advocated for the inclusion of peer respite during the CRPD drafting process. See below comments on paragraph 71.
	6. Add in Section IX,‘*Reparation must go beyond state obligations to become a whole-society effort. Persons who participated in institutionalizing others, including members of their families and communities, should make amends to those they have wronged***.**’
3. Ensuring independent living support as a primary service
4. To ensure effective deinstitutionalization and implementation of the Guidelines, people with psychosocial disabilities need to have the flexibility to pursue innovative law and policy frameworks to provide for their support needs, that are based entirely outside the health sector or that treat the health sector as subsidiary to a disability human rights agency which takes primary responsibility and allows for a wide range of options outside the health system. Many provisions throughout the Guidelines are welcome in this regard, and we call for the following additions and minor changes:
	1. In paragraph 10, replace ‘forced medicalization’ with ‘*default medicalization*’.
	2. Paragraph 74 should add the concept that ‘*these forms of support, along with personal assistance and personally designed support arrangements, must be made available to all people with psychosocial disabilities as primary services without need for mental health diagnosis or treatment, according to the will and preferences of the person concerned*.’
	3. Paragraph 101 should add the concept that health care services should ‘*refrain from medicalizing disability*’.
5. Short-term disability-based detention (a clarification)
6. To ensure states parties’ understanding of and compliance with the elimination of deprivation of liberty in mental health settings, it is necessary to specify that any duration of such deprivation of liberty amounts to institutionalization. For most inclusive effect, in paragraph 19, add in the final sentence, ‘*or the duration of any placement or detention*’.
7. Deinstitutionalization process to be reparative
8. Deinstitutionalization must be viewed as an act of reparative justice in conceiving and carrying out the deinstitutionalization process, as well as its goal of righting an egregious wrong. The draft Guidelines does not yet adequately capture the reparative process which starts from an equalization of power and takes the will and preferences of each person concerned as a starting point.
	1. The first sentence of paragraph 91 should be rephrased as two sentences: ‘*The deinstitutionalization process reverses the unjust practice of institutionalization. It begins while the person is still in the institution and entails planning processes customized to each individual*.’ This wording acknowledges upfront the intention to reverse injustice and characterizes planning as active and ongoing rather than a blueprint that will be followed. The second sentence in the draft Guidelines, beginning ‘All persons,’ should remain as is.
	2. Paragraph 92 should be similarly revised to reflect a reparative process, to read as follows: ‘*States Parties should ensure that planners, implementers and institutional staff are trained on a human-rights, reparative and person-centred meaning of deinstitutionalization, providing communication assistance and using methods such as appreciative inquiry to ensure that the worldview, knowledge and priorities of individuals are respected. Trusted persons, which may include family members, friends and others, should be involved in planning processes in accordance with the will and preferences of the person concerned. Peer support for institutionalized persons and survivors of institutionalization should be facilitated as part of planning and transition to promote full inclusion through self-initiated action in the community. Family members of persons who are institutionalized should be provided with knowledge to confront the harms caused by institutionalization and prepare to constructively support their family members leaving institutions in accordance with the will and preferences of those concerned*.’
	3. In paragraph 93, the clause ‘and their will and preferences should be reflected in the plan,’ now in subparagraph (d), should be moved to subparagraph (b) to follow ‘have an individualized plan in place’. Subparagraphs (c) and (d) should be revised as follows: ‘*be respected as a survivor to whom reparations are due and be provided with information and opportunities to participate fully in the planning and implementation of deinstitutionalization, truth commissions and reparations*’. The concept of a person being ‘at the core of individualized planning’ is both repetitive of 91 and 92 and vague as to meaning and is unnecessary in this paragraph.
9. Additional comments for consistency with Convention and good practice
10. Respect for legal capacity and privacy
11. The second sentence of paragraph 55 should be reframed to clarify the difference between consent and the standard for best interpretation, as follows: ‘*This should only happen based on the person’s free and informed consent or, when the person’s rights are at stake and it has not been feasible to obtain an expression of will from the person, despite real, considerable and pertinent efforts and the provision of accessibility and reasonable accommodations, based on a best interpretation of the will and preferences of the person concerned*.’[[2]](#footnote-2)
12. In paragraph 61, second sentence, ‘based on’ should be changed to ‘*subject to*’. The mapping of ties can replicate invasions of privacy characteristic of institutionalization.
13. In paragraph 64, third sentence, children’s evolving legal capacity should be respected in directing support workers. Suggest ‘*or the parents or guardians of children with disabilities, giving due weight to the child’s views*.’
14. Paragraph 127, second sentence, is overly broad and does not consider the privacy rights and concerns of persons with disabilities, especially those who are institutionalized. The problem is that institutional staff invoke the inmates’ ‘privacy’ to shield the institution. Replace the second sentence with: ‘*Nevertheless, existing laws often fail to respect the legal capacity of persons with disabilities, leading to violation of their privacy and undermining human rights monitoring and advocacy*.’ In the third sentence, insert ‘*ensuring compliance with the Convention and*’ before ‘meeting internationally-established standards,’ before the remainder of the paragraph.
15. In paragraph 134, first sentence, change ‘either… or’ to ‘*and/or*’ and add ‘*in accordance with the person’s will and preferences*’. This allows for the option of receiving the records oneself and having them expunged anywhere that the institutionalization is still recorded.
16. Representation
17. In paragraphs 35, 65, 66, 107, 120, 124, 139 replace ‘through their representative organizations’ with ‘*and their representative organizations.*’ In 120, change the wording to read ‘*persons with disabilities, particularly survivors of institutionalization, including children with disabilities, and their representative organizations*.’ The regional consultations demonstrated the value of including individuals as well as representative organizations, and this is reflected in some but not all provisions in the draft Guidelines.
18. In paragraph 63, consultation with DPOs should cover the identification of gaps in support as well as the creation of pilot projects.
19. Additional clarifications
20. In paragraph 39, insert a comma and the word ‘*including*’ before ‘through a lack of support services.’ (As the examples demonstrate, it is not only through lack of support services that discrimination results in institutionalization.)
21. In paragraph 53, delete ‘orders’ after ‘forced mental health treatment’, consistently with GC1 paragraph 7. Not all regimes of forced treatment rely on orders.
22. In paragraph 71, the second sentence should be amended as follows: ‘*It is especially important for survivors of institutionalization, and can include consciousness-raising, supported decision-making, crisis support and crisis respite, living independently, income generation, political participation, and/or participating in social activities.*’ Modifications are to correct unclear syntax, and to add crisis support and crisis respite among the needs that can be addressed with peer support.
23. In paragraph 97, ‘to experience’ can be omitted.
24. In paragraph 138, first sentence, add ‘*or disability-based coercive measures*’.
1. The best internationally known example is Afiya House <https://wildfloweralliance.org/afiya/>, spotlighted in WHO’s compilation of good practices. (We mention WHO’s endorsement to demonstrate wide recognition, but do not support the absorption of peer respite or crisis support into a health law or policy framework.) [↑](#footnote-ref-1)
2. GC1 paragraph 21; Legislative Decree 1384 (Peru), Article 3 – chapter 659-E, Exception to the Judicial Designation of Supports (excerpt): ‘This measure is justified after having made real, considerable and pertinent efforts to obtain an expression of will from the person, and having provided them with measures of accessibility and reasonable accommodations, and when the designation of supports is necessary for the exercise and protection of their rights.’ [↑](#footnote-ref-2)