

Center for the Human Rights of Users and Survivors of Psychiatry

Submission to the Open-ended Working Group on Ageing, with reference to:

Identification of possible gaps in the protection of the human rights of older persons and how best to address them

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The Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP) is a nongovernmental organization that works actively to promote the full implementation of the Convention on the Rights of Persons with Disabilities with respect to persons with psychosocial disabilities and survivors of psychiatric institutionalization. CHRUSP has contributed significantly to the work of the Committee on the Rights of Persons with Disabilities and other international and regional human rights mechanisms in their development of the normative framework to be applied under the Convention, including the Guidelines on Deinstitutionalization, Including in Emergencies.

In light of its focus and expertise, CHRUSP addresses in this submission the gaps in the normative framework for older persons with disabilities with respect to the CRPD Guidelines on Deinstitutionalization, as well as our concern regarding the intersectional issue of domestic violence, and the value of a new international convention to promote more robust elaboration of these standards with respect to older persons with disabilities.

- 1) Gaps in the normative framework
- d) Autonomy and independence

The Committee on the Rights of Persons with Disabilities' Guidelines on Deinstitutionalization, Including in Emergencies, provide valuable normative standards for older persons with disabilities but nevertheless contain gaps.

The 2022 CRPD Guidelines on Deinstitutionalization briefly addresses the situation of older persons with disabilities, identifying 'dementia villages' among the forms of institutionalization that affect older persons with disabilities and must be targeted for elimination in a

deinstitutionalization.¹ The Guidelines call for older persons with disabilities to retain their homes in the community and to continue receiving support such as personal assistance as they age, with such support increasing over time as needed, rather than resorting to institutionalization.²

These standards interpret the Convention on the Rights of Persons with Disabilities, which is binding on 188 States Parties.

However, the Guidelines do not otherwise address the particular situations of persons for whom ageing intersects with disability, regarding questions such as the kinds of support people with dementia find useful; how interactions with family members providing support may be different for older persons with disabilities compared with younger adults and with children who receive support from their family members; whether older persons currently residing in institutions may need different kinds of support compared with younger adults and with children, in order to exercise their rights to leave and to live in the community.

The Guidelines on Deinstitutionalization are an important normative development that is highly dense and abbreviated as it addresses a wide scope of situations that all fall under the concept of institutionalization and States Parties' obligations to implement full-scale deinstitutionalization. The standards applicable to all persons with disabilities need to be explored and further elaborated, in active consultation with older persons with disabilities, to advance in implementing the human rights of older persons with disabilities to autonomy and independence.

b) Violence, neglect and abuse, and its linkage with autonomy and independence

Older persons can easily become victims of domestic violence. In many cases, they depend on support and at the same time, their possibility to ask for help are very limited, as in many countries there are no reasonable accommodations and procedural accommodations which can make this process accessible for them. In many cases, the acts of domestic violence lead to institutionalization as a result. It can happen as a form of "protection," after a period of serious neglect and different form of violence, or it can be an element of the violence.

The existing legal framework does not recognize this specific vulnerability and doesn't provide remedies to overcome it. For example, CEDAW doesn't content any specific rules related to older women (in contrary, there are specific rules for pregnant women and those who are caring for a child/children). This means, that the needs of the group of the older women and especially those with disabilities is not recognized as a group with specific needs from protection. This gap must be considered in the future discussions and development of the legal framework.

¹ CRPD/C/5, para 52.

² Id, para 81.

On another hand, even though the CRPD recognized institutionalization as a violation of the human rights of the persons with disabilities, it has never been discussed that the institutionalization can be a form of domestic violence and courts have not examined whether the act of placement of an institution, a violation of human rights in itself under the CRPD, is a result of domestic violence or it is a part of such violence itself. This is a problem not only for older people with disabilities, but they are in huge risk to be subjected to such violence, especially when there is no proper support to them and their families and where there is no proper remedies for older people with disabilities (especially dementia) to seek protection and justice.

2. How to address these gaps

CHRUSP considers that an international convention on the rights of older persons would most strengthen the prospects of a more robust elaboration of the rights of older persons with disabilities. The CRPD brought exponentially greater focus on the rights of persons with disabilities throughout the international human rights regime, including by prompting attention to the intersectionality of disability with other thematic treaties. A treaty regime, with regular reporting and communications under an Optional Protocol, serves a promotional purpose by integrating a thematic dimension of equality and non-discrimination (i.e. based on ageing in this case) that has been indispensable to the advancement of human rights.

As older persons with disabilities comprise more than 46% of older persons,³ a new convention and the corresponding treaty body should be able to devote significant attention and resources to their situation and concerns, including in the area of autonomy and independence. Mutual sharing of expertise with the Committee on the Rights of Persons with Disabilities, including the possibility of joint General Comments or Guidelines, should also be pursued.

A binding treaty regime also promotes greater capabilities on the part of civil society, particular the persons whose rights are directly affected, to engage in reporting processes, advocacy for implementation and participation in their country's implementation processes. A new treaty should ensure that there is both an explicit reference to the significant intersection between ageing and disability, and transversal attention throughout the text to the situations of older persons with disabilities, including those who are currently residing in institutions, at risk of institutionalization, or who are survivors of institutionalization living with the impact of that trauma.

³ https://www.un.org/development/desa/disabilities/disability-and-ageing.html.