



Submission on the CRPD Committee's “Draft Guidelines on De-institutionalization, including on emergencies.”

July 2022

by

the Dementia Alliance International (DAI)

The Dementia Alliance International is a global organization of persons with disabilities (DPOs) and a registered US Corporation with 501(c)(3) status, whose membership is inclusively for people with a diagnosis of any type of a dementia from all around the world. DAI advocates for the more than 57 million people living with dementia globally, and represents, supports, and educates others living with the disease, and the wider dementia community. It is an organization striving to provide a unified voice of strength, advocacy and support for our rights, individual autonomy and improved quality of life. DAI is the peak organisation globally representing persons with dementia, and thus widely accepted as the global voice *of* dementia. DAI's mission is to advance the human rights of persons with disabilities, more specifically those caused by a diagnosis of any type of dementia, as people with dementia have been left behind. The DAI provides a united voice and advocates for the human rights of its members in 49 countries, through utilising the Convention on the Rights of Persons with Disabilities and other human rights instruments.

DAI Submission on the CRPD Committee’s “Draft Guidelines on De-institutionalization, including on emergencies”

1. Introduction

1. The Dementia Alliance International (DAI) is extremely grateful to the Committee on the Rights of Persons with Disabilities (CRPD) for the opportunity to provide comments on the “Draft Guidelines on deinstitutionalization, including in emergencies.” DAI is supportive of this process, and we appreciate the transparent and highly participatory process. We are confident the Guidelines will be an important and useful contribution to accelerating States’ deinstitutionalisation efforts, consistent with international human rights standards, and that they will include the more than 57 million people living with dementia¹, a condition causing acquired cognitive and multiple other disabilities.

2. In general terms, DAI welcomes the purpose, structure, and content of the document. We provide comments on the next sections directed specifically to ensure people with dementia are included in the work of the committee on deinstitutionalisation, and to improve the scope of application of the document and of specific recommendations. States and State officials should be the main, although not exclusive, addressees of this guidance.

2. Specific comments (identifying paragraphs)

3. When providing concrete drafting proposals, new paragraphs and added phrasing is indicated in bold letters and we use single strikethrough over the words we suggest being removed.

¹ GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence through 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health* 2022; 7: e105–25.

Paragraph 2:

4. DAI proposes to reflect that institutionalization also impacts on the rights of persons with disabilities:

“... of institutionalization on the **rights and** well-being of persons...”

Paragraph 6:

5. The Human Rights Council has recently considered “institutionalization” as a form of violence, which should be reflected in these guidelines from the outset. DAI proposes then to add the following phrase to paragraph 6.

“6. [...] **The Human Rights Council has recently expressed that “forced institutionalization is a form of violence that deprives women and girls of liberty on the basis of disability.”**”²

Paragraph 12:

6. Current paragraph 12 referring to children with disabilities should be placed after paragraph 8.

Proposal for a new paragraph 10

7. DAI proposes the following four sections for a new paragraph to be added following current para. 12, once placed after para. 8

(1) “Older persons with disabilities, including those with acquired progressive disabilities due to dementia, are either institutionalised or at risk of institutionalisation, both at disability specific institutions or at institutions for older persons. Wherever institutionalised, and whatever care and support policy or system tackle their situation, these guidelines include them, and deinstitutionalization efforts should consider them from the outset.”

(2) “The growing recognition globally that people with dementia re people with disabilities³ makes it critical to include this cohort. In 2010, the WHO launched the updated version of

² Human Rights Council, Res. 47/15, PP20.

³ Steele, L & Swaffer, K (2022). Reparations for Harms Experience In Residential Aged Care, Health and Human Rights Journal, <https://www.hhrjournal.org/2022/06/reparations-for-harms-experienced-in-residential-aged-care/>

the WHO Disability Assessment Schedule (WHODAS 2.0)⁴, the internal classification of functioning, disability, and health. At the same time, the WHO stated, that ‘dementia is a condition which is the leading cause of disability and dependence in older persons globally’ although now says a major cause of disability and dependence⁵. At the 2017 mental health GAP (mhGAP) Forum, the WHO re-categorised dementia as a condition causing cognitive disabilities; it had previously been listed under psychosocial disabilities. Dementia is now recognised by the CRPD Committee and the Special Rapporteur on the Rights of Persons with Disabilities as a condition causing cognitive and other disabilities⁶, and the International Disability Alliance⁷ includes DAI as an Observer member, in recognition of dementia as a condition causing acquired cognitive (and other) disabilities.”

- (3) “Fundamental to recognising the human rights of people with dementia, in the community and in long term residential care, is equal access to the CRPD and other international human rights instruments, including OPCAT. Recognition of human rights of people living with dementia includes ‘deinstitutionalisation and de-segregation of housing and support for people with dementia including aged care facilities and secure dementia units.’⁸”
- (4) “DAI endorses ‘The call for recognition of human rights through redress for past and future systemic and structural harms experienced by people living with dementia (‘people with dementia’) in residential aged care, and argument that States and State officials, dementia care service providers including for-profit, religious, and charitable organizations, along with the broader community, must acknowledge and seek reparations for past injustices experienced by people with dementia in institutional care, in order to stop the violence, abuse and neglect^{9,10}.’”

⁴ World Health Organisation, 2010, WHO Disability Assessment Schedule 2.0 (WHODAS 2.0), <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health/who-disability-assessment-schedule>

⁵ World Health Organisation, 2022, Dementia, https://www.who.int/health-topics/dementia#tab=tab_1

⁶ United Nations, 2019, https://www.un.org/ga/search/view_doc.asp?symbol=A/74/186

⁷ International Disability Alliance, Observer Members, <https://www.internationaldisabilityalliance.org/observer-members>

⁸ Grenfell, L. (2019). Aged care, detention and OPCAT. *Australian Journal of Human Rights*, 25(2), 248-262.

⁹ Steele, L & Swaffer, K (2022). Reparations for Harms Experience In Residential Aged Care, *Health and Human Rights Journal*, <https://www.hhrjournal.org/2022/06/reparations-for-harms-experienced-in-residential-aged-care/>

¹⁰ Spivakovsky, C., Steele, L. and Weller, P. eds., 2020. *The Legacies of Institutionalisation: disability, law and policy in the ‘deinstitutionalised’ community*. Bloomsbury Publishing.

Paragraph 14: Scope of the concept of “institutionalization”

8. Paragraph 14 begins with the uncompromising statement: “Institutionalization includes all forms of placement and detention,” followed by a long list of forms of institutionalization and a sentence requesting the inclusion in deinstitutionalization efforts of “mainstream institutional settings,” including “prisons.” DAI proposes the following inclusion:

“Secure dementia wards and locked aged care institutions must be deemed as prisons, to ensure they are included under the OPCAT monitoring, as well as their rightful access to the CPRD as people with disabilities, and all other human rights mechanisms.”

Paragraph 18:

9. DAI proposes the following for clarity purposes:

“Due to potential conflict of interests, processes of deinstitutionalization should not be led by public officials or third parties who have involved in any way, including aged and dementia care providers, directly or indirectly in the management and/or functioning, with relevant decision-making power, of institutions, due to conflicts of interest and the profit-making nature of aged and dementia care institutions.

Paragraph 22: Distinguishing supports under articles 12 and 19(b) CRPD

10. DAI highlights the need to prevent confusing support in decision-making under Article 12 CRPD with support systems and services under Article 19(b) CRPD, given the different kinds of obligations stemming from them, according to CRPD Committee’s jurisprudence.¹¹ In addition, the phrase of paragraph 21 would be better placed to conclude a new paragraph 22. Thus, the following proposal for para. 22 (and a new 23).

“22. [...] networks.¹² In order to be aligned with the Convention, support services for living independently should be available, accessible, acceptable, affordable, and adaptable.¹³ States

¹¹ See CRPD/C/GC/1, para. 26 (stating that “[a]s such, the rights provided for in article 12 apply at the moment of ratification and are subject to **immediate realization**. ... Progressive realization (art. 4, para. 2) does not apply to article 12.”); and CRPD/C/GC/5, para. 39 (stating that “Article 19 (b), the right to access individualized, assessed support services, is an economic, social and cultural right.”)

¹² A/HRC/34/58.

¹³ Brought up from current para. 23 of the draft.

Parties should prioritize the development of a range of individualized supports, while advancing on making mainstream services in the community accessible and inclusive without delay.”

23. Persons with disabilities or their care-partners should be enabled to exercise their legal capacity in line with General Comment No. 1 on articles 12 CRPD, thus with immediate application,¹⁴ in choosing, managing and terminating the provision of community-based support. Support in exercising legal capacity can be provided as a service funded by the State,¹⁵ or by a person’s informal networks.”

Paragraph 33: Priority to the views of organizations of persons with disabilities

11. DAI highlights the need to refer to and utilize language of CRPD Committee’s general comment no. 7 on articles 4(3) and 33(3). Thus, the following proposal:

“33. ... in line with articles 4(3) and 33 and General Comment No. 7.¹⁶ States parties should give priority to the views of organizations of persons with disabilities, as they address issues related to persons with disabilities.¹⁷ Service providers, ...”

Paragraph 36:

12. Understanding the intention by CRPD Committee, but in order to avoid sounding paternalistic towards persons with disabilities in institutions, DAI proposes the following:

“36. [...] Individuals or their families and care partners who have been denied the right, to decision-making ~~may not initially immediately realize the value of their freedom or community life~~ feel comfortable with being invited to live independently and included in the community, even if offered support...”

Paragraph 37:

13. DAI emphasises the need to acknowledge and protect the *de facto* support role family members and care partners or other informal advocates of people with dementia usually assumed due to lack of alternatives and avoid restrictions to the rights of care-partners in the design and requirements of social protection schemes providing any support,

¹⁴ See CRPD/C/GC/1, para. 26.

¹⁵ CRPD/C/GC/1, para. 16

¹⁶ CRPD/C/GC/7, para. 12(c).

¹⁷ CRPD/C/GC/7, paras. 13, 14 and 23.

e.g., financial support schemes should not prevent care-partners from engaging in employment compatible with their support role. A similar concern is expressed in paragraph 87.¹⁸ For para. 37, DAI proposes:

“37. ... States Parties should ensure that the family has access to adequate financial, social, and other assistance to fulfil their support role, **and that support schemes do not restrict automatically and unnecessarily the rights of care-partners, e.g., support allowance should not prevent care-partners from seeking employment compatible with the care-partner role.** State support ...”.

Paragraph 41:

14. DAI highlights the relevance of including a subsection on older persons with disabilities following the subsection on women and girls with disabilities, as they are disproportionately affected by dementia, either with a diagnosis themselves, or as unpaid care-partners, and women and girls particularly in low- and middle-income countries are being denied education and employment because of this disparity.

Paragraph 54: broad scope of procedural accommodations

15. DAI considers it important to portray a broad scope of procedural accommodations through examples not limited to issues of accessibility of information and communication.¹⁹ Hence, DAI proposes:

“54. Procedural accommodations, such as Easy Read materials, plain language **and cognitive ramps such as communication accessibility,** and **procedural flexibility, extending or adjusting procedural deadlines and adjusting procedural formalities,**²⁰ should be made available.”

Paragraph 59:

16. DAI suggests part c) requires more clarity to better reflect the connection between violations of rights and their causes:

¹⁸ Current para. 87, in fine, reads: “Family members whose support responsibilities have disadvantaged them in other life paths should be provided with additional support.”

¹⁹ Current para. 87, in fine, reads: “Family members whose support responsibilities have disadvantaged them in other life paths should be provided with additional support.”

²⁰ See A/HRC/37/25, para. 24.

“(c) [...] against institutionalization and discrimination on the basis of disability, including ~~the failure to provide reasonable accommodations or support in the community~~ **respectively the failure to provide support in the community and/or reasonable accommodation.**”

Paragraph 73:

17. The second phrase is excessively categorical and prevents the possibility of benefitting from medical expertise:

“72. ... States Parties should not **rely exclusively nor mainly on the** use medical criteria when developing new needs assessment tools, and medical professionals should not **be granted with prevailing or higher status over other professionals involved in assessments nor any decision-making power over persons with disabilities** ~~be involved.~~”

Paragraph 75:

18. DAI proposes further clarifying in this way:

“75...The use of day-care centres **that segregate persons with disabilities, including people with dementia, and other all institutional settings that impose a routine, in addition to typically infringing access to the community and other individualised activities,** are paternalistic and do not comply with the Convention.”

Paragraphs 83:

19. DAI proposes to add the criterion of “affordability”.

“84. States Parties should increase and ensure access to **and affordability of** assistive technology...”

Paragraphs 84:

20. To distinguish concepts and purposes of social protection more clearly for persons with disabilities, DAI proposes revised language for paragraphs 84 and 85.

“84. Persons with disabilities **and other survivors and victims of institutionalization, including family members or care-partners of deceased institutionalised persons,** should receive individualized and direct funding that provides for ~~income replacement and covers disability-related costs~~ **basic income security, coverage of health care cost and disability-related costs,** including [...]”

For further information, please contact:

Kate Swaffer, kateswaffer@infodai.org

Human Rights Adviser and Co-founder

Dementia Alliance International

Postal address: C/- Patrick with Durio & Korpai, P.C
6575 West Loop S, Ste 400, Bellaire TX 77401-3512