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# Deinstitutionalization as Reparative Justice: A Commentary on the *Guidelines on Deinstitutionalization, including in Emergencies*

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Tina Minkowitz

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Article

# Deinstitutionalization as Reparative Justice: A Commentary on the Guidelines on Deinstitutionalization, including in Emergencies

Tina Minkowitz

Center for the Human Rights of Users and Survivors of Psychiatry, Chestertown, NY 12817, USA; tminkowitz@earthlink.net

**Abstract:** In this paper, I argue that the Committee on the Rights of Persons with Disabilities Guidelines on Deinstitutionalization, Including in Emergencies function as an instrument and template for reparative justice towards persons still in institutions and survivors of institutionalization. The Guidelines construct deinstitutionalization as a reparative process at both the systemic and individual levels, as well as calling for the creation of reparation and redress mechanisms. I examine the entire body of the Guidelines, highlight their reparative content, and point out where the text may fall short of this perspective and how the shortcomings might be remedied. This paper is grounded in the situation of psychiatric institutionalization and the concerns of people subjected to that system, emphasizing issues faced by this constituency and its human rights concerns for redress and legal and societal change. The issues addressed include the following: the strengthening of normative standards with regard to the abolition of psychiatric institutionalization and forced interventions and the obligation to immediately end these violations; a policy shift towards the de-medicalization of psychosocial disability; the implications of reparative justice in diminishing the role and authority of those that have operated institutions including the mental health system; the role of adult persons with disabilities as members of families and the role played by some family members in institutionalization; issues to be considered in designing reparations processes and mechanisms. Following some introductory remarks, this paper is structured to follow the outline of the Guidelines, quoting the text with interspersed comments and ending with a brief conclusion.



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**Keywords:** deinstitutionalization; reparations; reparative justice; CRPD; Convention on the Rights of Persons with Disabilities; psychiatric institutionalization; psychiatric survivor; psychiatric survivor movement

## Introduction

In 2022, the Committee on the Rights of Persons with Disabilities adopted the Guidelines on Deinstitutionalization, Including in Emergencies. The development of the Guidelines responded to concerns that arose during the COVID-19 pandemic, when people in institutions were particularly vulnerable to infection and death and the destructive impact of institutionalization was heightened due to the isolation imposed by lockdowns. It proved to be an important endeavor that built on the earlier jurisprudence of the Committee related to the right to live independently in the community, the right to legal capacity (equal recognition before the law), and the right to liberty and security of the person.

In this paper, I argue that the Guidelines function as an instrument and template for reparative justice towards persons still in institutions and survivors of institutionalization, constructing deinstitutionalization as a reparative process as well as calling for the creation of reparation and redress mechanisms.<sup>1</sup>

I examine the entire body of the Guidelines as a human rights lawyer who works on normative development from the perspective of the movement of survivors of psychiatric

<sup>1</sup> Guidelines on Deinstitutionalization, Including in Emergencies, CRPD/C/5 (2021) [hereafter DI Guidelines], paras 53 and 115–123.

institutionalization, drawing on both personal and collective knowledge bases from that standpoint and on the discourse of a community of practice related to the Convention on the Rights of Persons with Disabilities. The present paper does not attempt to demonstrate the wrongfulness of institutionalization, describe the practices of institutionalization, or review the literature on deinstitutionalization. It is intended to serve as a resource for the community of practice that may find it useful.

This paper invokes the concept of reparative justice as a tool for approaching the vast and multifaceted needs relating to transforming society away from institutionalization. It does not attempt to theorize reparative justice<sup>2</sup> but rather explores its content using the framework of the Guidelines, making explicit the use of reparative justice and reparations beyond the dedicated Section 9 on ‘Remedies, reparation and redress’. A simple definition of reparative justice from a United States organization working on racial equity can serve as an approximation of the concept for the purposes of this paper:

Reparative Justice . . . centers those who have been harmed, and focuses on repairing past harms, stopping present harm, and preventing the reproduction of harm. (New England Board of Higher Education n.d.)

The instinct to repair and redress the wrongs of psychiatric oppression has inspired my work, as a civil society representative and independently, in contributing to the drafting, negotiation, interpretation, and application of the Convention on the Rights of Persons with Disabilities.<sup>3</sup> I became aware of the international framework on reparations through my law school experience of working with the International Women’s War Crimes Tribunal on Japanese Military Sexual Slavery, a civil society tribunal convened to address survivors’ demands for a meaningful apology from the Japanese state, historical accuracy, and other reparations along with the accountability of the perpetrators.<sup>4</sup> The success of that tribunal in giving legal weight to the victims’ standing and claims inspired me both in the drafting of the CRPD, which took place from 2002 through 2006, and, subsequently, in promoting the use of a reparations framework to conceptualize the totality of transformation needed to make CRPD implementation meaningful to survivors of psychiatric oppression. Reparative justice can also be understood as transformative justice in that it seeks real solutions and rejects superficial reforms.<sup>5</sup>

The forms of reparation prescribed under international law are satisfaction (including cessation of violations), guarantees of non-repetition, restitution, (re)habilitation, and compensation.<sup>6</sup> Throughout this paper, I point out elements within the Guidelines that support one or another of these forms of reparation for the ‘multiple violation’ constituted by institutionalization.<sup>7</sup>

<sup>2</sup> For an excellent theoretical survey and examination, see Margaret Urban Walker (2015).

<sup>3</sup> Convention on the Rights of Persons with Disabilities, adopted 13 December 2006 by General Assembly Resolution A/61/106, entry into force 3 May 2008, UNTS Vol 2515, p. 3. See Minkowitz (2012a).

<sup>4</sup> See Chinkin (2001); see also for primary source materials Women’s International War Crimes Tribunal Archives (n.d.).

<sup>5</sup> See Kaba and Ritchie (2022), pp. 131–39 for an analogous approach in a related social justice movement. See also sources in note 227 for the conceptualization of reparations in the survivor of psychiatric oppression movement and note 8 for its use in advocacy related to these Guidelines.

<sup>6</sup> Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law, A/RES/60/147 (2005) [‘Basic Principles and Guidelines on Reparation’], paras 18–23. See also notes 32–33, 37, 38–40, 59–61, 65–66, 72, 82, 107, 110–122, 125–128, 129–130, 152–155, 167, 173–176, 180–195, 196–198, 200–201, 204–205, 206–210, 257, 271–272, 277–278 and 280, and their accompanying text (calling attention to the forms of reparation corresponding to particular measures) and the discussion of Section 9. (Note that there are many other provisions that can be analyzed as reparative, even where I have not made this explicit.) In general, guarantees of non-repetition are also upheld by the targeted shifting of law and policy to eliminate and prevent violations, and habilitation/rehabilitation along with cessation of violations and restitution are upheld by support to leave institutions and resettle in communities. Note that habilitation/rehabilitation as a form of reparation should not equate to psychosocial rehabilitation in the mental health field; it is rather the services or supports needed to repair the harms done by institutionalization itself; see DI Guidelines para 37 and note 239 and its accompanying text).

<sup>7</sup> DI Guidelines, para 115.

The Guidelines make use of a reparations framework regarding deinstitutionalization both explicitly and implicitly.<sup>8</sup> It is most explicit in the detailed call for reparations mechanisms and processes to be instituted for survivors of institutionalization in Section 9 of the Guidelines. The concept of reparations or reparative justice is also explicitly invoked in connection with the processes for individuals to leave institutions:

Deinstitutionalization reverses the unjust practice of institutionalization.<sup>9</sup>

States Parties should ensure that institutional staff are trained on a human-rights, reparative and person-centred meaning of deinstitutionalization.<sup>10</sup>

Persons leaving institutions should:

Be respected as survivors 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.<sup>11</sup>

A reparations framework is invoked in connection with diverse obligations throughout the Guidelines, for example, the reference to income support to individuals that includes ‘components related to repairing the harm caused by institutionalization’ and the provision of guidance to family members ‘to address the harms caused by institutionalization to their relative’.<sup>12</sup> Also reparative in nature is the emphasis on the immediate cessation of violations and the restitution of liberty, which includes economic assistance with resettlement as a facilitative component.<sup>13</sup> Throughout this paper, I will highlight the reparative content of these Guidelines and will also point out where a reparative lens should be applied beyond the stated content to further the reparative intent in implementation.

An important shift of a reparative nature is the recognition of survivors of institutionalization as a specific group of rights holders who are to be actively involved and closely consulted in policymaking and processes related to deinstitutionalization and who are entitled to comprehensive remedies and reparations.<sup>14</sup> The involvement of persons with disabilities in policymaking through their representative organizations is enshrined in Article 4.3 of the Convention and reflects the decisive influence of such organizations in the drafting and negotiations.<sup>15</sup> Bringing survivors of institutionalization to the forefront

<sup>8</sup> In the process leading to the development of the Guidelines, I called for a ‘reparations approach to deinstitutionalization’ and encouraged other survivors to do the same in their submissions—<https://www.madinamerica.com/2021/02/crpd-reparations-approach/>, accessed on 20 February 2024. Several did, as reflected in the outcome documents of regional consultations in the EU and other Western European countries and states; Eastern Europe and Central Asia; the Caribbean and North America; and Central and South America. Available online: <https://www.ohchr.org/en/treaty-bodies/crpd/regional-consultations-and-guidelines-deinstitutionalisation-article-19>, accessed on 20 February 2024. See also the COSP15 Side Event on Remedy and Reparation for Institutionalization, organized by the Center for the Human Rights of Users and Survivors of Psychiatry, in cooperation with Transforming Communities for Inclusion and Validity Foundation (28 June 2002). Available online: <https://youtu.be/UOSp719z0Nk?si=R11EyGnf2kt9GLBE>, accessed on 20 February 2024.

<sup>9</sup> DI Guidelines, para 93.

<sup>10</sup> Id, para 94. On the limitations of such training, see the discussion below on Section 7.

<sup>11</sup> Id, para 95 (d).

<sup>12</sup> Id, paras 86 and 94, respectively.

<sup>13</sup> Id, paras 13, 31, 57, 58, and 105.

<sup>14</sup> Id, paras 3, 20 (‘those affected by institutionalization’), 34, 35, 53, 67, 68, 70, 73, 94, 95(d), 100, 109, 119, 121, 122, 123, 130, 132, 134, 135, 137, 140, 142, and 143. Of these, paras 95(d), 119, 121, 122, 123, 132, 134, and 135 relate to remedy and reparations. Paras 70, 73, 94, and 100 relate to the role of survivors in peer support, support networks, and community inclusion. The remainder relate to consultation and participation in various aspects of policymaking linked to deinstitutionalization including survivors’ participation in the development of the Guidelines.

<sup>15</sup> Article 4.3 reads as follows:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

For one account of an organization’s influence on the negotiations, see [Minkowitz \(2012a\)](#). Even before the CRPD, Rule 17 of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

is in keeping with this tradition and is reparative, particularly towards those of us who identify primarily as survivors of psychiatric institutionalization and may not identify as persons with disabilities, despite having been perceived as such and discriminated against on that basis.

The term ‘survivor’ should be taken to include people still living in institutions, even when those individuals are not referred to explicitly. Surviving institutionalization speaks to survival despite victimization by a systematic and multiple violation of human rights and cannot mean only those whose direct experience is past tense. The Guidelines themselves were informed by numerous contributions from people living in institutions as well as past survivors.<sup>16</sup>

In addition to accommodating the specific identity of survivors of institutionalization, the Guidelines in most contexts call for consultation with individuals whose rights are affected as survivors or more generally as persons with disabilities as well as with their representative organizations.<sup>17</sup> This approach, also taken in the development of the Guidelines, encourages wider participation, particularly of activists who contribute independently or who may not yet have been able to form organizations.

Also significantly reparative is the Guidelines’ challenge to the medicalization of experiences of distress and unusual perceptions as ‘mental health conditions’, which is intimately linked to the legitimization of involuntary practices. The Guidelines call for not only the elimination of psychiatric incarceration and forced interventions but also the drastic limitation of the scope of action and policymaking authority of the mental health system as such.<sup>18</sup> These prescriptions, together with proactive measures for mainstream community accessibility, community-based support networks and support services, economic and social justice, and the recognition and redress of harm through reparations processes map out a new world that is worth fighting for.

## 1. Purpose and Process

The Guidelines begin with a statement of purpose and process (paragraphs 1–3). The Guidelines are intended to be the basis for planning and implementing deinstitutionalization, complementing General Comment No. 5 on living independently and being included

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(A/RES/48/96) called for organizations of persons with disabilities to have ‘considerable influence’ within a national coordinating committee, envisioned as a public–private collaboration ‘to serve as a national focal point on disability matters’.

<sup>16</sup> See <https://www.ohchr.org/en/calls-for-input/2022/call-submissions-draft-guidelines-deinstitutionalization-including-emergencies>, accessed on 20 February 2024.

<sup>17</sup> Paragraphs 3, 34, 67, 68, 109, 125, 130, 140, 142, and 143 refer to both individuals and organizations; paragraphs 65, 70, 131, and 137 refer only to organizations; paragraphs 20, 41, 100, and 122 refer to ‘persons with disabilities’ and/or ‘survivors’, without specifying individuals or organizations; paragraph 35 refers to providing support and accessible information to facilitate the participation of persons living in institutions, survivors, and those most at risk of institutionalization—suggesting outreach at the individual level.

<sup>18</sup> The elimination of psychiatric incarceration and forced interventions is a bedrock premise of these Guidelines as it was of the Guidelines on Article 14. See paragraphs 6, 10, 13, 15, 17, 20, 28, 32, 55, 57, 58, 61, 62, 64, 90, 93, 98 (see note 186 and accompanying text), 103, 108, 115, 120, 123, 126, and 143.

On rejecting medicalization, see paras 10 (a crisis is not a medical condition requiring treatment), 64 (community-based services that are medicalized should be discontinued), 76 (requiring options for primary support services outside the health system and not requiring mental health diagnosis or treatment), 90 (‘finding of “mental health condition” prohibited as disqualifier’), and 143 (‘medical model approach and coercive mental health laws’ are bad practices).

On limiting the scope of action of the mental health system in the transformative processes and transformed supports and services envisioned, see paras 20 (‘those involved in managing or perpetuating institutions’ should not lead deinstitutionalization processes), 32 (housing for people leaving institutions cannot be ‘under the control of the mental health system’), 34 (‘service providers . . . should be prevented from influencing decision-making processes related to institutionalization’), 66 (‘those responsible for human rights violations should not be licensed to provide new services’), 73 (peer support should be ‘independent of institutions and medical professionals’), 98 (‘institutional authorities and personnel should not provide “continuity of care” in the community’), 117 (‘authorities and experts implicated in institutionalization should not have a role in creating or implementing mechanisms for redress and reparations, but should be invited to accept accountability’), 122 (‘ensure that perpetrators do not hold positions of authority or expert status in [redress and reparations] mechanisms or processes and are not called upon to provide habilitation, rehabilitation or other services’), and 130 (‘exclude staff of institutions from deinstitutionalization monitoring processes’).

in the community and the Guidelines on the right to liberty and security of persons with disabilities (Guidelines on Article 14).<sup>19</sup> The Guidelines are said to ‘draw on the experiences of persons with disabilities before and during the coronavirus (COVID-19) pandemic, which uncovered widespread institutionalization, highlighting the harmful impact of institutionalization on the rights and lives of persons with disabilities’.<sup>20</sup> Over 500 persons with disabilities, including self-identified survivors of institutionalization, contributed to their development through a participatory process that included seven regional consultations.<sup>21</sup>

Significant elements here are the reference to the Guidelines on Article 14 alongside General Comment No. 5 as a foundation for these Guidelines on Deinstitutionalization, the characterization of institutionalization as harming individuals’ rights and lives, and the grounding of the Guidelines in a participatory process that responds to the experiences of those who have been harmed. The coupling of the two foundational documents was significant in the development of the Guidelines to ensure that the full scope of psychiatric institutionalization, including short-term as well as long-term stays and its statutory character as a detention that the person is not legally permitted to leave, is addressed in the Guidelines on par with other forms of institutionalization.<sup>22</sup> As I will point out in detail below, this has been achieved through transversal attention to psychiatric institutionalization, highlighting particularities as needed, without separating this form of institutionalization into a distinct sphere of policymaking. That is a significant achievement, building on the CRPD and all its normative standards to date, that sets the stage for the development of support services and policymaking for people with psychosocial disabilities based entirely on a social model outside the health sector.<sup>23</sup> Such a shift is discussed further below and will need to be elaborated on in a focused collaborative process with survivors of psychiatric institutionalization and people with psychosocial disabilities.

## 2. Duties of States

Section 2 of the Guidelines (paragraphs 4–13) sets out the foundational premises of deinstitutionalization under the CRPD. Institutionalization is not only contradictory to the right to live independently and be included in the community, it is also a discriminatory practice, encompassing de facto denial of legal capacity, detention based on impairment, and a form of violence that exposes persons with disabilities to ‘forced medical intervention with psychotropic medications, such as sedatives, mood stabilizers, electro-convulsive treatment, and conversion therapy’ and interventions without free, prior, and informed consent, thus violating multiple articles of the Convention including Article 15 on the right to be free from torture and other ill-treatment.<sup>24</sup>

<sup>19</sup> A/72/55, Annex (Adopted by the Committee at its fourteenth session (17 August–4 September 2015) [hereafter Article 14 Guidelines].

<sup>20</sup> DI Guidelines, para 2.

<sup>21</sup> Id, para 3. See <https://www.ohchr.org/en/treaty-bodies/crpd/regional-consultations-and-guidelines-deinstitutionalisation-article-19> (accessed on 20 February 2024) for more details of the regional consultations, including downloadable outcome documents that memorialize the concerns and recommendations expressed by participants.

<sup>22</sup> See Concept Note on Guidelines on Deinstitutionalization. Available online: [https://www.ohchr.org/sites/default/files/2021-12/CRPD-Draft\\_Guidelines-English.docx](https://www.ohchr.org/sites/default/files/2021-12/CRPD-Draft_Guidelines-English.docx) (accessed on 20 February 2024); see also on transversal inclusion at the stage of development, Informative Note for Stakeholders. Available online: <https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/24thSession/Consultation-process-Informative-note-OPDs.docx> (accessed on 20 February 2024).

<sup>23</sup> Survivors of psychiatry adapt the social model of disability so that it is simultaneously a social model of impairment, that is, we contest the notion that psychosocial disability implies an underlying medical condition (see note 239 and also Article 14 Guidelines, para 6). This view is compatible with a human rights and non-discrimination model that goes beyond the social model of disability as it is commonly understood (see Degener 2014).

<sup>24</sup> DI Guidelines, paras 7 and 6, respectively. Articles mentioned in paragraph 6 are 5, 12, 14, 15, 16, 17, and 25. See also Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment of punishment, A/HRC/43/49 (14 February 2020) [‘Melzer Report’], paragraph 37:

It must be stressed that purportedly benevolent purposes cannot, *per se*, vindicate coercive or discriminatory measures. For example, practices such as involuntary abortion, steriliza-

The Committee observes that states have not complied with their obligations to end institutionalization, saying that ‘deinstitutionalization processes are either not compliant with the Convention or are overdue’.<sup>25</sup> This is certainly the case with respect to the ending of psychiatric institutionalization, which is still widely practiced despite initiatives in some countries to reduce or eliminate long-stay, stand-alone psychiatric institutions in favor of short-term hospitalization in psychiatric wards of general hospitals.<sup>26</sup> In order to truly eliminate the regime of psychiatric institutionalization, deinstitutionalization must comprise short-term inpatient hospitalization, both as an involuntary practice and as a policy-driven medicalization of diversity and distress.

States are directed to ‘abolish all forms of institutionalization, end new placements in institutions and refrain from investing in institutions. Institutionalization must never be considered a form of protection of persons with disabilities, or a “choice”’.<sup>27</sup> The rejection of institutionalization as a ‘choice’ should be understood in light of the defining elements of institutions set out in paragraph 14, which manifest a deprivation of personal autonomy and individuality that contradicts the possibility of free choice.

Underscoring the non-derogable character of the rights related to living independently and being included in the community, ‘the exercise of [these rights] cannot be suspended in situations of emergency, including in public health emergencies’.<sup>28</sup> ‘There is no justification to perpetuate institutionalization’, in particular this cannot be excused by a ‘lack of support and services in the community, poverty or stigmas’ or by the long-term character of certain processes such as ‘inclusive planning, research, pilot projects or the need for law reform’.<sup>29</sup>

States’ obligations to end ‘all forms of institutionalization, isolation and segregation of persons with disabilities’ apply in the private sphere as well as the public sphere.<sup>30</sup> This encompasses both the full implementation of deinstitutionalization processes in public and privately-run institutions and the prevention of new forms of institutionalization and restrictive practices from emerging in service provision, as well as a duty to combat practices by families and communities that segregate people within homes or neighborhoods.<sup>31</sup>

The obligation to refrain from the medicalization, forced intervention, and institutionalization of individuals experiencing a personal crisis is highlighted, along with the obligation to ensure that children with disabilities are not placed anywhere except in a family setting. These paragraphs signal early on an attention to important dimensions

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tion, or psychiatric intervention based on “medical necessity” of the “best interests” of the patient (A/HRC/22/53, para. 20, 32–35; A/63/175, para.49), or forcible internment for the “re-education” of political or religious dissidents, the “spiritual healing” of mental illnesses (A/HRC/25/60/Add.1, para. 72–77), or for “conversion therapy” related to gender identity or sexual orientation (A/74/148, para. 48–50), generally involve highly discriminatory and coercive attempts at controlling or “correcting” the victim’s personality, behaviour or choices and almost always inflict severe pain or suffering. In the view of the Special Rapporteur, therefore, if all other defining elements are given, such practices may well amount to torture [internal footnote omitted].

<sup>25</sup> Id, paras 4 and 5. See also paragraph 20, which highlights practices that perpetuate institutionalization that are to be avoided. Though not stated explicitly, those practices emerged in earlier deinstitutionalization initiatives that were non-compliant with the Convention.

<sup>26</sup> See [WHO Mental Health Atlas \(2020\)](#). Psychiatric institutionalization in all its forms is a global concern, with varying intensity skewing towards high and upper-middle-income countries. Taking the United States as an example, see [Wipond \(2023\)](#).

<sup>27</sup> Id, para 8.

<sup>28</sup> Id.

<sup>29</sup> Id, para 9.

<sup>30</sup> Id, para 11; see also para 16 (‘All institutions, including those run and controlled by non-State actors, should be included in deinstitutionalization reforms’) and CRPD Article 4.1(e) (‘States Parties undertake . . . to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise’).

<sup>31</sup> On the prevention of bad practices from emerging in service provision, see paras 20, 28, and 143. On the need to combat segregative practices by families, see Summary Notes of the Regional Consultation of Africa, the Regional Consultation of Central and South America, and the Regional Consultation of the Middle East and North Africa. Available online: <https://www.ohchr.org/en/treaty-bodies/crpd/regional-consultations-and-guidelines-deinstitutionalisation-article-19> (accessed on 20 February 2024).

of deinstitutionalization that must be fully incorporated in states' understanding of their duties under Article 19.

Paragraph 10 prohibits the institutionalization of people experiencing individual crises and maintains that 'individual crisis should not be treated as a medical problem requiring treatment or as a social problem requiring state intervention, forced medication or forced treatment'.<sup>32</sup> Further on in the Guidelines, crisis support is promoted as a function carried out by peer support networks and as a support service, particularly one that is provided outside the health system without the need for mental health diagnoses or treatment.<sup>33</sup> Paragraphs 10 and 76 together comprise the cornerstone of a reparative justice approach to support services for people with psychosocial disabilities, situating individual crisis (a time when involuntary interventions have been most likely) outside the ambit of specialized medical knowledge so that it can be addressed in the spirit of solidarity as a part of human diversity.

Paragraph 12 maintains that, in respect of children with disabilities, institutionalization means 'placement in any non-family setting' and that children with disabilities 'have the right to family life and a need to live and to grow up with a family in the community'.<sup>34</sup>

Turning to the immediate character of the obligation to end institutionalization, states must 'immediately provide individuals with opportunities to leave institutions, revoke any detention authorized by legislative provisions that are not in compliance with Article 14 of the Convention, whether under mental health acts or otherwise', and 'halt new placements in institutions, adopt moratoria on new admissions'.<sup>35</sup> They must also 'adopt moratoria . . . on the construction of new institutions and wards' and 'refrain from refurbishing and renovating existing institutions'.<sup>36</sup>

This section reflects a reparative justice approach in absolute rejection of institutionalization as a measure that is without justification; in the sensitivity to forms of institutionalization, isolation, and segregation that were brought forward in the consultations (including paragraphs 10–12 inclusive); and in the immediate obligations designed to directly redress present and continuing violations and prevent any new ones. These immediate actions can in particular be understood within the reparations framework as 'effective measures aimed at the cessation of continuing violations' and guarantees of non-repetition.<sup>37</sup>

### 3. Understanding and Implementing Key Elements of Deinstitutionalization Processes

Section 3, on key elements of deinstitutionalization processes, comprises paragraphs 14–36, divided into seven parts: (A) Institutionalization; (B) Deinstitutionalization processes; (C) Respect for the right to choose and individual will and preferences; (D) Community-based support; (E) Allocation of funding and resources; (F) Accessible housing; (G) Involvement of persons with disabilities in deinstitutionalization processes.

After establishing the foundational premises for deinstitutionalization in the previous section, the Guidelines now begin to explore states' obligations in greater detail. Most of these areas are further elaborated on in subsequent sections of the Guidelines. In addition, as we have already seen from the previous section, action-oriented obligations as well

<sup>32</sup> DI Guidelines, para 10.

<sup>33</sup> Id, paras 26, 70, 73, and 76. See also [Minkowitz \(2021a\)](#). Thus, an individual crisis requires a response based on social solidarity with the person experiencing it, rather than one that treats the crisis, and the person experiencing it, as objects of intervention.

<sup>34</sup> DI Guidelines, para 12.

<sup>35</sup> Id, para 13. With respect to immediately revoking detentions under mental health laws, this obligation builds on General Comment No. 5, which included as a dimension of 'respect' for the rights under Article 19 'the obligation to release all individuals who are being confined against their will in mental health services or other disability-specific forms of deprivation of liberty'. CRPD/C/18/1 (2017), para 48.

See also as emphasizing immediacy and rejecting any case-by-case approach to release from disability-based detention, para 57: 'Releasing persons with disabilities from disability-based detention and preventing new detentions are immediate obligations, and not subject to discretionary judicial or administrative procedures'.

<sup>36</sup> Id, para 13.

<sup>37</sup> Basic Principles and Guidelines on Reparations, note 6 above, para 22(a). See also the discussion below on Section 9.



as conceptual dimensions of norms are contained throughout the Guidelines, making it necessary to study the document and cross-reference relevant provisions pertaining to a particular obligation to obtain a complete understanding of the norms involved. (For instance, with respect to economic assistance provided to leave institutions, addressed in Section 3 for the first time in the document, we also need to refer to paragraphs in Sections 5 and 7, and it should also be coupled with the immediacy of the right to leave institutions contained in Sections 2 and 7.)

Section 3 begins in part A by defining the parameters for which settings are to be understood as institutions and thus targeted for closure and elimination. First, paragraph 14 sets out defining elements of institutions, which are taken nearly verbatim from General Comment No. 5:

There are certain defining elements of an institution, such as obligatory sharing of assistants with others and no or limited influence as to who provides the assistance; isolation and segregation from independent life in the community; lack of control over day-to-day decisions; lack of choice for the individuals concerned over with whom they live; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of individuals under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and a disproportionate number of persons with disabilities in the same environment.<sup>38</sup>

These elements, defined non-exhaustively ('such as'), fit psychiatric inpatient settings (psychiatric wards in a general hospital as well as stand-alone psychiatric institutions) as well as 'transitional' or 'supportive' housing arrangements and adult homes that have housed people leaving psychiatric institutions who cannot live with family (or choose not to) and do not have savings to establish themselves. In case there is any doubt as to the kinds of settings contemplated by this definition, paragraph 15 lists a number of them:

Disability-specific detention typically occurs in institutions that include, but are not limited to, social care institutions, psychiatric institutions, long-stay hospitals, nursing homes, secure dementia wards, special boarding schools, rehabilitation centres other than community-based, half-way homes, group homes, family-type homes for children, sheltered or protected living homes, forensic psychiatric settings, transit homes, albinism hostels, leprosy colonies and other congregate settings.

Paragraph 15 provides additional detail regarding mental health settings, emphasizing their character as places of detention:

Mental health settings where a person can be deprived of their liberty for purposes such as observation, care or treatment and/or preventive detention are a form of institutionalization.

Like paragraphs 10 and 76, this element of paragraph 15 is a cornerstone of reparative justice towards survivors of psychiatric institutionalization. It refers broadly to any mental health setting, not limited to the large stand-alone settings usually referred to as psychiatric institutions. The purposes mentioned correspond to those typically found in mental health-related legislation as grounds for deprivation of liberty. The phrasing 'can be deprived' addresses the threat to liberty posed by legislation or customs that authorize detention to be imposed even if the threat is not actualized in a particular instance. Any mental health setting that is authorized under a state's law to practice detention, or that can practice detention with impunity, would be considered an institution under this standard.

The concept that all institutionalization constitutes detention is underscored in the introductory sentence to paragraph 15:

<sup>38</sup> DI Guidelines, para 14. Compare with General Comment No. 5, CRPD/C/GC/5 (2017), para 16(c). Paragraph 16 of the Guidelines adds the point that 'the absence, reform, or removal of one or more institutional elements cannot be used to characterize a setting as community-based'.

Institutionalization of persons with disabilities refers to any detention based on disability alone or in conjunction with other grounds such as “care” or “treatment”.

The characterization of institutionalization generally as disability-based detention may seem confusing to those of us who are most familiar with mental health detention as a formal deprivation of liberty that has been wrongfully legitimated under a rule of law, in contrast to most other forms of institutionalization. Some other forms of institutionalization may amount to a de facto deprivation of liberty, or may not constitute detention at all in the sense of ‘confinement of the body,’<sup>39</sup> as individuals are in principle permitted to leave, either to pursue their daily life or to move out permanently, but are prevented from doing so by the inaccessibility or unaffordability of housing and transportation or the unavailability of needed support or assistive devices.

In any case, it is best to read paragraphs 14 and 15 together in light of the comprehensive aim to eliminate all forms of institutionalization so that no one remains in a place that restricts their autonomy in any of the forms described.<sup>40</sup>

Paragraphs 16 and 17 continue to emphasize the broad scope of deinstitutionalization: ‘living independently and being included in the community refer to life settings outside residential institutions of all kinds. . . . Regardless of size, purpose or characteristics, or the duration of any placement or detention, an institution can never be regarded as compliant with the Convention’.<sup>41</sup>

The question arises as to whether the concept of ‘residential institutions’ encompasses all mental health settings where a person can be deprived of their liberty, and, if not, what are the implications for the Guidelines. ‘Residential’ is not defined and is not included in the sentence beginning ‘regardless of size . . . or the duration of any detention’. Paragraph 15 views all mental health settings that can entail the deprivation of liberty as forms of institutionalization, including those having a purpose of ‘observation’, which is generally short-term and may not entail an overnight stay (for example, not being allowed to leave a psychiatric emergency room or outpatient setting). Given the dual grounding of the Guidelines in Articles 14 and 19, the concept of ‘institutions’ as the object of prohibition is probably best understood as distinguishing regimes of ‘placement’ or ‘detention’ that qualify as institutions under paragraphs 14 and/or 15, from service settings, such as sheltered workshops or day centers that restrict autonomy without preventing the person from leaving and without being intended as a form of housing. Either a deprivation of liberty or a placement intended as a living arrangement, if it is disability-based, characterizes a setting as an institution for the purposes of these Guidelines.<sup>42</sup>

The Human Rights Committee defines the ‘deprivation of liberty’ as involving ‘more severe restriction of motion within a narrower space than mere interference with liberty of movement [under Article 12 of the Covenant, movement within a State or territory]<sup>43</sup> . . . . Examples . . . include police custody . . . and confinement to a restricted area of an airport, as well as being involuntarily transported’.<sup>44</sup> The deprivation of liberty based on disability would therefore also include not only the briefest confinement in a psychiatric emergency

<sup>39</sup> ICCPR General Comment No. 35, CCPR/C/GC/35 (2014), para 3; see also paras 5 and 6.

<sup>40</sup> The Queensland Advocacy for Inclusion has used the defining elements in paragraph 14 to design a ‘deinstitutionalization report card’, a draft of which was presented at the 16th CRPD Conference of States Parties. Available online: <https://qai.org.au/deinstitutionalisation-report-card/>, accessed on 20 February 2024. This is one approach to identifying institutions, and might be built on to take into account paragraphs 15–17 as well.

<sup>41</sup> DI Guidelines, para 17.

<sup>42</sup> Such a reading is confirmed by the intent stated in paragraph 1 that these Guidelines complement both General Comment No. 5 on Article 19 and the Guidelines on liberty and security of persons with disabilities (Article 14). Key provisions in the Guidelines on Article 14 regarding the scope of the absolute prohibition of disability-based detention include paragraphs 6, 10, 13, 20, and 21. See also Wipond (2023) as to the necessity to include a wide variety of sites of detention and placement (e.g., emergency rooms, ‘scatter beds’ in general hospitals, among others) within the concept of institutionalization, with reference to the mental health system in the United States.

<sup>43</sup> CRPD addresses ‘liberty of movement’ in this sense in Article 18.

<sup>44</sup> Human Rights Committee, General Comment No. 35, CCPR/C/GC/35 (2014), para 6. For the Human Rights Committee, the deprivation of liberty includes both arrest and detention.

room (which would amount to an institution under paragraph 15) but also related acts that take place outside the institution itself, such as ‘mental health arrests’ by police or involuntary transport (by anyone) to a psychiatric setting.<sup>45</sup> All such acts would no longer be authorized once the entire regime of involuntary measures in psychiatry is abolished by law and no longer tolerated in practice.

Paragraph 16 emphasizes that the defining elements of institutionalization do not all have to be present to characterize a setting as institutional, giving the following examples as further detail about the settings contemplated for closure and elimination:

[S]ettings where adults with disabilities continue to be subjected to substituted decision-making or to compulsory treatment, or where they have shared assistants; settings located “in the community” where service providers set a routine and deny autonomy; or “homes” where the same service provider packages housing and support together.<sup>46</sup>

The reference to both compulsory treatment and the packaging together of housing and support reminds us that institutionalization encompasses all mental health settings where involuntary practices are used whether as a matter of law or fact, as well as mental health housing schemes that bundle support with housing.

Paragraph 18 addresses the intersection of disability rights and deinstitutionalization with other detention settings such as ‘prisons, refugee camps, migrant shelters, shelters for homeless persons and prayer camps’. In these settings, states should ‘ensure the rights of persons with disabilities’ and ‘eradicate discriminatory practices on the basis of disability to which they are subject’.

The inclusion of prayer camps among detention settings that are not disability-based is problematic. Human rights advocacy and academic literature on the prayer camps of Ghana describe them as places used for the healing of ‘mental illness’, and they are thus analogous to psychiatric inpatient settings (Benyah 2023; Barriga 2014; Kamundia 2023). Special Rapporteur on Torture Nils Melzer included ‘forcible internment for the purpose of . . . the “spiritual healing” of mental illnesses’, alongside forced psychiatric interventions among practices that likely amount to torture,<sup>47</sup> and this accords with the depiction by Human Rights Watch. However, Benyah’s informants found the prayer camps to be effective in their healing using culturally grounded practices that resolved issues of meaning and connection with the community, rather than, as in psychiatry, focusing only on ‘symptom’ reduction. The discrepancy can be explained by Benyah’s reliance on prayer camp staff to select ‘patients’ for him to interview; nevertheless, his point about cultural meaning cannot be dismissed. When I visited Uganda in 2009 for an assembly of the World Network of Users and Survivors of Psychiatry, I spoke to some Ugandans with psychosocial disabilities who felt similarly about prayer camps in that country.

From this evidence, it would appear that prayer camps should both be assimilated under paragraphs 14 and 15 as a type of disability-based institutionalization, whose practitioners must be held fully accountable for human rights violations, and assessed as to the potential for some of the underlying non-medical, culturally specific practices to be incorporated into new supports as envisioned, for example, under paragraphs 65 and 76.

With respect to the penal system, note that forensic psychiatric institutions are listed as a form of disability-based institutionalization in paragraph 15. Deinstitutionalization in the penal context, encompassing both the elimination of forensic psychiatric institutions in favour of full respect for human rights within an inclusively designed system for individual

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CRPD Article 14 refers to ‘deprivation of liberty’ but not ‘detention’; in the Guidelines, the two concepts are indistinguishable (compare paragraphs 6, 15, 17, 18, 57, 58, 108, and 120).

<sup>45</sup> See, for example, New York State Mental Hygiene Law §§ 9.37 (mandatory duty of police to take persons into custody and involuntarily transport them to a mental health facility on the application of a state mental health official) and 9.41 (discretionary power of police to do the same on their own judgment).

<sup>46</sup> See also paragraphs 28 and 32 (on segregated services that should be prevented from emerging and the reiteration of the right to housing that is not conditioned on the acceptance of unwanted services, respectively.)

<sup>47</sup> Melzer Report, A/43/49, para 37; see note 24 for text.

criminal responsibility and the elimination of discriminatory practices in jails and prisons as well as in police investigations and legal proceedings, requires further elaboration in conception and implementation.<sup>48</sup>

Given the intersection of disability, poverty, and other marginalized statuses with criminalization and punishment as well as the other areas addressed in paragraph 18, deinstitutionalization processes ought to consider the extent to which prisons may discriminate based on disability beyond obvious ways such as their co-optation as places of disability-based detention and the administration of forced psychiatric interventions. For example, the African Commission on Human and Peoples' Rights has recommended the decriminalization of petty offenses because of their discriminatory character of punishing and segregating people based on their socioeconomic status or other marginalization, including people with disabilities ([African Commission on Human and Peoples' Rights 2017](#)). Similar intersections should allow human rights defenders to raise questions about shelters for homeless persons and other marginalized populations as they are not solutions to poverty any more than to disability-related needs.

Part B emphasizes that deinstitutionalization aims to 'restore autonomy, choice and control to persons with disabilities as to how, where and with whom they decide to live'.<sup>49</sup> It consists of 'interconnected processes' 'led by persons with disabilities, including those affected by institutionalization, and not by those who manage or perpetuate institutions', and must avoid the renovation of settings, adding more beds, replacing large institutions with smaller ones, renaming institutions, or applying standards such as the 'principle of least restriction' in mental health legislation.<sup>50</sup> The reparative purpose of deinstitutionalization ('restore autonomy, choice and control') is declared here as a first premise, and some of its implications are elaborated on in the guidance as to what to avoid. The characterization of deinstitutionalization as 'interconnected processes' is apt to describe the wide range of measures called for in the Guidelines in areas such as law reform, service assessment and reconceptualization, the cultivation of informal support, and the transformation of mainstream public services and infrastructure for the inclusion of formerly institutionalized persons and other persons with disabilities—as well as direct undertakings to identify existing institutions and assist everyone found there to leave in keeping with the person's own will and preferences, and the creation of reparations mechanisms and processes. That these processes will be led by the persons whose rights are at stake rather than those who are complicit in the rights violations is a profound paradigm shift in the concept of deinstitutionalization itself. This reflects the difference between a medical and social welfare model of disability to a social model based on non-discrimination and human rights.

Part C reaffirms the core premise of respect for choice and individual will and preferences as integral to the right to live independently and be included in the community. This includes respect for decision-making by persons with disabilities and the evolving capacities of children with disabilities, along with ensuring 'access to housing, support and service options that are accessible and enable persons to regain control of their lives'.<sup>51</sup>

In part D, community-based support is said to comprise both formal assistance (i.e., hired services) and informal networks.<sup>52</sup> Support should be 'quality, individualized and personalized'; support services should be 'available, accessible, acceptable, affordable and adaptable'.<sup>53</sup>

<sup>48</sup> See also notes 86–89, 116, and their accompanying text.

<sup>49</sup> DI Guidelines, para 19.

<sup>50</sup> Id, para 20. See also paragraph 28.

<sup>51</sup> Id, para 21.

<sup>52</sup> Id, para 23.

<sup>53</sup> Id, paras 22 and 25, respectively.

Legal capacity is re-emphasized in connection with the choice, management, and termination of support, and support in exercising legal capacity can itself be provided as a service or through an individual's networks.<sup>54</sup>

Personal assistance is emphasized among the support services and must be made available to all persons with disabilities. It must be 'individualized, based on individual needs, and controlled by the user', including user choice about whether to '[act] as an employer or [engage] the service from a variety of providers'.<sup>55</sup> The other kinds of services enumerated are

... peer support, supportive caregivers for children in family settings, crisis support, support for communication, support for mobility, provision of assistive technology, support in securing housing and household help, and other community-based services, [along with] support ... to gain access to and use mainstream services such as education, employment, the justice system and healthcare.<sup>56</sup>

Finally, the definition of community-based support services 'should prevent the emergence of new segregated services, group housing—including "small group homes"—sheltered workshops, institutions for the provision of "respite care", transit homes, day-care centres, or coercive measures such as community treatment orders'.<sup>57</sup>

Parts C and D emphasize individualized support, especially personal assistance, as central to deinstitutionalization. Support in exercising legal capacity is associated with 'enabling' the exercise of legal capacity in relation to the choice, management, and termination of support. While crisis support and peer support are mentioned here, the need for de-medicalized support options related to experiences of distress or unusual perceptions is found only in the detailed discussion of support services in Section 6 Part B.

This portion of the Guidelines, if read as a starting point for policy on deinstitutionalization and support measures, risks a submersion of the support needs of people with psychosocial disabilities and survivors of psychiatric institutionalization into a version of the social model of disability that cannot contest medicalization or the concept of 'impairment'. The references to the elimination of coercive measures in mental health systems are welcome, as is the duty to make personal assistance available to all persons with disabilities. It might have been emphasized that people with psychosocial disabilities have been unjustly excluded from personal assistance schemes that they might have adapted to meet support needs they may have, including any or all of the needs enumerated in paragraph 76 as they relate to experiences of distress or unusual perceptions.

Part E turns to the question of resource allocation and insists on the prohibition of investment in institutions. Rather, 'investments should be directed towards the immediate release of residents and the provision of all necessary and appropriate support for living independently'.<sup>58</sup> This is an important reparative obligation, emphasizing both direct justice towards individual victims and the decisive shift of the state's material support away from the rights-violating regime of institutionalization and in favor of supporting the needs of those leaving institutions in the immediate term and longer term. Public funds, including those from international cooperation, are to be re-allocated away from institutional investments to measures that 'ensure the sustainability of inclusive community support systems and inclusive mainstream services'.<sup>59</sup> The obligation to shift resources concretizes the commitment to both end the violative practices and begin to repair the harm.

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<sup>54</sup> Id, para 24.

<sup>55</sup> Id, para 27.

<sup>56</sup> Id, para 26.

<sup>57</sup> Id, para 28.

<sup>58</sup> Id, para 29.

<sup>59</sup> Id, para 30. See also para 63 (calling on states to 'identify funding currently going into institutions and reallocate these to services that respond to the expressed requirements of persons with disabilities').

People leaving institutions should be provided with ‘a comprehensive compensatory package comprising goods for daily living, cash, food vouchers, communication devices and information about services available, immediately upon departure’.<sup>60</sup> The characterization of this package as compensatory suggests it is viewed as reparative; however, it cannot be the sum total of compensation due as reparation for a serious human rights violation. It is better viewed as facultative to restore the individual to liberty in the community (cessation of violations and restitution) and prevent the emergence of new violations (guarantees of non-repetition). It is meant to ‘provide basic security, support and confidence . . . in order that they can recover, seek support when they require it, and have an adequate standard of living in the community without risk of homelessness or poverty’.<sup>61</sup> From this, it can be inferred that the amount and quality of the package should be sufficient for the intended purpose.

Substantial investment will be required to begin deinstitutionalization processes, including the allocation of resources to respond to the material needs of people exercising their immediate right to leave. States will need to plan carefully, including through international cooperation, to allocate and shift resources throughout the process of deinstitutionalization, including the investments for developing inclusive community supports and mainstream services and meeting individuals’ needs, which require an outlay of funds before the full savings from divestment from institutionalization will be realized.

Part F addresses accessible housing—a core component of the right to an adequate standard of living that distinguishes the CRPD approach to deinstitutionalization from earlier initiatives that transferred large numbers of people from large long-term institutions to transitional institutions, halfway homes, housing supervised by mental health personnel, and other forms of housing that constitute institutionalization.<sup>62</sup> It is common knowledge among survivors that people leaving psychiatric institutions face high levels of discrimination and lack of affordability to obtain housing on the open market, leading many to resort to mental health-supervised housing instead. The emphasis on accessible and affordable housing is consistent with the CRPD concept of inclusive equality, in which people with disabilities are envisioned as having full lives and unmediated access to mainstream public goods such as housing, employment, and community life.

States must ensure ‘safe, accessible, affordable housing in the community’ to people leaving institutions ‘through public housing or rental subsidies’.<sup>63</sup> They must ‘enjoy the right to enter into legally binding rental or ownership agreements’.<sup>64</sup> These are the housing standards applied to the general population to be fulfilled for people leaving institutions through measures of social and economic equity within ordinary housing. The specification of means concretizes the paradigm shift away from any segregated, medical, or supervised approach to housing provision.

It is incompatible with Articles 19 and 18(1) (liberty of movement) to aggregate people leaving institutions into assigned neighborhoods or communal living arrangements or to bundle together support packages with housing.<sup>65</sup> The mental health system and other service providers that have managed institutions are explicitly denied any role in the operation of housing, a measure that can be understood as a guarantee of non-repetition, reflecting the paradigm shift noted above, along with its particular application to people leaving psychiatric institutions:

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<sup>60</sup> *Id.*, para 31.

<sup>61</sup> *Id.* See also para 58 (calling for ‘emergency assistance’ to leave places of arbitrary detention) and paras 90, 92, and 105 (calling for a ‘robust social protection package to meet immediate and medium-term needs’ as well as longer-term social protection as needed).

<sup>62</sup> See discussion above on paragraphs 14 and 15.

<sup>63</sup> DI Guidelines, para 32.

<sup>64</sup> *Id.*

<sup>65</sup> *Id.*

Housing should be neither under the control of the mental health system or other service providers that have managed institutions nor conditioned on acceptance of medical treatment or specific support services.<sup>66</sup>

Singling out the mental health system here indicates an awareness of that system's specificity as a perpetrator of institutionalization, which includes its subsuming the provision of public goods to people with psychosocial disabilities under a medicalized rationale and authority.

Since Article 19(b) of the Convention refers to 'residential services' as a form of support for living independently in the community, the Guidelines clarify that this reference 'should not be used to justify the maintenance of institutions'.<sup>67</sup> 'Residential services' are said to be aimed at ensuring equality and non-discrimination, giving examples such as 'social housing, self-managed co-housing, free matching services, and assistance in challenging housing discrimination'.<sup>68</sup> The clarification and the concretizing of an alternative interpretation are necessary since the concept of residential services could otherwise be understood as housing that would amount to institutionalization under these Guidelines.

Part G, covering the participatory dimension of deinstitutionalization processes, takes a reparative approach in three ways.

First, these processes should closely consult persons with disabilities and prioritize the views of persons leaving institutions and survivors of institutionalization, together with their representative organizations.<sup>69</sup> This follows the approach the Committee used in developing the Guidelines and reflects the acknowledgment of the value of knowledge gained by experience of human rights violations as well as the most significant legitimate interest in the outcome of these processes.

Secondly, perpetrators and those having an interest in continuing the violations—'service providers, charities, professional and religious groups, trade unions and those with financial or other interests in keeping institutions open'—are to be prevented from influencing decision-making.<sup>70</sup> This is especially key with respect to the mental health sector (as service providers that have interests in maintaining various kinds of institutions), which, in previous iterations of deinstitutionalization, has taken the leading role.

Finally, planning processes are to be 'open and inclusive . . . , ensuring the public understands article 19 of the Convention, the harms of institutionalization and exclusion of persons with disabilities from society, and the need for reform'.<sup>71</sup> The involvement of the public on the basis of accurate information, grounded in the values of human rights and non-discrimination, is needed to promote the actualization of community as a social environment in which people with disabilities participate together with others. Awareness-raising about the harms and need for reform relates to the 'satisfaction' element of reparations through the construction of new understanding and social knowledge as well as a more dynamic, whole-society approach to the meaning of reparations beyond the obligations of the state.<sup>72</sup>

#### **4. Deinstitutionalization Grounded in the Dignity and Diversity of Persons with Disabilities**

Section 4 comprises paragraphs 37–52, divided into four parts after some general remarks on dignity and diversity, and regarding the involvement of family members: (A) Intersectionality; (B) Women and girls with disabilities; (C) Children and adolescents

<sup>66</sup> Id. Perpetrators of institutionalization are also to be precluded from providing habilitation and rehabilitation or other services (para 122).

<sup>67</sup> Id, para 33.

<sup>68</sup> Id.

<sup>69</sup> Id, para 34.

<sup>70</sup> Id.

<sup>71</sup> Id, para 36.

<sup>72</sup> See the COSP15 Side Event on Remedy and Reparation for Institutionalization. Available online: <https://youtu.be/UOSp7I9z0Nk>, accessed on 20 February 2024. Speakers addressed, among other questions, the state's role and the value of whole-society initiatives.

with disabilities; and (D) Older persons with disabilities. Part C is the most substantial, detailing obligations for the deinstitutionalization of children and adolescents that differ in some respects from the rights of adults with disabilities.

The section begins by addressing the tension between the right of all people with disabilities to live in the community and the possibility that ‘individuals who have been denied their right to decision-making may not initially feel comfortable with being invited to live independently and being included in the community, even if offered support . . . the institution may be the only living environment that they know’.<sup>73</sup> The impact of institutionalization on a person’s feelings and choices and leaving this setting is addressed by holding states ‘accountable for limiting the personal development of institutionalized people’ and to not ‘create new barriers to leaving institutions by attributing “vulnerability” or “weakness” to persons with disabilities’.<sup>74</sup> Instead of assessing the ‘capacity for independent living based on impairment’, assessments should be made of ‘individualized requirements and barriers for independent living in the community’.<sup>75</sup>

The Guidelines never directly address the implications of respect for legal capacity in relation to an expressed choice to remain in an institution, though the premise of respect for decision-making in relation to leaving institutions is affirmed in other sections.<sup>76</sup> Rather, the onus is placed on states to eliminate all the causes of institutionalization including structural discrimination (such as inaccessible or unaffordable housing, job discrimination, lack of robust social protection), attitudinal discrimination, lack of availability of needed supports, and the statutory frameworks that authorize disability-based detention such as Mental Health Acts. The link between the individuals’ choices about leaving institutions and the actual realization of effective measures to change the social and economic circumstances facing them in the world beyond the institution is not pursued in the Guidelines but is essential to address when implementing both the systemic and personalized dimensions of deinstitutionalization processes.

The Guidelines declare that ‘deinstitutionalization reverses the unjust practice of institutionalization’<sup>77</sup> and that ‘deinstitutionalization comprises interconnected processes that should focus on restoring autonomy, choice and control to persons with disabilities as to how, where and with whom they decide to live’.<sup>78</sup> To uphold these intentions when implementing the Guidelines, it will be essential to honor and give space to the knowledge, feelings, and views that people have developed under the constrained and violent circumstances of institutionalization, including their real concerns about material survival, their claims for compensation and the restoration of lost possessions, and their choice to leave on their own terms and be able to meet their needs effectively. The obligations of Article 12 apply with full force, including respecting a person’s refusal of any or all support offered and refraining from any kind of undue influence on that person’s decision-making.<sup>79</sup> Would-be supporters should approach this work with great sensitivity and respect, and in a spirit of solidarity.<sup>80</sup>

The role of family members as support providers is addressed in paragraph 38, situating family members and their ‘involvement in deinstitutionalization processes’ incongruously within a section dealing with the ‘dignity and diversity of persons with disabilities’. The

<sup>73</sup> DI Guidelines, para 37.

<sup>74</sup> Id.

<sup>75</sup> Id.

<sup>76</sup> See paragraphs 95(a) (‘Persons leaving institutions should be respected as decision makers, with support if required, in respect of all aspects of leaving the institution’) and 55 (‘The exercise of decision-making by persons with disabilities who are currently placed in institutions should be respected within the deinstitutionalization process’).

<sup>77</sup> DI Guidelines, para 93.

<sup>78</sup> Id, para 19.

<sup>79</sup> See Article 12, para 4, and GC1 para 22 (‘Undue influence is characterized as occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation’).

<sup>80</sup> See notes 149–150 and accompanying text.



linkage to dignity and diversity could have been strengthened by grounding this paragraph in the right to home and family life of adults and children with disabilities on an equal basis as other adults and children, respectively. Home and family life is part of living in the community as an adult, whether with a spouse or partner, children, extended family, chosen family, or the choice to maintain a household as a single person. Intersectional respect for diversity could have been strengthened by acknowledging same-sex relationships.<sup>81</sup>

Unfortunately, these were missed opportunities, and the Guidelines largely fail to recognize the diverse family roles played by persons with disabilities, particularly their exercise of responsibility as spouses and parents, and address adults with disabilities only as potential receivers of support.<sup>82</sup> This imbalance is heightened by an over-emphasis on the agency of non-disabled supporters in the family context rather than the agency of persons with disabilities, including those leaving institutions, as members of families. The responsive agency of having a right to accept or reject family support, consistently reiterated,<sup>83</sup> only underscores an implication of dependency that infantilizes people with disabilities, in particular those leaving institutions.

A further dimension of the Guidelines' regrettable flaw in this respect is the failure to examine the impact on people with disabilities and their families of family members' roles in instigating or authorizing institutionalization, or the tension between this complicity in abuse and a present-day willingness to act as supporters. Just as the Guidelines call for service providers who have been involved in institutionalization to be excluded from the provision of new services, there must be some greater wariness about family members acting as supporters of people leaving institutions and, at the very least, their complicity in human rights violations must be confronted.

Following the introductory portion of Section 4, diversity is addressed in Part A as the intersectionality of disability with other factors that shape identity, in particular, 'race, sex and gender, gender identity and expression, sexual orientation, sexual characteristics, language, religion, ethnic, indigenous or social origin, migrant or refugee status, age, impairment group, political or other opinion, experience of imprisonment, or other status'.<sup>84</sup> In addition to taking these intersections into account in deinstitutionalization processes, states are particularly called upon to 'tackle structural racism, to prevent discrimination and institutionalization based on race and ethnic origin, in conjunction with disability'.<sup>85</sup>

The inclusion of 'political or other opinion' and 'experience of imprisonment' as well as 'impairment group' are worth highlighting in relation to people leaving psychiatric institutions. Psychiatric institutions function as a carceral system of state-authorized detention that can be used interchangeably with the penal system, particularly in relation to petty offenses and survival crimes.<sup>86</sup> Psychiatry can also be used for political repression, including in situations where disability-based discrimination and the suppression of dissent are joint motivating factors in repressive actions.<sup>87</sup> For these reasons, decarceration work should

<sup>81</sup> Compare with paragraph 44 describing the diversity of families in a discussion of children with disabilities: 'A family may include married and unmarried parents, single parents, same-sex parents, adoptive families, kinship care, sibling care, extended family, substitute families or foster care'.

<sup>82</sup> The few exceptions I have found are paragraph 89 (income support for persons with disabilities and their dependents), paragraph 90 ('family life' listed among other areas of mainstream services), paragraph 120 (restitution as including the re-establishment of relationships with children or family or origin).

<sup>83</sup> E.g., in para 38, involvement in deinstitutionalization is 'allowed only with . . . express consent'; 'state support for family members should be provided only with full respect for the right of persons with disabilities to have choice and control over the kind of support received and the way in which it is used'.

<sup>84</sup> DI Guidelines, para 39.

<sup>85</sup> Id, para 41.

<sup>86</sup> See also notes 51 and 116 and their accompanying text.

<sup>87</sup> For example, Robert Ho was detained in a mental health facility 'at the president's pleasure' after distributing flyers about the election system in Singapore ('Robert Ho threatened with IMH detention at President's pleasure', [https://yoursdp.org/2005/04/08/robert\\_ho\\_threatened\\_with\\_imh\\_detention\\_at\\_president\\_s\\_pleasure/](https://yoursdp.org/2005/04/08/robert_ho_threatened_with_imh_detention_at_president_s_pleasure/), accessed on 20 February 2024). Boon Suan Ban was similarly detained after being acquitted of defamation charges as being 'of unsound mind' in connection with a financial matter involving the Chief Justice ('1994–2015: A Chronology of Authoritarian Rule in Singapore', <http://singaporerebel.blogspot.com/2011/03/1994-2011-chronology-of-authoritarian.html>, accessed on 20 February 2024).

always involve survivors of psychiatric institutionalization and people with psychosocial disabilities, and deinstitutionalization should take account of these intersections and contribute to a wider decarceration.<sup>88</sup>

Furthermore, race and social origin, as well as sex and gender, expose people to systemic lifelong violence and discrimination that can be causal factors in institutionalization both directly and indirectly. It is welcome that the Guidelines address structural racism directly, which is a new dimension not present in the text of the Convention or in General Comment No. 5. Structural racism has been a significant factor in police violence in the United States, constructing social narratives that place individuals outside the protection of ordinary duties to respect and ensure human rights.<sup>89</sup> This fits closely with the narrative of institutionalization as ‘necessary’, which places people with disabilities outside such protection (Leah Ashe 2019).

With respect to sex and gender, Part B highlights multiple discrimination against women and girls with disabilities, emphasizing their ‘heightened risk of violence, exploitation and abuse . . . , and of gender-based violence and harmful practices, such as forced contraception, forced abortion and sterilization, during institutionalization’, as well as the denial of their right to exercise legal capacity.<sup>90</sup> The emphasis on risk may be problematic if it results in over-cautiousness or a paternalistic orientation in supporting women and girls to leave institutions. Feminist consciousness-raising and access to female-only peer support options, including collaboration with feminist community groups, can help to build strength and solidarity while confronting the persistence of inequality and systemic male violence, including predation on women disabilities, as a social problem and not just a personal risk.

Part C on children and adolescents with disabilities emphasizes the requirement of family placements rather than any ‘family-style’ institutions, prioritizing placement within the family of origin if possible.<sup>91</sup> This is stated in multiple paragraphs, and most emphatically below:

A healthy living arrangement should allow a child to establish a stable relationship with a committed adult caregiver, and every effort should be made to avoid multiple placements of children who do not live with their family of origin.<sup>92</sup>

The Guidelines assert unequivocally that ‘children and adolescents with disabilities cannot “choose” to live in an institution’, while ‘young persons with disabilities should be provided with opportunities to choose where and with whom they live, taking into consideration that independent living arrangements refer to “life settings outside residential institutions of all kinds”’.<sup>93</sup> As the category of ‘youth’ overlaps with that of ‘children and adolescents’,<sup>94</sup> the implication is that independence from family, similarly to decision-making, is part of children’s ‘evolving capacities’ and is to be respected on an equal basis

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‘Singapore’s most prominent human rights lawyer’ M Ravi has been subjected to repeated actions designed to prevent him from carrying out his work, some of which have been based on his psychosocial disability (‘Singapore’s Bipolar Human Rights Lawyer Faces Disbarment’, August 28, 2015, <https://www.asiasentinel.com/p/singapore-bipolar-human-rights-lawyer-ravi-disbarment>, accessed on 20 February 2024; Lawyers’ Rights Watch Canada, ‘Singapore: Discontinue disciplinary action against lawyer M. Ravi | Letter’, 11 August 2015, <https://www.lrw.org/singapore-in-the-matter-of-m-ravi-so-madasamy-letter/>, accessed on 20 February 2024).

<sup>88</sup> See note 48 and accompanying text.

<sup>89</sup> See Kaba and Ritchie (2022). Kaba and Ritchie also address the link between police violence and disability and include involuntary commitment as ‘soft policing’.

<sup>90</sup> DI Guidelines, para 42.

<sup>91</sup> Id, paras 43–46.

<sup>92</sup> Id, para 44.

<sup>93</sup> Id, para 49.

<sup>94</sup> ‘The United Nations, for statistical purposes, defines “youth”, as those persons between the ages of 15 and 24 years, without prejudice to other definitions by Member States’. <https://www.un.org/esa/socdev/documents/youth/fact-sheets/youth-definition.pdf>, accessed on 20 February 2024. Under the Convention on the Rights of the Child, Article 1, ‘a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier’. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>, accessed on 20 February 2024.

for children with disabilities as for others—so that, for example, older adolescents leaving institutions might be better served by their own housing with any needed support and connections to community.

Support services including peer support and personal assistance, as well as inclusive education in mainstream schools, are highlighted along with the provision of accessible information to families as complementary measures for community inclusion and the prevention of institutionalization.<sup>95</sup> Peer support and other mainstream and social model services, including support to confront and heal from abuse and violence, or simply to be heard without judgment or diagnosis, is important for children and adolescents who experience distress or unusual perceptions. The medicalization of children’s distress and diversity is an ongoing problem that must be resisted.<sup>96</sup>

The Guidelines furthermore affirm the right of children with disabilities to have their views be given due weight on matters affecting them and to be provided with support for this purpose in ‘matters of personal choice and public policymaking’.<sup>97</sup> The stipulation that not only support but the ‘due weight accorded’ should bear a relationship to gender as well as to disability and age is surely a typographical error. We should assume that the weight accorded to children’s views should in no way be differentiated by sex or gender<sup>98</sup> but rather that duty-bearers should be conscious of the potential for discrimination in this area and ensure gender equality.

The duties of ‘parents, relatives and caregivers’ to take the child’s views into account and their role in supporting children to express their views are highlighted.<sup>99</sup> Parents, caregivers, and other adults in the child’s life such as teachers, should be reminded of these duties and given the opportunity to learn more about how to undertake this support role in the information provided to families to support community inclusion. Supporting the child to be heard and taking their views into account within the family setting is especially important with respect to children and adolescents who experience distress or unusual perceptions or whose behaviour has caused concern to others, to avoid scapegoating and medicalization as well as institutionalization.

Lastly, in Part D, older persons with disabilities must be included in deinstitutionalization, which should target ‘disability-specific and other institutional settings for older persons, including “dementia villages”’.<sup>100</sup> While this area is not developed in the Guidelines,

<sup>95</sup> DI Guidelines, paras 50 and 51, respectively. See also paragraph 45, ‘Support for children with disabilities and families, as early as possible, should be included in mainstream support for all children. Peer support for children and adolescents is essential for full community inclusion’.

<sup>96</sup> For example, see [Simons \(2020\)](#).

<sup>97</sup> *Id.*, para 48.

<sup>98</sup> See CEDAW, Article 15.2: ‘States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity’. The evolving capacities of girls with disabilities are surely to be recognized on an equal basis as those of boys with disabilities. This is different from the parameters of age and maturity, which do imply differentials.

<sup>99</sup> DI Guidelines, para 48.

<sup>100</sup> *Id.*, para 52. See also Article 7, Right to Independence and Autonomy of the Inter-American Convention on Protecting the Human Rights of Older Persons (drawing on CRPD text and general comments):

State Parties to this Convention recognize the right of older persons to make decisions, to determine their life plans, to lead an autonomous and independent life in keeping with their traditions and beliefs on an equal basis, and to be afforded access to mechanisms enabling them to exercise their rights.

States Parties shall adopt programs, policies, or actions to facilitate and promote full enjoyment of those rights by older persons, facilitating their self-fulfillment, the strengthening of all families, their family and social ties, and their affective relationships. In particular, they shall ensure:

- (a) Respect for the autonomy of older persons in making their decisions, and for their independence in the actions they undertake.
- (b) That older persons have the opportunity, on an equal basis with others, to choose their place of residence and where and with whom they live, and are not obliged to live in a particular living arrangement.
- (c) That older persons progressively have access to a range of in-home, residential, and other community-support services, including personal assistance necessary to support living and inclusion in the community and to prevent their isolation or segregation from the community.

its inclusion provides a basis for further standard-setting and policymaking within CRPD deinstitutionalization processes.

Recognizing the intersection of age and disability, the Guidelines call on states ‘to prevent discrimination against older persons with disabilities in accessing support and services in the community and their own homes’. The failure of both age-related and disability-related support mechanisms in many countries to account for older persons with disabilities has been noted in United Nations consultations on the rights of older persons as a gap to be remedied.<sup>101</sup>

## 5. Enabling Legal and Policy Frameworks

Section 5 comprises paragraphs 53–68 and is divided into three parts after an introductory paragraph: (A) Creating an enabling legal environment, further divided into (1) Right to legal capacity, (2) Right to access to justice, (3) Right to liberty and security of the person, and (4) Right to equality and non-discrimination; (B) Legal framework and resources, further divided into (1) Legislation, (2) Institutional settings and the situation of persons living in institutions, (3) Community-based services, (4) Identifying new elements of support systems, and (5) Workforce analysis.

This section outlines the requisites of law and policy reform to support deinstitutionalization, including the need for detailed action plans. Obligations related to legal capacity, access to justice, and liberty and security of the person are reiterated and operationalized for the context of deinstitutionalization. The enactment of a justiciable guarantee of the right to live independently and be included in the community is highlighted,<sup>102</sup> along with ‘the creation of a reparations mechanism’ and ‘the availability, accessibility and effectiveness of remedies for survivors of institutionalization’.<sup>103</sup> Substantial mapping activities are set out to inform the shifting of resources, the elimination of services that do not comply with the Convention, and the development of new support services and mechanisms. Mapping should ‘accelerate deinstitutionalization and not delay the closure of institutions’.<sup>104</sup>

Part A begins by addressing the right to legal capacity as both a synergistic reform that should be carried out simultaneously with deinstitutionalization, and a right to respect for decision-making within the context of deinstitutionalization. Support for exercising legal capacity is to be provided in deinstitutionalization processes and continue once the individual has established a life in the community.<sup>105</sup> The centrality of decision-making in planning processes to leave an institution, as well as the need for the continuity of such support, suggests that those most directly involved in undertaking planning together with the individuals leaving institutions should not be institutional staff but rather independent individuals who are trustworthy and who are capable of establishing accessible communication and providing support in decision-making.<sup>106</sup>

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Article 12 of that Convention addresses ‘long-term care services’ and will need to be considered in light of these Guidelines to ensure that services for older persons do not amount to institutionalization and are fully compliant with CRPD in states parties. (See also Article 30, which virtually copies the CRPD on legal capacity, applying the same text to older persons.)

<sup>101</sup> Report of the Independent Expert on the enjoyment of all human rights by older persons, A/HRC/39/50 (July 10, 2018), para 9; Report of the Special Rapporteur on the rights of persons with disabilities, A/74/186 (July 17, 2019), paras 33–35.

<sup>102</sup> DI Guidelines, paras 54 and 61 (b) and (c) (legal recognition and enforceability of these rights, and effective remedies against institutionalization and discrimination ‘including the failure to provide reasonable accommodations or support in the community’).

<sup>103</sup> *Id.*, para 53. See further detail below on Section 9 of the Guidelines dealing extensively with ‘Remedies, reparations and redress’.

<sup>104</sup> *Id.*, para 60.

<sup>105</sup> *Id.*, para 55.

<sup>106</sup> See discussion at notes 182–189 and accompanying text.

Underscoring the Guidelines' orientation to ending human rights violations and preventing their recurrence,<sup>107</sup> all guardianship, substitute decision-making, and forced mental health treatment 'should immediately be lifted'.<sup>108</sup> Immediacy and the rejection of any case-by-case approach to ending disability-based detention are underscored in the section on access to justice: 'Releasing persons with disabilities from disability-based detention and preventing new detentions are immediate obligations, and not subject to discretionary judicial or administrative procedures'.<sup>109</sup>

The dual implications of immediacy and the rejection of discretionary procedures are twofold. While judicial cases might be pursued by advocates to enforce a state's compliance with the obligation of immediate release from disability-based detention and the immediate lifting of substitute decision-making and forced mental health regimes, it would be onerous to require every individual affected to litigate their freedom. Courts hearing such cases should order systemic as well as individual relief if it is in their power to do so.<sup>110</sup> States should not rely on the right to access to justice to implement their duty under Articles 14 and 19 to immediately release everyone who is under disability-based detention, but must use executive and legislative powers proactively once they have made a commitment to implement these Guidelines.

The standard of consent applicable to the mental health context is strengthened to require 'affirmative, free and informed expression of consent by the person concerned'.<sup>111</sup> This is said to be necessary to 'prevent forced mental health treatment'.<sup>112</sup> Requiring an affirmative expression of consent was proposed by advocates to prevent the administration

<sup>107</sup> These measures correspond to the cessation of violations, considered to be 'the first requirement in eliminating the consequences of wrongful conduct' (International Law Commission, Commentary to the Article 30 of the Articles on State Responsibility for Internationally Wrongful Acts, (2001) II(2) *Yearbook of the ILC*, para (4)) and 'an essential element of the right to an effective remedy' (Human Rights Committee, General Comment No. 31 on the Nature of the General Legal Obligation Imposed on States Parties to the Covenant, UN Doc CCPR/C/21/Rev.1/Add.13 (2004), para 15), both cited in International Commission of Jurists, *The Right to a Remedy and Reparation for Gross Human Rights Violations: Practitioners Guide No. 2* (revised edition 2018). Available online: <https://www.icj.org/wp-content/uploads/2018/11/Universal-Right-to-a-Remedy-Publications-Reports-Practitioners-Guides-2018-ENG.pdf>, accessed on 20 February 2024. Cessation is also said to include the repeal of legislation associated with a violative regime (which is also often addressed as guarantees of non-repetition): 'All legislative and regulatory acts adopted with a view to its construction and to the establishment of its associated regime, must forthwith be repealed or rendered ineffective' (*Legal Consequences of the Construction of a Wall in the Occupied Palestine Territory (Advisory Opinion)*, ICJ Judgment of 4 July 2004, para 151), also cited in the International Commission of Jurists' Practitioners Guide.

<sup>108</sup> DI Guidelines, para 55.

<sup>109</sup> *Id.*, para 57.

<sup>110</sup> The Working Group on Arbitrary Detention suggested the following actions by a court as a means for individuals 'detained in a psychiatric hospital or subjected to forced treatment' to 'effectively and promptly secure their release':

Injunctive relief should consist in an order requiring the facility to release the person immediately and/or to cease immediately any forced treatment and any systemic measures, such as those requiring mental health facilities to unlock their doors and to inform persons of their right to leave, and establishing a public authority to provide for access to housing, means of subsistence and other forms of economic and social support in order to facilitate de-institutionalization and the right to live independently and be included in the community. Such assistance programmes should not be centred on the provision of mental health services or treatment, but free or affordable community-based services, including alternatives that are free from medical diagnosis and interventions. Access to medications and assistance in withdrawing from medications should be made available for those who so decide.

United Nations Basic Principles and Guidelines on Remedies and Procedures on the Right of Anyone Deprived of Their Liberty to Bring Proceedings Before a Court, A/HRC/30/37 (2015), para 107 (d) and (e).

See also Tina Minkowitz, Center for the Human Rights of Users and Survivors of Psychiatry, Supporting opinion, amicus curiae, in a trial regarding the involuntary hospitalization of persons with disabilities in psychiatric hospitals in Mexico, Queja 7/2023. Available online: [https://www.academia.edu/110901519/CHRUSP\\_Amicus\\_Mexico\\_SJCN](https://www.academia.edu/110901519/CHRUSP_Amicus_Mexico_SJCN), accessed on 20 February 2024.

<sup>111</sup> *Id.*, para 55.

<sup>112</sup> *Id.* Recall that forced treatment violates the right to be free from torture and other ill-treatment (Article 14 Guidelines, para 12; GC1, para 42) and 'may well amount to torture' (Melzer Report, A/43/49, para 37; see note 24).

of mental health treatment based on non-response or a hypothetical ‘best interpretation of will and preferences’.<sup>113</sup>

The heightened standard is reparative and corresponds to a guarantee of non-repetition. As a result of the systemic practice of disability-based detention and forced interventions, these services are fraught with power inequalities, which are likely to remain even once the legislative authority to impose involuntary measures is removed. The impact of power inequalities on consent is also addressed by the phrasing in paragraph 15, referring to ‘mental health settings where a person can be deprived of their liberty’ as a form of institutionalization, to be monitored through records of ‘numbers and demographics of persons in psychiatric or mental health settings, records of whether the duty to allow persons with disabilities to leave institutions has been fulfilled, the number of persons who have exercised the option of leaving, and other information concerning planning for those who are yet to leave institutions’.<sup>114</sup> In a context where the deprivation of liberty is feasible technologically and operationally (e.g., the facility is equipped with doors that lock from the inside and to which only staff have the keys) and/or has been legally authorized and widely practiced, any instance of apparent consent or non-coercion should be questioned. The threat of deprivation of liberty renders the admission or decision to remain involuntary and thus a detention even if it is not recorded as such.

In addition to repealing ‘involuntary commitment or treatment based on “mental illness or disorder”’ and other disability-based restrictions on liberty and security, emergency assistance must be provided to leave places of arbitrary detention.<sup>115</sup> These measures, similarly to the lifting of guardianship and forced treatment discussed above, fulfill the duty of ceasing violations and guaranteeing non-repetition; the provision of emergency assistance enables the cessation of violations and can also be understood as restitution, in the sense of restoring people to liberty in the community.

States are reminded of their obligation to ‘reform penal and procedural law to eliminate declarations of incapacity to participate in proceedings or to be held criminally responsible’ and to repeal security measures.<sup>116</sup> The Guidelines correctly list ‘forensic psychiatric institutions’ as a place of disability-based detention, implying that individuals currently detained under security measures may be equally entitled to release as those civilly detained under mental health laws. Interactions with fair trial guarantees and other general aspects of criminal procedure should be explored to flesh out the requirements of deinstitutionalization in this context, which overlaps the penal system and disability-based institutionalization.

Finally, states are called on to legally recognize institutionalization as a prohibited form of discrimination when ‘based on disability, separately or in combination with other

<sup>113</sup> Hege Orefellen has emphasized this point:

Due to the controversial, intrusive and potentially irreversible and harmful nature of psychiatric interventions, there needs to be a high requirement for consent, and an affirmative expressed consent should always be required for such procedures to be carried out. In situations where it after significant efforts have been made is not practicable to determine the persons will and preferences, psychiatric treatment should not be inflicted based on presumed or hypothetical consent (as might happen with other medical procedures in urgent situations) and should not without an advance directive or earlier expressed preferences be interpreted as the (default) will of the person. Without a prior, affirmative expressed consent, no psychiatric procedures should be carried out. Ever. As recognized by the UN Special Rapporteur on torture in his report on psychological torture, involuntary psychiatric interventions generally involve highly discriminatory and coercive attempts of controlling or correcting the victim’s personality, behaviour or choices, almost always inflict pain or suffering and may amount to torture. There can be no justification for such practices; not crisis, not medical emergency, not “danger to self”, not “danger to others”. Nothing. The first step must be absolute prohibition of forced treatment and commitment.

Presentation delivered on June 18, 2021, in *Reimagining Crisis Support* Book Launch, a side event of the Center for the Human Rights of Users and Survivors of Psychiatry at the Conference of States Parties to the Convention on the Rights of Persons with Disabilities. Available online: [https://youtu.be/F53PcGXwmGQ?si=nbpCVV\\_0d\\_OJk95R](https://youtu.be/F53PcGXwmGQ?si=nbpCVV_0d_OJk95R), accessed on 20 February 2024.

<sup>114</sup> DI Guidelines, para 126.

<sup>115</sup> Id, para 58. On the provision of emergency assistance to leave, see also paragraphs 31 and 105.

<sup>116</sup> Id, paras 56 and 58. See also note 48 and accompanying text.

grounds'.<sup>117</sup> This also serves as a guarantee of non-repetition, by strengthening the legal framework to combat the persistence or reintroduction of institutionalization of any kind. Its phrasing echoes the Guidelines on Article 14 and is aimed at the typical formulations in mental health legislation.<sup>118</sup>

Part B on the legal framework and resources addresses the task of mapping the existing situation with respect to institutionalization and accessible living in the community, and initiating transformations. These activities should cover 'existing laws, regulatory frameworks, policies, budgets, formal service structures, informal community-based support, new elements of support and the workforce'.<sup>119</sup>

A comprehensive review of legal provisions should include 'legal capacity, disability laws, anti-discrimination laws, family laws, health laws, civil laws, laws governing social care provision for children, adults and older persons, and social protection legislation'.<sup>120</sup> 'Provisions that enable or facilitate institutionalization', including those in mental health laws, are to be identified and abolished.<sup>121</sup> Gaps should be identified and addressed through legislation regarding the 'legal recognition and enforceability of the right to live independently and to be included in the community, and related rights', and effective legal remedies should be ensured.<sup>122</sup>

Existing institutions and their funding are to be mapped, and these resources reallocated to 'services that respond to the expressed requirements of persons with disabilities'.<sup>123</sup> Included here, along with the systemic mapping otherwise addressed in this section, is a suggestion to map 'the support networks and important relationships' of persons living in institutions, subject to the will and preferences of the person concerned, for use in planning their support and services in the community.<sup>124</sup> While mapping might be useful to individuals in planning support and services, it should not be made a requirement of receiving support in planning; 'subject to will and preferences' entails the right to refuse one part of a service offered and accept others. In any case, such mapping should be part of the individualized planning processes addressed in Section 7 and should not be carried out in conjunction with the mapping of institutions. Any mapping of needs for the purpose of systems planning should be carried out without addressing details of the personal relationships of individuals leaving institutions.

Community-based services are to be mapped, and those 'that are segregated, medicalized or segregated, medicalized or not based on the will and preferences of persons with disabilities should be discontinued'.<sup>125</sup> The workforce should be mapped to assess 'the feasibility of workforce transformation to ensure the provision of services compliant with the Convention', with the caveat that 'those responsible for human rights violations should not be licensed to provide new services'.<sup>126</sup> Workforce transformation also entails that 'services should be provided solely under the direction of the persons with disabilities concerned, or the parents or guardians of children with disabilities, giving due weight to the child's views'.<sup>127</sup>

The obligation to map services and workforces with the aim (in part) of removing those linked to human rights violations is significantly reparative to cease violations and guarantee non-repetition. The discontinuation of services 'that are segregated, medicalized or not based on the will and preferences of persons with disabilities' is far-reaching in

<sup>117</sup> Id, para 59.

<sup>118</sup> See Article 14 Guidelines, paras 6 and 7.

<sup>119</sup> DI Guidelines, para 60. See also note 189 and accompanying text.

<sup>120</sup> Id, para 62.

<sup>121</sup> Id, paras 61 and 62.

<sup>122</sup> Id, para 61.

<sup>123</sup> Id, para 63. See also paragraph 30 and the discussion above on Section 3 Part E.

<sup>124</sup> Id. See also the discussion below regarding Sections 10 and 11 on data collection and the monitoring of deinstitutionalization. Respect for legal capacity and privacy is essential in carrying out all such activities.

<sup>125</sup> Id, para 64.

<sup>126</sup> Id, para 66.

<sup>127</sup> Id, para 66.

scope and would apply to much of what now exists in community-based mental health services that rely on psychiatric diagnosis and the use of medications, whether alone or in combination with social support, and which also tend to segregate service users and to promote compliance with treatment rather than creating the space to take risks and be supported.<sup>128</sup>

Those responsible for planning deinstitutionalization at the national level, in consultation with persons with disabilities and survivors of institutionalization, will need to define these terms with reference to the country context, and this definition may also evolve as the mapping exercise takes place.

Similarly, definitions will be needed to investigate which members of the workforce are responsible for human rights violations. This should include, at a minimum, anyone who has carried out involuntary hospitalization, forced or non-consensual medication, restraint, and similar practices amounting to torture and other ill-treatment. This process too may need to be iterative as new information comes to light.

These mapping exercises can also reveal good practices that should be maintained and workers who can readily shift to services that comply with the Guidelines.

In close consultation with persons with disabilities and their organizations, needs assessments and overall planning should be carried out to ‘ensure that a wide range of support services and mechanisms exist in the community and that all persons with disabilities can plan and direct their own support . . . and that families of children with disabilities are equally supported’.<sup>129</sup> Included elements are the identification of gaps in support, the need for new service structures, and the development and evaluation of pilot projects.

The consultative obligation is also applied to ensuring that ‘support services respond to the will and preferences of persons with disabilities’, and that users, ‘including those who may require support in choosing and managing their support, have real choice and are not obliged to choose between services that do not comply with the Convention’.<sup>130</sup>

The needs assessment and overall planning, including building in the option for people with disabilities to plan their own support, aim to ensure that real options exist that comply with the Convention from which people with disabilities can choose and that all such services not only respect but ‘respond to’ the individual’s will and preferences, which is central to the implementation of deinstitutionalization. Without good support options, practices that violate human rights will persist or re-emerge. These obligations can be understood as guarantees of non-repetition by meeting the human needs that institutionalization exploits and can never fulfill.

As a whole, the obligations of mapping and systems reform contribute to the reparative aim of guaranteeing the non-repetition of institutionalization by comprehensively assessing and implementing the actions needed in a particular country context to transform laws, policies, and services, guided by principles and values that uphold the rights of all persons with disabilities to legal capacity, liberty, and independent living in the community.

Part C brings together states’ systemic obligations in the formulation of comprehensive deinstitutionalization strategies and action plans. Deinstitutionalization plans should be ‘high quality . . . structured . . . comprehensive and contain a detailed action plan with timelines, benchmarks and an overview of the necessary and allocated human, technical and financial resources’, and should ‘make maximum use of available resources without delay’.<sup>131</sup> Deinstitutionalization strategies should be ‘cross-governmental . . . entailing high-level political leadership and coordination at ministerial or equivalent level, with sufficient authority to initiate and lead law reform processes and to direct policymaking,

<sup>128</sup> See [Wipond \(2023\)](#). The United States, while hardly representative of the global situation, can stand as a warning as to the actual conditions in a country that exports its models widely.

<sup>129</sup> DI Guidelines, para 65.

<sup>130</sup> Id.

<sup>131</sup> Id, para 67.



programming and budgeting’.<sup>132</sup> In other words, the Guidelines call for deinstitutionalization to be viewed as a governmental priority with appropriate dedication of leadership, attention, and resources.

These strategies and action plans should be based on ‘a clearly stated declaration of what is to be achieved through the deinstitutionalization process, prepared in consultation with persons with disabilities, especially survivors of institutionalization, and their representative organizations’.<sup>133</sup>

In making deinstitutionalization a priority, it will be necessary to ensure that all forms of deinstitutionalization, including the abolition of all deprivation of liberty and compulsory treatment in mental health settings. Selective implementation of the Guidelines to perpetuate any form of institutionalization should not be tolerated.

All groups of people with disabilities affected by institutionalization, including survivors of psychiatric institutionalization, need to be fully included and consulted in all their diversity. States and civil society will need to ensure that mapping, reforms, and all aspects of deinstitutionalization from the psychiatric system are carried out in full compliance with the Guidelines to guarantee the non-repetition of violations, either of institutionalization or the failure to fulfill economic, social, and cultural rights that leaves people vulnerable to new forms of institutionalization and other abuses. Especially important is to not revert to segregated or medicalized approaches to the provision of support services, housing, or any other measures to meet the needs of people with disabilities. Neither the mental health sector nor any other that has been closely associated with institutionalization must be placed in charge of policy, resources, and programs.

## 6. Inclusive Community Support Services, Systems, and Networks

Section 6 comprises paragraphs 69–89 and is divided into five parts: (A) Support systems and networks; (B) Support services; (C) Individualized support services; (D) Assistive technology; and (E) Income support. A distinction is made between support services in contrast to support systems and networks (the latter being characterized as ‘informal support’)<sup>134</sup>. Support services, systems, and networks are for the most part described as the needs of persons with disabilities generally, not limited to those leaving institutions.

Support systems and networks addressed in Part A ‘include relationships . . . with family members, friends, neighbours or other trusted persons who provide the support that a person requires for decision-making or daily activities’. Support systems ‘are key for some persons with disabilities . . . in navigating and determining the support services that they may require’.<sup>135</sup>

Peer support is included among ‘support networks’ here, along with ‘self-advocacy, circles of support, . . . organizations of persons with disabilities, particularly those of survivors of institutionalization—and centres for independent living’.<sup>136</sup> With respect to some of these initiatives, their characterization as ‘informal support networks’ is incorrect. DPOs can be formally organized and may have the purpose of advocacy, informal support, and/or the provision of support services. Centers for independent living can be service providers with paid staff. Peer support can be organized as mutual support groups or networks and, from my point of view, that is the most authentic understanding of peer support. But there are also peer support services that are autonomously organized and employ paid or unpaid staff who share an identity or experience with those they serve. (Mutual support networks too may be highly structured in their processes.) The grouping in paragraph 70 might best be understood as initiatives self-organized by people with disabilities that have support to individuals as a primary or secondary function.

<sup>132</sup> Id.

<sup>133</sup> Id, para 68.

<sup>134</sup> Id, paras 23, 24, 60, 71, and 74.

<sup>135</sup> Id, para 69.

<sup>136</sup> Id, para 70.

States are directed to encourage the creation of such ‘networks’, provide them with financial support, and fund their ‘access to training in human rights, advocacy and crisis support’.<sup>137</sup> The Guidelines do not address the overlap between self-organized support by and for persons with disabilities, characterized here as informal support, and support services, including personal assistance and other individualized forms of support. This overlap should be addressed in deinstitutionalization plans and strategies in a manner that respects the right to self-organize autonomously in informal networks and also upholds the rights of those using any support provided as a service (having a defined service provider and service recipient) to have some quality control and complaints mechanisms, for example. The mental health system should never be placed in charge of peer support, whether conducted informally or as an organized service; rather, any quality control and funding needed should be overseen by a disability human rights agency competent in the lived experiences of people with psychosocial disabilities and survivors of psychiatric institutionalization.

The Guidelines specify the autonomous character of peer support and describe some of the needs it can meet:

Peer support should be self-directed, independent of institutions and medical professionals, and autonomously organized by persons with disabilities. It is especially important for survivors of institutionalization, and in the interest of consciousness-raising, supported decision-making, crisis support and crisis respite, living independently, empowerment, income generation, political participation, and/or participating in social activities.<sup>138</sup>

Survivors of psychiatric institutionalization have developed diverse practices of peer support, including crisis respite and other support services as well as mutual support networks.<sup>139</sup> Peer-run crisis respite centers are places where a person can stay temporarily to get their needs met and receive support during a personal crisis. Crisis support might also be provided by other means such as personal assistance or mobilizing members of an informal friendship network or mutual support network.

‘Crisis respite’ should be disambiguated from the concept of ‘respite care’ as a service provided to family members. The latter is a concept that frames support for a person with a disability as meeting third-party needs, and it is not found in the Guidelines;<sup>140</sup> one civil

<sup>137</sup> Id.

<sup>138</sup> Id, para 73.

<sup>139</sup> The classic text is Judi Chamberlin, *On Our Own: Patient Controlled Alternatives to the Mental Health System* (1978). As examples of present-day autonomous peer support practices, see Redesfera Locura Latina, Primer Ciclo de Webinars: Grupos de Apoyo Mutuo (26 July 2019), [https://youtu.be/PMYjwIbz\\_w?si=s-KhHtw-XK01puO1](https://youtu.be/PMYjwIbz_w?si=s-KhHtw-XK01puO1), accessed on 20 February 2024; Afiya Peer Respite, <https://wildfloweralliance.org/afiya/>, accessed on 20 February 2024; and Intentional Peer Support, <https://www.intentionalpeersupport.org/>, accessed on 20 February 2024.

<sup>140</sup> The Committee’s decision in *Bellini v. Italy*, CRPD/C/27/D/51/2018, adopted 26 August 2022, took a contrary approach, as had General Comment No. 5 (paragraph 68), treating ‘respite care services’ as a service provided to ‘family caregivers’. *Bellini* found that Articles 19, 23, and 28, read in conjunction with Article 5, required the provision of ‘individualized support services’, including ‘respite care services’, to the family of a non-disabled complainant who provides support to her daughter and husband, both of whom are persons with disabilities (paragraph 8 (a) (ii)). Article 5 prohibits discrimination based on disability, which can encompass discrimination based on association with a person with a disability.

The provision of support to family members that they require in order to provide support to persons with disabilities, within the context of family relationships and/or living together as a household, is a complex issue. While it makes sense to ground the decision in Article 5, the question of choice and agency by persons with disabilities with respect to receiving support from family members should have been recognized and addressed in regard to both admissibility and merits, including by inquiring about the provision of support in decision-making and whether recourse was had to the ‘best interpretation of will and preferences’ of the persons concerned (specifying the basis for determining that the criteria were met for doing so), and by including decision-making support in the recommendations of support to be provided to the persons with disabilities and their family member.

The concept of ‘respite care’ as a service provided to family members who provide support is especially problematic as it positions the supporter as the primary rights holder with respect to the alternate support being offered to the person with a disability. The need for alternate supporters is addressed in paragraph 74 of these Guidelines as a feature to be built into all support arrangements so that it remains clearly subject to the

society organization specifically argued for its removal from an earlier draft ([Comments of the Center for the Human Rights of Users and Survivors of Psychiatry n.d.](#)). ‘Institutions for the provision of “respite care”’ are specifically rejected.<sup>141</sup>

States are also directed to train and support ‘communities and families . . . to provide support that is respectful of the choices, will and preferences of persons with disabilities’.<sup>142</sup> Choosing family or community support cannot be exclusive; persons with disabilities should have ‘a wide range of options’. Furthermore, ‘the choice to return to one’s family home after institutionalization [must] not disqualify a person from eligibility for permanent independent housing’.<sup>143</sup> The concept of ‘community support’ is not further elaborated on here but is revisited in the section on equal access to mainstream services:

Community-based organizations, individuals and neighbourhood groups may play a diversified role in the provision of social support, connecting persons to local resources, or provide support as a member of the broader social capital of the community.<sup>144</sup>

Community support should be understood as including peer support networks and mutual aid, since ‘community’ is not only geographical but can be understood thematically (as is the case with virtual communities or in-person gatherings that bring together people with a shared interest or identity). People with disabilities, including those leaving institutions, might find support in women’s groups, LGBT groups, groups pertaining to their religious or ethnic identity, as well as those specifically organized by and for people with disabilities.

To address the need for continuous quality support, ‘support arrangements can include a multiplicity of supporters acceptable to the person using support, and to the families of children with disabilities . . .’.<sup>145</sup> While this premise is advanced in discussing support that people receive from their families, it has wider applicability and should be built into the design of any support plan, whether informal or provided as a service. Such an approach does away with the need for any separate concept of ‘respite care’ as a service provided to family members who provide support.<sup>146</sup>

Support services are nevertheless envisioned to enable ‘family caregivers’ in particular to fulfill their role, and this cannot entail the placement of an adult or child in an institution for any period of time.<sup>147</sup> The concept of support services to ‘family caregivers’ (better phrased as family members who provide support to persons with disabilities) must similarly be understood to not entail family members choosing supporters for the person with a disability or insisting that they receive any unwanted support.

The Guidelines remind us that ‘support persons, circles of support and support networks may be chosen by persons with disabilities only, and not by third parties such as judicial or medical authorities, family members or service providers’.<sup>148</sup> This applies

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will and preferences of the person receiving support, as required under paragraph 72 of the Guidelines and under Article 12.

See also notes 146–150 and their accompanying text, and see additionally General Comment No. 1, paragraphs 29 (a) (people with high support needs should not be excluded from support in decision-making) and 21 (setting out ‘best interpretation of will and preferences’ standard and criteria for its application).

The reference to ‘respite care’ in Article 28 should be interpreted consistently with these Guidelines and with the totality of the Convention as referring to support services offered to the person with a disability when they need a temporary break from their usual environment or routine, which may include their family members or not (as in the concept of crisis respite discussed in the main text). Such a construction would follow the example in paragraph 33 of these Guidelines regarding the interpretation of ‘residential services’ in Article 19 (b).

<sup>141</sup> DI Guidelines, para 28; see also paragraph 74.

<sup>142</sup> Id, para 71.

<sup>143</sup> Id, para 79. This paragraph is placed anomalously in the section on support services.

<sup>144</sup> Id, para 100.

<sup>145</sup> Id, para 74.

<sup>146</sup> See note 140 and accompanying text.

<sup>147</sup> DI Guidelines, para 74.

<sup>148</sup> Id, para 72.

to all decisions about whether to use support as well as the choice of individuals to provide the support, in keeping with General Comment No. 1.<sup>149</sup> I have written about a solidarity-based approach to providing individuals with the degree and kind of assistance they may want and accept, including none if that is their wish, while maintaining a readiness to adapt if the situation should change.<sup>150</sup>

In part B, support services are addressed as to general features of how such services should function as well as specific types of services or populations of concern. As an entry point, the Guidelines state that ‘self-assessment tools’ should be prioritized in identifying needs in a person-centered process that is not dominated by medical criteria or medical professionals.<sup>151</sup>

The approach taken to incorporate medical assessment so long as it does not ‘dominate’ collapses the diversity among people with disabilities both in terms of needs associated with particular impairments and in terms of personal preferences. Psychosocial disability is not a medical condition and there is no reason to require any medical criteria or involvement at all in the assessment of support needs related to diversity of consciousness, communication, behavior, or distress.<sup>152</sup> Given the substantial harm caused by the medicalization of psychosocial disability and its link with arbitrary detention and torture, it would be counter-reparative and re-traumatizing to require people with psychosocial disabilities to submit to medical gatekeeping to access support services or any other disability-related entitlements. Instead, the tools should be adaptable to different constellations of needs and personal preferences and should never require medical assessment as a condition of accessing non-medical support services.

In fact, the Guidelines contain the most advanced development yet of CRPD jurisprudence on support related to psychosocial disability that is free from any medical or health system involvement:

States parties should ensure that options outside the health-care system, that fully respect the individual’s self-knowledge, will and preferences, are made available as primary services without the need for mental health diagnosis or treatment in the individual’s own community. Such options should meet requirements for support related to distress or unusual perceptions, including crisis support, decision-making support on a long-term, intermittent or emergent basis, support to heal from trauma, and other support needed to live in the community and to enjoy solidarity and companionship.<sup>153</sup>

This paragraph outlines how the social model of disability should include people with psychosocial disabilities in the provision of support services, cataloging a range of needs that can arise with experiences of distress or unusual perceptions. It is reparative in supporting the demedicalization of psychosocial disability and creating pathways to shift resources and policy towards social model provision both for individuals and as a systemic paradigm shift that complements legal measures to guarantee the non-repetition of violations.

A few details are worth highlighting. The support services envisioned in paragraph 76 are to be provided outside the health system and without the need for mental health diagnosis or treatment. They are meant to be primary services, not auxiliary to either medical or psychological treatment. The respect for self-knowledge is related to de-medicalization and the values of peer support and consciousness-raising, as well as the pedagogy of liberation,

<sup>149</sup> GC1, paras 19 (‘Some persons with disabilities only seek recognition of their right to legal capacity on an equal basis with others . . . and may not wish to exercise their right to support’) and 29(g) (‘The person must have the right to refuse support and terminate or change the support relationship at any time’).

<sup>150</sup> *Reimagining Crisis Support*, pp. 14–27.

<sup>151</sup> DI Guidelines, para 75.

<sup>152</sup> See below under Section 7 Part B for a discussion of the obligation to refrain from embedding a medical model of disability, note 205 and accompanying text (referencing some of the harms caused to health), and note 239 (concept of psychosocial disability is defined by the movement, and not linked to ‘psychosocial rehabilitation’).

<sup>153</sup> DI Guidelines, para 76.

all of which assume the inherent capacity of human beings to reflect on their inner and outer worlds.<sup>154</sup>

The catalog of support needs in paragraph 76 is well-rounded and not exhaustive, comprising practical support, decision-making support, and healing support, among others. Note that most kinds of support, not only decision-making support, can be ‘long-term, intermittent or emergent’. Crisis support is roughly equivalent to support on an ‘emergent’ basis, in other words, to meet needs that have not been planned for and that may be urgent to the person concerned.<sup>155</sup>

What might it mean to rely entirely on these supports, not only for individual survivors who navigate their own way to staying outside the mental health system, but for communities and social-model services to gain confidence and gain the confidence of those who need them, on a wide scale? To realize its full potential will require investigation, reflection, and concerted action by those involved in deinstitutionalization plans and processes, with the leadership of survivors of psychiatric institutionalization and people with psychosocial disabilities.

The Guidelines acknowledge community-based rehabilitation or inclusive development as a framework for the provision of disability-related support services but caution that such services must ‘link with existing services and networks in the community’ and not isolate people with disabilities. The cautionary note is welcome and should include a warning against medicalization as well.

Day-care centers and sheltered workshops cannot be included as they do not comply with the Convention.<sup>156</sup> This is another example of an element that should be cross-referenced with other parts of the Guidelines when developing deinstitutionalization plans and conducting mapping activities, since references to practices that should be discontinued should be brought together to develop parameters for evaluation.

Funding is to be flexible ‘to respond to the demands of diverse individuals . . . including the option of designing new forms of support’.<sup>157</sup> This provision can help in the shift from the mental health-centric provision of primary and secondary support services related to psychosocial disability to services outside the healthcare system, to the extent that people desiring such support are made aware of the option and use it, either by designing new forms of support and finding individuals to provide that support or by choosing peer support, new services under paragraph 76, or personal assistance, which must be proactively developed and established to be made available.

Addressing specific populations, older persons should be supported to remain in their own homes and should not lose access to personal assistance.<sup>158</sup> Specific support services for children ‘should enable [them] to reach their full potential’.<sup>159</sup>

As mentioned above, a choice to return to one’s family home after institutionalization should not disqualify the person from permanent independent housing.<sup>160</sup> Housing is not otherwise addressed in this section as a kind of support, but this paragraph reminds us of the complementary obligations related to housing availability set out in paragraphs 32 and 33 under Section 3, Key elements of the deinstitutionalization process.

Support must ‘remain subject to the choice and control of persons with disabilities’, and safeguards should be put in place to ensure that it is not ‘imposed involuntarily or delivered in a way that infringes upon the person’s autonomy, liberty or privacy’.<sup>161</sup> The safeguards include ‘accessible and confidential means of reporting abuse’ as well as

<sup>154</sup> Mead et al. (2001); Minkowitz (2021b), pp. 19–27 (Decision-making support for personal crisis).

<sup>155</sup> See Minkowitz (2021b), pp. 14–15.

<sup>156</sup> DI Guidelines, para 77; see also paragraph 28.

<sup>157</sup> Id, para 78.

<sup>158</sup> Id, para 81.

<sup>159</sup> Id, para 82.

<sup>160</sup> Id, para 79.

<sup>161</sup> Id, para 80.

‘individualized arrangements that conform with the will and preferences of the person’.<sup>162</sup> Support services are to be ‘based on ethical regulatory frameworks that comply with the Convention’.<sup>163</sup> The need for accessible and confidential means of reporting abuse is not limited to support services and should be viewed as applicable to support systems and networks, including both peer support and family or community support, as also contemplated in Article 16 of the Convention with respect to the family setting. It is not apparent what other kinds of safeguards the Guidelines contemplate to ensure that support services do not infringe on autonomy and are not imposed involuntarily, but regular monitoring, as contemplated in Article 16 (3), applies to ‘programmes’ as well as ‘facilities’ that are designed to serve persons with disabilities, and could be invoked to require accountability of structured forms of support. The use of individualized safeguards ought not to be a mandatory requirement but, as any form of support, should be subject to the person’s choice to refuse entirely as well as to shape it according to their own will and preferences.

Personal assistance and other individualized support services, addressed in Part C, must be ‘made available to all persons with disabilities, including those leaving institutions’.<sup>164</sup> In its Concluding Observations, the Committee has criticized the failure to make personal assistance available to people with psychosocial disabilities.<sup>165</sup> This form of support can be personalized to meet ongoing, intermittent, or emergent needs, and should be included, along with diverse forms of peer support and new forms of support services, among the measures that can fulfill the requirements of paragraph 76.

Turning to Part D, states should ‘ensure access to modern information and communication technology and devices’ and other advanced technologies that become available to the general population.<sup>166</sup>

Income support as support to live in the community is addressed in Part E. ‘Individualized and direct funding’ should be adapted across the lifespan and to cover inflation, and should cover ‘basic income security [and] coverage of health-care and disability-related costs, including components related to repairing the harm caused by institutionalization’.<sup>167</sup>

The provision of funding for basic income security and the coverage of healthcare addresses the economic vulnerability of people leaving institutions, even beyond an initial period of resettlement, due to direct and indirect discrimination, the impact of institutionalization on a person’s capabilities, and the intersection of disability with generalized economic hardship and inequality within a society. Coverage of disability-related costs is justified as a measure of equity since it is an expenditure beyond the necessities of life that persons with disabilities have in common with others; this can also be said of the coverage of healthcare costs to the extent that an impairment or the effects of institutionalization have made such healthcare necessary. The inclusion of costs related to repairing the harms done by institutionalization as disability-related costs acknowledges the impact of institutionalization as a disability-based human rights violation and allows survivors the freedom to imagine what might serve them best as a means of repair.

Disability-related costs should be funded ‘regardless of job-related income’.<sup>168</sup> Family members of adults with disabilities would be covered by the individual’s general income support if they are dependents or act as supporters; family members whose role as supporters has ‘disadvantaged them in other life paths’ qualify for additional support.<sup>169</sup>

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<sup>162</sup> Id.

<sup>163</sup> Id.

<sup>164</sup> Id, paras 83–84. See also para 27, describing key features of personal assistance as ‘individualized, based on individual needs, and controlled by the user’, and stating that people leaving institutions should be able to connect with personal assistance schemes before leaving institutions so as to access them immediately in the community.

<sup>165</sup> Concluding Observations on Austria (2013), CRPD/C/AUT/CO/1, paras 38–39.

<sup>166</sup> DI Guidelines, para 85.

<sup>167</sup> Id, para 86.

<sup>168</sup> Id, para 87.

<sup>169</sup> Id, para 89.

Management of income support is vested in the individual with a disability or the primary caregiver of children with disabilities, in keeping with the CRPD premise of legal capacity and respect for individual autonomy.<sup>170</sup>

The obligation to provide income support is not based on institutionalization and applies generally to persons with disabilities. Complementary to the support package allocated to a person on leaving the institution,<sup>171</sup> the income support described in this section addresses the general impoverishment of people with disabilities and their families,<sup>172</sup> as well as their extra expenses.

The obligations regarding support networks and services are reparative in the sense of rebuilding at the systemic level the capacities within communities to meet a wide spectrum of needs that were neglected and exacerbated through the violent practices of institutionalization. The promotion of autonomous peer support and support services that replace the medical model and paternalism are elements of such rebuilding that contribute to the cessation of violations as well as satisfaction and restitution by reconstructing social relations on the basis of solidarity and respect. To the extent that people leaving institutions want to rely on family members for support, the Guidelines set out enabling frameworks for this purpose, which should be complemented by a reparative lens considering the harm caused to family relationships by regimes of institutionalization and the interpersonal harm caused to persons with disabilities by family members who have been complicit in institutionalization.

## 7. Access to Mainstream Services on an Equal Basis with Others

Section 7 comprises paragraphs 90–106 and is divided into two parts after introductory paragraphs: (A) Preparations for leaving the institution and (B) Living independently in the community.

This section combines the process for individuals to leave institutions with the creation of conditions for them to live independently in the community. These two dimensions are joined in a stringent standard that rejects transitional forms of institutionalization as ‘stepping-stones’, so that people leaving institutions have immediate access to life in the community, which, in turn, must be made more livable and welcoming for diverse individuals.<sup>173</sup>

Deinstitutionalization plans generally are to ensure access by all persons with disabilities to ‘accessible, affordable, high-quality mainstream services in all aspects of life’.<sup>174</sup> Taking into account likely barriers facing people leaving institutions, the Guidelines provide that such access must be ‘without discrimination and . . . not conditioned by, withheld or denied on the basis of assessments, family or social support, medication compliance, any determination of “severity” of disability or perceived intensity of support requirements, any finding of a “mental health condition”, or any other disqualifiers’.<sup>175</sup> Note the mention of ‘medication compliance’, ‘perceived intensity of support requirements’ and ‘finding of a “mental health condition” as disqualifiers against which the Guidelines caution—all of which are relevant to people with psychosocial disabilities and survivors of psychiatric institutionalization to ensure their full access to mainstream services. These services will need to adapt themselves to accommodate a wider spectrum of diversity and eschew discriminatory attitudes and assumptions. ‘Mental health condition’ as well as ‘severity’ of disability are placed in quotation marks as suspect concepts, especially when being applied to disqualify a person from access to mainstream services.

<sup>170</sup> Id, para 88.

<sup>171</sup> Addressed with some variations in paras 31, 58, and 105.

<sup>172</sup> DI Guidelines, para 89.

<sup>173</sup> Id, para 92.

<sup>174</sup> Id, para 90 (‘areas such as, personal mobility, accessibility, communication, health-care, family life, an adequate standard of living, inclusive education, participation in political and public life, housing, social protection, and participation in cultural and community life, leisure, recreation and sport’) and para 92, respectively.

<sup>175</sup> Id, para 90.

Access to mainstream services is also emphasized in the individualized planning processes carried out with persons leaving institutions, to be planned for and ensured both in the preparatory stages and during and after their settlement in a community.<sup>176</sup> Access to an adequate standard of living and social protection are also reiterated, underscoring the importance of social and economic conditions to securing the right to independent living for people with disabilities.

The approach outlined in the Section 7 introductory paragraphs is reparative in that it responds to the obstacles faced by survivors in accessing a full life after institutionalization.

Part A sets out a process intended to equip people leaving institutions to navigate an independent life in the community with any and all needed support.<sup>177</sup> As with all measures undertaken to implement the CRPD, all phases and aspects of the process by which individuals leave institutions must be in accordance with the person's will and preferences and respect their decision-making.<sup>178</sup> Deinstitutionalization must be available to everyone, including those 'with intense support requirements', not leaving anyone behind. Planning processes are customized to each individual; however, they can also choose to leave at any time (and, as we have seen, are entitled to emergency assistance to leave the place of arbitrary detention).<sup>179</sup>

Reparative justice towards people who have been institutionalized is directly invoked in several ways. The discussion is introduced by affirming that 'deinstitutionalization reverses the unjust practice of institutionalization'.<sup>180</sup> The concept of 'reversing injustice' is reparative and indicates that deinstitutionalization processes aim to negate the paternalism, abuse, segregation, discrimination, and other features of institutionalization at every phase and in all their components. Thus, respect for legal capacity, diversity, and agency is paramount, without invoking these concepts as an excuse to maintain institutionalization. The reparative purpose applies to the systemic tasks of deinstitutionalization (such as the creation of action plans and strategies, law reform, mapping, etc.) as well as the processes for individuals to leave.

Persons leaving institutions must 'be respected as survivors 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'.<sup>181</sup> The recognition of individuals leaving institutions as survivors to whom reparations are due should recursively inform all aspects of their leaving the institution, including any individualized planning process that they may accept according to their will and preferences. Their participation in the systemic tasks of deinstitutionalization is welcomed, as it was during the development of the Guidelines.<sup>182</sup>

Institutional staff are to be 'trained on a human-rights, reparative and person-centred meaning of deinstitutionalization'.<sup>183</sup> The Guidelines leave unstated who is to conduct the individualized planning processes that provide the maximum support in leaving institutions, beyond the training of staff and the involvement of 'trusted persons, which may include family members, friends and others, ... in accordance with the will and

<sup>176</sup> Id, para 92.

<sup>177</sup> Id, paras 93–98 inclusive. See also para 37 ('Assessment of capacities for independent living based on impairment are discriminatory and should shift to assessments of individualized requirements and barriers for independent living in the community').

<sup>178</sup> Id, paras 94 and 95(a); see also para 55 (respect for decision-making and support to exercise legal capacity within the deinstitutionalization process) and para 63 (mapping of individuals' important relationships to facilitate planning for their support is subject to their will and preferences). See notes 73–80 and accompanying text for a discussion of decision-making in relation to leaving institutions.

<sup>179</sup> Id, paras 93 and 58, respectively.

<sup>180</sup> Id.

<sup>181</sup> Id, para 95(d).

<sup>182</sup> See notes 14–17 and accompanying text.

<sup>183</sup> DI Guidelines, para 94.



preferences of the person concerned'.<sup>184</sup> Giving the lead role to institutional staff, even assuming the best efforts at retraining, is problematic and counter-reparative.<sup>185</sup>

How are we to understand the obligations of institutional staff? A few paragraphs on, a related training obligation is found: 'Authorities and personnel responsible for running institutions, and justice and law enforcement personnel, should receive training on the right of persons with disabilities to live in the community and on accessible communication'. In context, particularly considering the grouping of institutional personnel with justice and law enforcement personnel, this is best understood as training on a duty to respect individuals' rights to live in the community and to be free from unwanted interventions, rather than an encouragement for them to be involved in providing support to individuals in their leaving. The paragraph goes on to direct states to 'prohibit administrative or legal surveillance of persons leaving institutions following their departure' and maintains that 'Institutional authorities and personnel should not provide "continuity of care" in the community'.<sup>186</sup> The role of institutional staff is thus to act within their competence and capability to cooperate with the ending of their regime, rather than to apply their own service paradigms (such as discharge planning) to the release from institutions.

The mistrust of institutional administrators and personnel is echoed elsewhere in the Guidelines: those involved in 'managing or perpetuating institutions' are excluded from leading processes of deinstitutionalization; perpetrators are excluded from providing services related to reparations; institutional staff are excluded from monitoring deinstitutionalization.<sup>187</sup>

The concern for keeping the old paradigm from undermining the new one by not involving institutional personnel as support providers for deinstitutionalization is especially relevant to supporting individuals to leave on their own terms, restoring to them respect for their autonomy and dignity and reversing the process of institutionalization. While arguments have been made for perpetrators to engage in care work for victims as part of reparations, this is highly risky,<sup>188</sup> and it is not the approach taken in these Guidelines. Rather than defaulting responsibility to institutional staff, the disability strategies and action plans should assign responsibility for supporting individuals to leave institutions based on a consideration of which sectors or agencies are well-grounded in the CRPD and these Guidelines and capable of taking a reparative approach to support that respects a person's will and preferences—perhaps those that have been involved in developing support in decision-making that is compliant with Article 12, including peer support and community support practices by survivors of psychiatric institutionalization and people with psychosocial disabilities.<sup>189</sup>

The requirements of these individualized processes include providing individuals 'with adequate time and opportunities to prepare physically and emotionally for living in the community' and offering them 'a wide range of experiences in the community in preparation for leaving the institution, to help build their experience, strengths, social skills and life skills, remove fears and gain positive experiences of living independently'.<sup>190</sup> These measures can be reparative if they acknowledge the traumatizing impact of institutionalization that can give rise to such needs and do not essentialize this vulnerability as part of a person's disability or identity.<sup>191</sup>

<sup>184</sup> Id, para 94.

<sup>185</sup> Id, para 98. See also note 106 and accompanying text.

<sup>186</sup> Id, para 98.

<sup>187</sup> Id, paras 20, 122, and 130, respectively. See additional references in note 18 above.

<sup>188</sup> Linda Radzik, *Making Amends: Atonement in Morality, Law, and Politics* (2009), pp. 99–100.

<sup>189</sup> Mapping exercises, addressed in paras 60–66 (see discussion under Section 5, Part B), should look into these capabilities as an early-stage priority to begin the needed support work as soon as possible, pursuant to the immediate obligation to cease violations.

On support practices by survivors and people with psychosocial disabilities, see notes 136–139 and accompanying text and note 154 and accompanying text.

<sup>190</sup> DI Guidelines, para 95 (b) and (e), respectively.

<sup>191</sup> Such an approach is contemplated in paragraph 37 of the Guidelines:

Respecting the individual as a decision-maker ‘with support if required, in all aspects of leaving the institution’ and putting the individual ‘at the core of processes of individualized planning’ should be implemented in a strong rather than a weak sense to be reparative.<sup>192</sup> Supporters should take the time and effort needed to allow the individual to express their wishes and concerns and respond to those, while also offering information that the individual is likely to not have because of having been deprived of access to the world or the information having been previously irrelevant to them.

Diversity of needs relating to the process of leaving institutions can be both subjective (different values or attitudes) and objective (different kinds of objective impact, for example, loss of housing and community ties, or on the other hand, maintaining strong connections despite institutionalization). This too should be part of the meaning of putting individuals—in all their diversity—at the core of these planning processes.<sup>193</sup>

Lastly, individuals are to ‘receive information about housing options, transport, work and employment, individualized funding and all other measures necessary to ensure an adequate standard of living’.<sup>194</sup> It should be contemplated that some support is going to be necessary for many individuals to make use of such information. Both connection with personal assistance schemes and support in exercising legal capacity (provided for decisions about leaving and to continue if required afterwards) are mentioned elsewhere in the Guidelines as steps to be taken before leaving the institution and should be built into these processes; similarly the obligations to provide economic and social assistance to individuals when they leave the institution should be implemented directly in these processes and not merely through the provision of information.<sup>195</sup>

Additional reparative measures related to the process of leaving institutions are those designed to prevent discrimination based on a person’s history of having been institutionalized. States are obligated to ‘provide official identification documents’ to persons leaving institutions, including ‘alternative documents for non-citizens and in humanitarian contexts’ and ‘retroactive documentation if necessary’, and ensure that no markers exist on such documentation that are discriminatory or derogatory or refer to the person’s former status.<sup>196</sup> In accessing services of financial institutions, ‘being subjected to inquiry, interrogation or background checks based on their former status constitutes prohibited discrimination’.<sup>197</sup> States must ensure the privacy of ‘health documentation’, bring laws on data protection into line with the Convention, and expunge or hand over to the person concerned all institutional records pertaining to that individual upon release from the institution.<sup>198</sup>

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States parties should be held accountable for limiting the personal development of institutionalized people and should not create new barriers to leaving institutions by attributing “vulnerability” or “weakness” to persons with disabilities. Deinstitutionalization processes should be aimed at restoring the dignity and recognizing the diversity of persons with disabilities. Assessment of capacities for independent living based on impairment are discriminatory and should shift to assessments of individualized requirements and barriers for independent living in the community.

<sup>192</sup> DI Guidelines, para 95 (a) and (c), respectively.

<sup>193</sup> See para 41 as well, on taking account of intersectionality, i.e., the diversity of identities and experiences and structural oppression beyond disability alone:

States parties should ensure that intersectionality is considered throughout all aspects of deinstitutionalization processes, especially in planning, implementing and monitoring the closure of institutions, in developing inclusive community support systems and inclusive mainstream services, and in ensuring the participation of persons with disabilities throughout these processes, while employing gender-sensitive and age-appropriate approaches.

<sup>194</sup> DI Guidelines, para 95 (f).

<sup>195</sup> Id, paras 27 (personal assistance) 55 (support in exercising legal capacity); and paras 31, 58 and 105 (provision of assistance upon leaving institutions).

<sup>196</sup> Id, para 96.

<sup>197</sup> Id, para 97.

<sup>198</sup> Id, paras 96, 128, and 135, respectively; see also para 134 (states cannot restrict or deny a person’s own access to their own records). A policy should be established on handing over and/or expunging all mental health-related records at the person’s request, even if they do not pertain to institutionalization, as they are used in a similarly discriminatory fashion as records of institutionalization. This approach would complement

Part B on equal access to mainstream services elaborates some of the actions needed to make communities accessible and welcoming to persons leaving institutions, whose rights must be upheld on an equal basis as others.<sup>199</sup> Among these actions is awareness-raising to 'build the capacities of families, neighbourhoods and communities on the values and practices of inclusion', actively seeking the participation of persons with disabilities, particularly survivors of institutionalization, in these activities.<sup>200</sup> Bringing a reparative lens to community welcome should incorporate an acknowledgment of the injustice, discrimination, and traumatization that has impacted these individuals' lives,<sup>201</sup> so that the experience of surviving institutionalization is not collapsed into a concept of psychosocial disability.

Access to transportation must be ensured as well as free movement in rural and urban areas and their neighborhoods and the use of public spaces on an equal basis.<sup>202</sup> This provision includes both simple equal treatment (to not prevent anyone from moving freely or using public spaces or transportation on the basis of disability) and accessibility. The concept of accessibility is deepened to include 'disability-friendly patrolling' as well as 'road-related accessibility' and 'fully accessible information and communication such as Easy Read, and support services, so that persons with disabilities can independently and safely navigate urban areas, including finding their way back safely to their homes and neighbourhoods'.<sup>203</sup> Disability-friendly patrolling is related to the promotion of non-discrimination by law enforcement against people with actual (apparent or non-apparent) or perceived disabilities (Article 13 obligations) as well as upholding the right of people with disabilities to freely move around in and use public spaces.

The remaining paragraphs deal with healthcare, employment, social protection, and inclusive education. Notable in addressing a guarantee of 'comprehensive healthcare' is a directive to 'refrain from embedding the medical model of disability' and provide 'assistance to withdraw from psychiatric medication, access nutritional and fitness programs, always on the basis of free and informed consent and with a view to retrieving overall health and wellbeing'.<sup>204</sup>

The implications of what it means to refrain from embedding a medical model in healthcare with respect to psychosocial disability will need to be addressed in policymaking, subject to robust consultation and collaboration with people with psychosocial disabilities and survivors of psychiatric institutionalization, taking a reparative approach to consider the full scope and extent of harm from the medicalization of crisis, distress, trauma, and diversity of consciousness.

One possible approach to de-medicalization is to shift away from mental health entirely in the creation of new services, which would be based on paragraph 76, while encouraging existing mental health services to refrain from using medical concepts like diagnosis and treatment, and conducting robust and objective reviews of the safety and effectiveness of psychiatric drugs and technological modalities like electroshock. These psychiatric interventions are known to cause severe and permanent impacts on health, including damage to the brain, endocrine system, and other bodily organs, and earlier death.<sup>205</sup>

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the strengthened requirement for consent to mental health services in paragraph 55 and is consistent with the de-medicalization of psychosocial disability.

<sup>199</sup> Id, para 99.

<sup>200</sup> Id, para 100.

<sup>201</sup> As an example of community-level awareness-raising regarding a traumatizing experience, consider Paula Caplan's project 'Listen to a Veteran', <https://www.madinamerica.com/2020/03/paula-caplan-listen-veteran/>, accessed on 20 February 2024.

<sup>202</sup> DI Guidelines, para 101.

<sup>203</sup> Id, para 102.

<sup>204</sup> Id, para 103.

<sup>205</sup> See Joint Submission to Human Rights Committee for its review of the United States in October 2013 on non-consensual psychiatric medication. Available online: <http://www.crpdcourse.org/course-content/segment-2-torture/chruspicccprshadowreportfinal/>, accessed on 20 February 2024; Breggin (1983, 2007); Andre (2009).

A reparative lens would reject the faulty science based on the medicalization of psychosocial disability that decontextualizes the human mind and emotions and overrides individual subjectivity. It would value the lives, physical health, and totality of emotional well-being of people who experience crisis, distress, trauma, or diversity of consciousness on an equal basis as everyone else and reject a focus on eliminating diverse ways of being, labeled as ‘symptoms’ above all else. It would root out the use of considerations in drug/technology approvals and prescribing practices that are based on a failure to accept individuals as they are within communities. Assisting people to withdraw from psychiatric drugs they are currently using needs to be linked in policymaking to awareness-raising measures in communities and among healthcare practitioners and scientific researchers that are based on a reparative approach to deinstitutionalization, including the de-medicalization of distress, crisis and unusual perceptions, and that are free from perpetrator agendas of any kind.

A distinct, straightforward implication of the obligation to refrain from embedding a medical model in health services is that people leaving psychiatric institutions must not be met with stereotypes or discrimination on that basis in their general healthcare. For instance, they should be able to openly discuss, and receive services for, tardive syndromes associated with psychiatric medications (that may be permanent despite withdrawal) and other health-related impacts of institutionalization, and should not thereby be labeled with a psychiatric diagnosis, disbelieved as to their health problems, or otherwise discriminated against.

In addition to prohibiting sheltered or segregated employment, states should eliminate barriers faced by people leaving institutions and ensure ‘a range of choices, allowing time and support for decision-making . . . to exercise their right to work and employment’.<sup>206</sup> The elimination of barriers to employment would benefit from an approach similar to that taken with financial services—that ‘being subjected to inquiry, interrogation or background checks based on their former status constitutes prohibited discrimination’.<sup>207</sup> The Center for the Human Rights of Users and Survivors of Psychiatry has also advocated for an inclusive design of hiring procedures to prevent the need for disclosure of disability or formerly institutionalized status, such as providing alternate ways of demonstrating capability and experience instead of providing a timeline of work history, to avoid any disadvantage from gaps in such a timeline related to institutionalization or disability-related absence from work.<sup>208</sup>

This section calls for a ‘robust social protection package’ to cover resettlement needs to avoid the serious risk of homelessness and poverty when leaving an institution.<sup>209</sup> Economic and social support throughout the life cycle and equal access to existing social protection programs must also be made available.<sup>210</sup> Addressing the elimination of barriers, ‘being a recipient of social protection should not be tied to treatment conditions, guardianship or eligibility criteria related to employment’.

As many children and adults leaving institutions will not have been able to complete their schooling, this opportunity must be provided along with access to lifelong learning, apprenticeships, and higher education, all under the framework of ‘inclusive education without discrimination’.<sup>211</sup> This is necessary ‘to promote their social and economic empowerment and prevent segregation and institutionalization’.

These measures, like those called for in the introductory paragraphs, are reparative in that they address obstacles that survivors face in life after institutionalization.

<sup>206</sup> DI Guidelines, para 104.

<sup>207</sup> Id, para 97.

<sup>208</sup> CHRUSP submission to CRPD for General Comment No. 8 on Article 27. Available online: <https://www.ohchr.org/sites/default/files/2021-12/CHRUSP.docx>, accessed on 20 February 2024.

<sup>209</sup> DI Guidelines, para 105.

<sup>210</sup> Examples given are ‘child support, unemployment benefits, rental subsidies, food stamps, pensions, public health schemes, subsidized public transport and tax credits’.

<sup>211</sup> DI Guidelines, para 106.

## 8. Emergency Deinstitutionalization in Situations of Risk and Humanitarian Emergencies, including Conflicts

Section 8 comprises paragraphs 107–114 and is not further divided.

Situations of collective risk, including conflicts, climate change, and pandemics, impose extra risks on persons with disabilities and intensify the harms of institutionalization. The Guidelines emphasize that emergency and recovery funding should not support continued institutionalization; rather, recovery efforts and national deinstitutionalization strategies should include ‘plans for accelerated deinstitutionalization’ to be implemented immediately in emergencies.<sup>212</sup> This section views situations of collective risk and emergency, in which persons with disabilities are among the most vulnerable to serious human rights violations, as opportunities to accelerate deinstitutionalization and never as a justification for the perpetuation of disability-based detention or segregation.

Emergency protocols should include deinstitutionalization, for example, ‘evacuation scenarios and the provision of accessible information and communication helplines’.<sup>213</sup> Those with the highest health risks should be prioritized for deinstitutionalization.<sup>214</sup> Children with disabilities should be included in all family tracing programs.<sup>215</sup>

After emergencies, states should not ‘rebuild or repopulate’ institutions but instead ensure that refugees with disabilities ‘have access to social assistance, mainstream services and reasonable accommodation, as required’.<sup>216</sup>

‘Measures for disability-inclusive resilience in the community’ are to be developed in consultation with organizations of persons with disabilities including those that represent those remaining in institutions; they should also be involved in the ‘design, implementation, monitoring and evaluation of emergency response, relief and recovery programmes and policies’.<sup>217</sup>

States are directed to ‘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’.<sup>218</sup> The right to legal capacity and the prohibition of disability-based detention ‘should be upheld including during emergencies’.<sup>219</sup> These standards address the positive and negative obligations to both ensure full inclusion in protection measures and refrain from disability-based paternalism, coercion, and segregation.

Given the heightened risk to women and girls with disabilities of violence, unequal access to recovery and rehabilitation services, institutionalization, and other forms of discrimination, the Guidelines recommend an intersectional approach that prioritizes their access to disability-inclusive relief programs and other services.<sup>220</sup> They should also include in national recovery strategies the ‘prevention and protection from sexual exploitation, abuse and harassment and measures to ensure gender equality’.<sup>221</sup>

States are directed to incorporate the principles of the Convention into ‘emergency preparedness, response and recovery’, ensuring the distribution of humanitarian aid ‘in an accessible, non-discriminatory manner’, and the accessibility of ‘water, sanitation and hygiene facilities in emergency shelters and camps for refugees, asylum seekers and internally displaced persons’.<sup>222</sup>

<sup>212</sup> Id, para 107. Such plans are to be ‘informed by persons with disabilities and their representative organizations, particularly those of survivors of institutionalization’, para 109.

<sup>213</sup> Id, para 112.

<sup>214</sup> Id, para 110.

<sup>215</sup> Id, para 108.

<sup>216</sup> Id, para 113.

<sup>217</sup> Id, para 109.

<sup>218</sup> Id, para 108.

<sup>219</sup> Id. See also notes 27–29 and accompanying text.

<sup>220</sup> Id, para 111. Detailed as ‘health services, sexual and reproductive health services, habilitation, rehabilitation, assistive devices, personal assistance, housing, employment and community-based services’.

<sup>221</sup> Id, para 112.

<sup>222</sup> Id.

This section applies the general premises of the Guidelines to the context of public emergencies, during which everyone is vulnerable to severe hardship. Its straightforward call for full inclusion, hard prohibition against disability-based detention, and call for the acceleration of deinstitutionalization efforts confront the most difficult context for the implementation of human rights obligations. International aid agencies as well as civil and military authorities will need to incorporate these standards for disability non-discrimination into their work proactively as well as in the context of current conflicts and other emergencies.<sup>223</sup>

## 9. Remedies, Reparations, and Redress

Section 9 comprises paragraphs 115–123 and is not further divided.

This section sets out requisites for reparations mechanisms and processes related to all forms of institutionalization and their consequent harms. It covers collective as well as individual measures of redress and measures oriented to societal transformation as well as those designed to meet victims' symbolic and material needs.

The theme of reparative justice, implicit throughout the Guidelines, is concretized by calling on states to recognize that institutionalization in all its forms is a multiple violation of the Convention and to identify and redress institutionalization and its consequential harms in accordance with their obligations under the Convention and other international law.<sup>224</sup> Survivors of psychiatric institutionalization have long advocated for reparations as a framework for comprehensive transformation incorporating a shift in public attitudes as well as decisively ending the violations and providing individuals with the assistance they need in recovering from the harms to their health, education, standard of living, life opportunities, and relationships.<sup>225</sup>

According to the Basic Principles and Guidelines on the Right to a Remedy and Reparation for Victims of Gross Violations of International Human Rights Law and Serious Violations of International Humanitarian Law, the duty to provide effective remedies and reparation to victims is a component of states' 'obligation to respect, ensure respect for and implement international human rights law'.<sup>226</sup> Arbitrary detention, torture and ill-treatment, and discrimination have all been said to warrant reparations, including in the Guidelines on liberty and security of persons with disabilities, one of the precursor documents to the Deinstitutionalization Guidelines.<sup>227</sup>

<sup>223</sup> See Reports by the Special Rapporteur on the rights of persons with disabilities, Gerard Quinn, A/76/146 (19 July 2021, 'protection of the rights of persons with disabilities in the context of armed conflict'); A/77/203 (20 July 2022, 'the protection of the rights of persons with disabilities in the context of military operations'); and A/78/124 (13 July 2023, 'highlight[ing] the moral agency of persons with disabilities in rebuilding broken societies in the post-conflict context'). Institutionalization is highlighted throughout these reports as a 'persistent and systemic violation' faced by persons with disabilities (A/77/203, para 19; see also A/76/146, para 51; A/77/203, para 16; and A/78/124, paras 22 and 26).

<sup>224</sup> *Id.*, paras 115 and 116, respectively. On the nature of the 'multiple' violation, see paragraph 6 enumerating articles of the Convention in addition to Article 19 that are violated by institutionalization. (This should not be viewed as exhaustive, for instance, the right to home and family (Article 23), the right to privacy (Article 22), and the right to an adequate standard of living (Article 28) are violated as well).

<sup>225</sup> See [Minkowitz \(2023\)](#). For earlier work, see [Minkowitz \(2021a\)](#), [Orefellen \(2015\)](#), and [Minkowitz \(2012b\)](#). See also note 8 regarding the promotion of reparations in the context of producing these Guidelines.

<sup>226</sup> Basic Principles and Guidelines on Reparation, paras 1 and 3.

<sup>227</sup> Article 14 Guidelines, para 24; see also International Principles and Guidelines on Access to Justice, Guidelines 8.1 and 8.2(m). On arbitrary detention, including in the disability context, see United Nations Basic Principles and Guidelines on Remedies and Procedures on the Right of Anyone Deprived of Their Liberty to Bring Proceedings Before a Court (A/HRC/30/37 (2015), paras 3, 25, 87–92, and 107(f); paras 107(d) and (e) indicate the potential form of a judicial remedy that would implement the cessation of violations towards a particular individual and at the systemic level). These documents, along with the Convention itself and the Basic Principles and Guidelines on Remedy and Reparation, are mentioned in paragraph 116 of the DI Guidelines as references for states' international obligations to redress institutionalization. On torture and other ill-treatment, see Committee against Torture, General Comment No. 3, CAT/C/GC/3 (2012). On discrimination, see Committee on the Elimination of Discrimination Against Women, General Recommendation No. 28 on the core obligations of States parties under Article 2 of the Convention on the Elimination of All Forms of Discrimination against Women, CEDAW/C/GC/28 (2010), para 32.

Aggravating factors compounding the violation that is institutionalization itself are suggested to include ‘the denial of effective redress, length of stay, infliction of forced medical interventions or other violence or abuse, and inhuman and degrading conditions’.<sup>228</sup> The denial of effective redress should be read broadly to encompass not only lack of access to a court but also the situation where a statutory scheme such as mental health legislation provides for a review of the appropriateness of individual detentions while legitimizing their discriminatory nature and purpose.<sup>229</sup> Any remedies within that scheme are insufficient to fully redress the harm caused and unlikely to result in obtaining release.

The forms of reparation under international law include restitution, compensation, rehabilitation, satisfaction (which includes ‘effective measures aimed at the cessation of continuing violations’), and guarantees of non-repetition.<sup>230</sup> This framework underpins the discussion of remedy, redress, and reparation in the Guidelines.

At the systemic level, states are directed to ‘create a mechanism to identify and raise awareness about the nature and scope of harms . . . and to recommend changes in law and policy’.<sup>231</sup> This obligation overlaps with the call to establish truth commissions ‘to investigate and promote public understanding of all forms of institutionalization, the full scope of harms caused to past and present survivors, and . . . the social harms inherent in historic policies that maintained systems of institutionalization’.<sup>232</sup> Truth commissions also have a relationship to measures of satisfaction such as ‘the provision of formal apologies to survivors of institutionalization, negotiated with all groups representing persons with disabilities having experienced institutionalization and provide for further educational, historical and other cultural measures to raise the status of survivors throughout society’.<sup>233</sup> Systemic measures of satisfaction have an important role as the outward-facing, public affirmation of a shift in policy and attitudes that must be underpinned by actual reforms and material redress with respect to all forms of institutionalization and all dimensions of harm. The mechanism tasked with recommending changes in law and policy might therefore complement deinstitutionalization planning processes but must not in any way delay compliance with the state’s immediate obligations.

States must furthermore ‘provide individualized, accessible, effective, prompt and participatory pathways to access to justice for persons with disabilities . . . to seek redress, reparations and restorative justice, and other forms of accountability’.<sup>234</sup>

The concepts of redress, reparation, and remedy are overarching and should be understood somewhat interchangeably within this document, and the framing of victims’ participation in terms of ‘access to justice’ does not imply that they are only beneficiaries and stakeholders. Victims have a protagonistic role of bearing witness and agenda-setting not only by seeking justice for themselves as individuals but also in the shaping of a collective narrative and societal change. The individualized pathways to justice should therefore be envisioned as mutually interdependent with the mechanisms of collective reparation; the functions overlap and need to be combined or articulated closely with one another.

Redress and reparations should ‘be responsive to the violations suffered and acknowledge all forms of violations’ and ‘address the impact on an individual’s life during and after institutionalization, including ongoing, consequential, and intersectional harms’.<sup>235</sup> The wide scope of harms to be considered allows survivors to make known the impact of

<sup>228</sup> DI Guidelines, para 115.

<sup>229</sup> See Guidelines on Article 14, para 19: ‘Review of detentions must have the purpose of challenging arbitrary detentions and obtaining the immediate release of persons found to have been arbitrarily detained; under no circumstances should it allow for the extension of arbitrary detention’.

<sup>230</sup> Basic Principles and Guidelines on Reparation, para 18, listing the forms, and paras 19–23, elaborating their content. See also note 107 and the ICJ Practitioners Guide cited in that note, and see the sources in note 227 which apply the forms of reparation to psychiatric institutionalization.

<sup>231</sup> DI Guidelines, para 117.

<sup>232</sup> *Id.*, para 121.

<sup>233</sup> *Id.*, para 119.

<sup>234</sup> *Id.*, para 117.

<sup>235</sup> DI Guidelines, para 118.

institutionalization on all areas of their life and life trajectories. For example, ongoing harm might include the threat of being re-institutionalized so long as the regime of disability-based detention remains in place. Consequential harm might include the loss of important relationships and opportunities when they are interrupted. Intersectional harm might include the reinforcement of negative stereotypes through the violent act of institutionalization, which conveys a message of the person's low status and value. Reparations mechanisms should respond to the full scope of harm through recognition, systemic reforms, and particularized redress due to survivors.

In particular, to individual victims, states 'should provide automatic compensation . . . at levels that redress [their] pain, suffering, and consequential damages', without undermining the right to litigate or seek justice in other ways.<sup>236</sup> Reparations should also 'include restitution, habilitation and rehabilitation . . . and should be accompanied by guarantees of non-repetition'.<sup>237</sup> Rehabilitation and habilitation 'may include measures covered in article 26 of the Convention, legal and social services to assist establishment in the community and securing all rights and entitlements, including health services and healing modalities to repair the damage caused by institutionalization'.<sup>238</sup> The reference to Article 26 should not be allowed to swallow the much broader content of habilitation/rehabilitation as a form of reparation or import the medical model or paternalism that persist in habilitation and rehabilitation programs.<sup>239</sup> Restitution is addressed here through 'measures such as re-establishing relationships with their children or their family of origin, or retrieving any possessions that can be found'. The restoration of legal capacity and liberty, discussed in an earlier section of the Guidelines, are obligations of cessation of violations as well as restitution.<sup>240</sup>

As guarantees of non-repetition, states are directed to 'criminalize disability-based detention and institutionalization, and other acts that result in disability-related torture and ill-treatment'.<sup>241</sup> Guarantees of non-repetition would also encompass the legal and policy reforms prescribed in Section 5.

As with other measures under the Guidelines, remedies must be 'designed and implemented with the consultation and involvement of persons with disabilities, particularly with survivors of institutionalization', and 'redress and reparations mechanisms must respect the will and preferences of survivors of institutionalization'.<sup>242</sup> Those implicated in institutionalization should not have a role in creating reparations mechanisms and processes or hold positions of authority or expert status within them.<sup>243</sup> They should instead be invited to accept accountability and should not be called on to provide habilitation, rehabilitation, or other services.<sup>244</sup>

<sup>236</sup> Id, para 119.

<sup>237</sup> Id, para 120.

<sup>238</sup> Id.

<sup>239</sup> The identity of 'psychosocial disability' is **not** affiliated with psychosocial rehabilitation, see World Network of Users and Survivors of Psychiatry, Psychosocial Disability. On file with author. See also the definition of psychosocial disability cited in the Center for the Human Rights of Users and Survivors of Psychiatry and Campaign to Support CRPD Absolute Prohibition of Commitment and Forced Treatment, Response to draft General Comment 7 on Article 4.3, paragraph 14(a) and (d) and transversal. Available online: [https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/DraftGC7/CHRUSPAbPros submission\\_1.docx](https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/DraftGC7/CHRUSPAbPros submission_1.docx), accessed on 20 February 2024.

The practice known as 'psychosocial rehabilitation' perpetuates a medical model of disability, see [Barbato \(2004\)](#). 'In the WHO/WAPR consensus statement jointly endorsed in 1996, psychosocial rehabilitation is defined as a process that facilitates the opportunity for individuals impaired, disabled or handicapped by a mental disorder to reach their optimal level of functioning in the community. It implies both improving individuals' competencies and introducing environmental changes in order to improve their quality of life'.

<sup>240</sup> See above notes 107–109 and accompanying text, as well as notes 60–61 and accompanying text (economic assistance as facultative to the restoration of liberty). As cessation of violations is preliminary to other measures, it is a stronger basis for victimized persons to assert their demand for immediate release.

<sup>241</sup> DI Guidelines, para 120.

<sup>242</sup> Id, para 122.

<sup>243</sup> Id, paras 117 and 122.

<sup>244</sup> Id.



Finally, states are reminded of their obligations under domestic and international law to prosecute perpetrators of violence and abuse and prevent reprisals against survivors of institutionalization.<sup>245</sup>

In implementing reparations, states and civil society will need to consider issues such as how to understand the relationships between political and legal dimensions of reparations,<sup>246</sup> how to constitute the mechanisms and pathways for individual access to redress, how to frame their legal mandates and aims, and how to ensure respect for the privacy, integrity, decision-making, comfort, and boundaries of survivors when they participate in reparations mechanisms or when the mechanisms receive evidence about violations against them as individuals.<sup>247</sup> They should take into account each distinct form and regime of institutionalization and draw on the work of survivor communities to collect information about harms and conceptualize reparations—both in the design and planning of mechanisms and processes as well as in the carrying out of their work. Responsiveness and adaptation to the collective and individual needs of survivors during the work of reparations mechanisms and tribunals make the process itself reparative of the relations between survivors, the state, and the community (conforming to the ‘satisfaction’ element of reparations), as well as being a basic requirement for access to justice.<sup>248</sup>

States and civil society will also need to consider the relationship between reparations, deinstitutionalization planning and implementation, and monitoring. I would suggest that the reparations obligations in Section 9, the international reparations framework, and the concept of reparative justice, should inform all work undertaken to implement the Guidelines, and that a reparations mechanism might serve as a guarantee of fidelity to these values, among its other mandates.

Reparations mechanisms and processes should not be used as preliminary inquiries by a state to determine whether to implement its obligation under the CRPD to end all forms of institutionalization, immediately cease violations, and guarantee non-repetition. Granted that most states have not yet determined in their national law or policy to end psychiatric institutionalization; there is a need for advocacy processes and some states will use commissions of inquiry as their first step.<sup>249</sup> However, an inquiry into harm that allows

<sup>245</sup> Id, para 123.

<sup>246</sup> The political dimension goes beyond the requirements of law. It should not be misused as a workaround by states or perpetrators to avoid legal responsibility but is complementary.

The political (and moral) dimension can be pursued by both official state bodies and civil society, including on the very granular level of interpersonal relationships, families and communities affected by institutionalization. Paragraph 121 of the Guidelines alludes to the granular level of repair needed when it calls for truth commissions to include in their scope of investigation the social harms inherent in institutionalization, as do paragraph 94 in signaling that families need to be prepared to address the harms of institutionalization caused to their relative, and paragraph 36 in calling for deinstitutionalization planning processes to incorporate public awareness-raising of the harms of institutionalization and the need for change. Thanks to Hege Orefellen and Ann Campbell for their comments that contributed to these points.

<sup>247</sup> On the last point, see DI Guidelines, para 122 (respect for will and preferences of victims) and Basic Principles and Guidelines on Reparation, para 10:

Victims should be treated with humanity and respect for their dignity and human rights, and appropriate measures should be taken to ensure their safety, physical and psychological well-being and privacy, as well as those of their families. The State should ensure that its domestic laws, to the extent possible, provide that a victim who has suffered violence or trauma should benefit from special consideration and care to avoid his or her re-traumatization in the course of legal and administrative procedures designed to provide justice and reparation.

See also the discussions on Disaggregated data (Section 10) and Monitoring deinstitutionalization processes (Section 11) below.

<sup>248</sup> Responsiveness to survivors’ needs as an adaptation of process was demonstrated, for example, as the ‘indigenization’ of a Truth and Reconciliation Commission on the removal of Native children from their homes by social workers. The film *Dawnland* depicts the work of this Commission as it ‘grapples with difficult truths, redefines reconciliation, and chart a new course for state and tribal relations’, see <https://upstanderproject.org/films/dawnland>, accessed on 20 February 2024.

<sup>249</sup> An initiative in the state of Victoria, Australia, has recently issued a report, led by people with lived experience of the mental health system, see <https://www.livedexperiencejustice.au> (accessed on 20 February 2024), recommending a restorative justice process and apologies for ‘harms caused by [Victoria’s] publicly funded mental health system’. The inquiry and its recommendations are flawed by taking place under the Minister of Mental Health and declining to recommend the cessation of violations and guarantees of non-repetition. The

for the perpetuation of violations as a possible outcome is not reparative and cannot be considered to fulfill the obligation to provide reparations and redress.

Questions arise as to the temporal dimension of reparations obligations. What do states owe to survivors who were institutionalized and released before the entry into force of the CRPD? The mandate of truth commissions set out in paragraph 121 refers to ‘harms caused to past and present survivors’. For purposes of an accurate historical record and knowledge base, it should be uncontroversial that past harms are included. Similarly with respect to the priority given to survivors in consultative processes on reparations and deinstitutionalization processes, it should be uncontroversial that this is not limited *ratione temporis*.

For purposes of individualized justice, continuing harm is recognized as founding claims for reparations related to past atrocities. In a case involving the demands of ‘comfort women’ survivors of Japan’s military sexual slavery system, the CEDAW Committee rejected the state party’s contention that the Committee was precluded from examining violations that occurred before the entry into force of CEDAW’s Optional Protocol and admitted a complaint against the Philippines for its continuing discrimination against these women, having failed to ‘provide them, as civilian victims of armed conflict and survivors of the wartime sexual slavery system, with adequate social support, reparation, benefits and recognition commensurate with the harm suffered’.<sup>250</sup> The CEDAW Committee has previously made recommendations to Japan regarding reparations towards the victimized women, since the past violations ‘have a continuing effect on the rights of victims/survivors . . . given the continued lack of effective remedies’.<sup>251</sup>

Survivors of past as well as present institutionalization experience continuing harm from the unredressed impact of institutionalization in their lives, the ongoing threat of its repetition through laws and policies that authorize the practice, and the absence of any

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restorative process envisioned would aim to ‘improve relations between those who use and administer the system, motivate cultural change in services, and reduce the prevalence of [not end] human rights violations’ (p. 55)—in other words, it is designed to adapt itself to the mental health system and provide a rationale for a recently redesigned mental health policy, rather than providing survivors with a platform to hold that system accountable for full CRPD compliance, including to record the violations and their needs entirely outside the perpetrator’s worldview and constraints.

An additional flaw is the inclusion of family members (‘carers’) alongside survivors as impacted persons. While some family members of persons who have been institutionalized have experienced their own pain and suffering by being separated from their loved one and witnessing that person’s pain and suffering, many have been complicit in institutionalization (see the discussion in Section 4 and note 31 and its accompanying text; see also note 140).

Survivors may hope that any report or follow-up that may take place will open the door to processes that will in turn lead to ending the violations. Perhaps even, similarly to the resolution depicted in *Dawnland* (see note 248), survivors can assert their primacy and transform the nature of the process.

<sup>250</sup> CEDAW/C/85/D/155/2020, para 9.3 (as quoted) and para 8.5 (rejecting the contention of *ratione temporis* as ground for precluding admissibility).

<sup>251</sup> CEDAW/C/JPN/CO/7-8 (2016), para 29. In full:

The Committee reiterates its previous recommendations (CEDAW/C/JPN/CO/6, paras. 37 and 38) and observes that the issue of “comfort women” gives rise to serious violations that have a continuing effect on the rights of victims/survivors of those violations that were perpetrated by the State party’s military during the Second World War, given the continued lack of effective remedies for those victims. The Committee, therefore, considers that it is not precluded *ratione temporis* from addressing such violations and urges the State party:

- (a) To ensure that its leaders and public officials desist from making disparaging statements regarding responsibility, which have the effect of retraumatizing victims;
- (b) To recognize the right of victims to a remedy, and accordingly provide full and effective redress and reparation, including compensation, satisfaction, official apologies and rehabilitative services;
- (c) To ensure that, in the implementation of the bilateral agreement announced jointly with the Republic of Korea in December 2015, the State party takes due account of the views of the victims/survivors and ensures their rights to truth, justice and reparations;
- (d) To adequately integrate the issue of “comfort women” in textbooks and ensure that historical facts are objectively presented to students and the general public;
- (e) To provide information in its next periodic report on the extent of consultations and other measures taken to ensure the rights of victims/survivors to truth, justice and reparations.

guarantees of non-discrimination based on past status of institutionalization. Continuing harm should be fully explored and redressed through individualized measures that take account of the lifelong impact even on those who were able to get free from the psychiatric system.

## 10. Disaggregated Data

Section 10 comprises paragraphs 124–128 and is not further divided.

This section calls on states to collect data to inform decision-making about deinstitutionalization.<sup>252</sup> The kind of data to be collected is specified in the greatest detail in regard to information about persons with disabilities in institutions:

Data collected by States parties should be disaggregated according to race, ethnic origin, age, gender, sex, sexual orientation, socioeconomic status, type of impairment, reason for institutionalization, date of admission, expected or actual date of release, and other attributes.<sup>253</sup>

Since that approach may not obtain the most relevant information for mental health settings, the following is added:

This includes collection of reliable, accessible and up-to-date records concerning the numbers and demographics of persons in psychiatric or mental health settings, records of whether the duty to allow persons with disabilities to leave institutions has been fulfilled, the number of persons who have exercised the option of leaving, and other information concerning planning for those who are yet to leave institutions.<sup>254</sup>

This ensures that all overnight mental health settings will be counted, which should include, for example, psychiatric wards within a general hospital, psychiatric emergency intake or crisis intervention settings, etc., and that the duty to allow people to leave these places of arbitrary detention is specifically monitored, in addition to the planning for deinstitutionalization for those who do not exercise this option immediately.

With regard to the demographic information sought in relation to institutionalized persons generally and in relation to those in mental health settings, some may be difficult to obtain, may be based on inaccurate reporting or guesswork by institutional staff, and may not have a clear link to complying with deinstitutionalization. Caution should be exercised to ensure that data collection is legitimately related to fulfilling rights and eliminating barriers<sup>255</sup> and that participation in it is subject to the will and preferences of the person concerned, insofar as it pertains to an individual's characteristics.

Such a limitation is not explicitly stated but should be considered a corollary of the duty to ensure that data collection is conducted while 'fully respecting the right to privacy of personal data', including by amending data protection laws to ensure respect for the legal capacity of persons with disabilities and bringing those laws into conformity with international standards, 'subject to their compliance with the Convention'.<sup>256</sup>

Furthermore, as mentioned above, people leaving institutions will have a right to exercise control over their own records, which are to be handed over to themselves and/or expunged upon leaving.<sup>257</sup> This reparative measure must be respected when conducting data collection related to the implementation of deinstitutionalization.

<sup>252</sup> DI Guidelines, para 124.

<sup>253</sup> Id, para 126.

<sup>254</sup> Id.

<sup>255</sup> See also CRPD Article 31, paras 1 (chapeau) and 2.

<sup>256</sup> DI Guidelines, para 128.

<sup>257</sup> Id, para 135. See note 198 and accompanying text.

Section 10 of the Guidelines, like General Comment No. 7,<sup>258</sup> allows for use of the Washington Group set of questions ('can use') while directing states to 'undertake other efforts to ensure that no groups are excluded'.<sup>259</sup>

The Washington Group set of questions, widely promoted as a tool to identify persons with disabilities in the context of a national census, are framed as questions about a person's 'functioning', linked to the 'bio-psychosocial' framework of the International Classification on Functioning, Disability, and Health and viewed as a replacement for the medical model.<sup>260</sup> The Washington Group's first set of questions did not account for psychosocial disability at all, and ongoing efforts remain incomplete and problematic. The ICF is inappropriate as applied to psychosocial disability since it is based on 'impairment' understood as a medical condition and a manifestation of an underlying pathology.<sup>261</sup>

Finally, states are directed to

facilitate the participation of persons with disabilities, and their representative organizations, in relevant data collection processes and exercises, such as defining data collection priorities, identifying persons with disabilities and providing information on their circumstances and requirements.<sup>262</sup>

The role envisioned is a collaborative one that is likely to be crucial for agenda-setting and policymaking, and the examples given suggest a need for qualitative information as well as pointing beyond demographics and institutional census-taking to the identification of support needs and gaps that states are to undertake in collaboration with organizations of persons with disabilities.<sup>263</sup> States are also directed to disseminate the data collected on deinstitutionalization in accessible formats.<sup>264</sup>

## 11. Monitoring Deinstitutionalization Processes

Section 11 comprises paragraphs 129–137 and is not further divided.

Independent monitoring is prescribed for 'all stages of deinstitutionalization processes'.<sup>265</sup> Mechanisms monitoring deinstitutionalization processes are to be 'mandated to undertake the full range of obligations ascribed under article 33 of the Convention in accordance with the Committee's guidelines on independent monitoring frameworks'.<sup>266</sup> This broad mandate, in addition to specifying their role to 'identify, prevent and remedy human rights violations [and] offer recommendations on best practices', is relevant to the totality of deinstitutionalization processes as described in these Guidelines, which all warrant monitoring by formal independent mechanisms and by civil society and DPO initiatives, to continue so long as needed and eventually merge with overall monitoring and advocacy activities related to the implementation of the Convention.

The remainder of Section 11 centers on the monitoring of both conditions within institutions and the component of deinstitutionalization that takes place within institutions, in particular the compliance by institutions with their duty to release those who are detained until 'all institutions are closed'.<sup>267</sup>

<sup>258</sup> CRPD/C/GC/7 (2018), para 91.

<sup>259</sup> DI Guidelines, para 124.

<sup>260</sup> <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>, accessed on 20 February 2024.

<sup>261</sup> International Classification on Functioning, Disability and Health: Short Version (World Health Organization 2001), p. 16.

<sup>262</sup> DI Guidelines, para 125.

<sup>263</sup> Id, para 65.

<sup>264</sup> Id, para 127.

<sup>265</sup> Id, para 129.

<sup>266</sup> Id, para 129.

<sup>267</sup> Id, para 137. The closure of institutions cannot be an endpoint for the monitoring of deinstitutionalization processes relating to matters such as ensuring the accessibility of mainstream services and communities to people leaving institutions, prevention of the emergence of new segregated services, and compliance with the economic and social assistance measures needed for resettlement, among other measures called for in

It is necessary that independent monitoring taking place in institutions be placed squarely under the obligation of deinstitutionalization, which includes the duty to allow people to leave any mental health setting.<sup>268</sup> In addition to the independent mechanisms that have been designated under Article 33(2), this section also refers to national preventive mechanisms (established under the Optional Protocol of the Convention against Torture to visit places of detention), national human rights institutions, and monitoring activities carried out by civil society and organizations of persons with disabilities.<sup>269</sup> The national preventive mechanisms may find it challenging to adhere to the CRPD and these Guidelines, given that their international body, the Subcommittee on Prevention of Torture, maintains that disability-based detention and forced interventions in psychiatric institutions are not only permissible but necessary to uphold the right to health.<sup>270</sup> If unable or unwilling to adhere to the CRPD, they are unreliable and can pose an obstacle to deinstitutionalization including its fundamental immediate dimension of revoking all detentions and forced treatment orders under mental health laws.<sup>271</sup>

Monitoring mechanisms are directed to ensure the ‘meaningful participation of persons with disabilities, particularly those who are in institutions or who are survivors, and their representative organizations’, and to ‘exclude staff of institutions from deinstitutionalization monitoring activities’.<sup>272</sup>

Civil society and DPO initiatives, along with Article 33(2) mechanisms, are to be given access to institutions, documents, and information (‘unrestricted’ in the case of the Article 33(2) mechanisms; removal of barriers in the case of civil society and DPOs).<sup>273</sup> It is not at all clear whether any standards exist or are to be applied to these activities, including obligations in this section said to be imposed generally on ‘monitoring mechanisms’ (the others of which are established by states to function independently). In Section 5.A.2 above on access to justice, a standard is articulated for free and informed consent, including criteria to apply a ‘best interpretation of will and preferences’, in connection with the filing of complaints on behalf of people in institutions:

Where children or adults are in institutions and are unable to file complaints themselves, national human rights institutions and advocacy organizations may be authorized to take legal action. 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 efforts based on a best interpretation of the will and preferences of the person concerned.<sup>274</sup>

This standard only reflects a portion of the activities that civil society and DPO initiatives may end up conducting in relation to institutions, and it would be worthwhile for DPOs to lead in the development of standards and protocols for monitoring that respect individuals’ legal capacity and privacy, not only in the context of institutions but generally regarding the rights of persons with disabilities.

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these Guidelines that relate specifically to deinstitutionalization and may not otherwise be prioritized within monitoring mechanisms or civil society and DPO initiatives.

<sup>268</sup> Id, paras 15 and 126.

<sup>269</sup> Id, paras 130 and 131.

<sup>270</sup> The SPT’s approach regarding the rights of persons institutionalized and treated medically without informed consent, CAT/OP/27/2 (2016).

<sup>271</sup> DI Guidelines, paras 13 and 55. The SPT and other treaty bodies that maintain medical-coercive standards conflicting with the CRPD should reconsider so that they can play a constructive role in deinstitutionalization and other redress for violations of the human rights of persons with disabilities. Thanks to Ann Campbell for suggesting this point.

<sup>272</sup> Id, paras 130 and 137. Paragraph 130 specifically mentions national preventive mechanisms and national human rights institutions as needing to exclude institutional staff. This is welcome but insufficient to ensure their compliance with CRPD so as to be useful and not counterproductive to deinstitutionalization.

<sup>273</sup> Id, para 131.

<sup>274</sup> Id, para 57.

A second paragraph addresses the tension between the investigative work of monitoring mechanisms and the privacy of those referred to as ‘survivors’ (which must include persons still living in institutions).<sup>275</sup> ‘All’ monitoring mechanisms are to be ‘allowed to freely investigate conditions and human rights violations within public and private institutions’. A duty to ‘respect and protect survivors’ privacy’ is immediately coupled with the obligation of states to ‘refrain from obstructing publication of human rights reports’ and a bar against states’ invocation of ‘privacy and confidentiality as barriers to independent monitoring’. This reflects the very real concerns that states do invoke privacy inappropriately on behalf of people in institutions; however, privacy should not be given short shrift, and it should be emphasized that monitoring mechanisms like any other actors are obligated under the CRPD to respect survivors’ legal capacity to invoke privacy and confidentiality for themselves.<sup>276</sup>

The paragraph goes on to call for the protection of ‘the ability to obtain, store and publish information’ (including ‘photographic and video documentation’) regarding ‘conditions in institutions’, without any further discussion of privacy or confidentiality of the persons living in institutions whose information and likenesses are likely to be captured in the information-gathering activities. Both the obligation to respect legal capacity and the right of survivors to have their records handed over or expunged when they leave should be superior to any privileges granted to monitoring mechanisms for the purposes of reporting and advocacy.<sup>277</sup> Control over personal data relating to time spent in an institution is an ingredient of reparations to respect the dignity and privacy of victims.<sup>278</sup>

## 12. International Cooperation

Section 12 comprises paragraphs 138–143 and is not further divided.

This section straightforwardly promotes international cooperation as ‘key to supporting deinstitutionalization reforms’ while cautioning that states cannot rely on international cooperation for the ‘long-term provision of community-based support and services’ and must complete the process of deinstitutionalization themselves.<sup>279</sup> Supporting deinstitutionalization entails prohibitions on the use of funds to maintain institutionalization or disability-based coercive practices.<sup>280</sup>

In addition to mainstreaming the rights of persons with disabilities in their international cooperation initiatives, ‘all measures to implement the 2030 Agenda for Sustainable Development [must] support deinstitutionalization’.<sup>281</sup>

States are directed to closely consult persons with disabilities and their representative organizations, including persons in institutions and survivors, ‘on the design and implementation of development projects funded by international cooperation’ and to support such consultative processes by international cooperation ‘where civil society organizations lack awareness of the right to live independently and to be included in the community’.<sup>282</sup>

States are asked to consider ‘establishing an international platform for good practices on deinstitutionalization, in close consultation with persons with disabilities, especially survivors of institutionalization, and their representative organizations’, as a means of

<sup>275</sup> Id, para 132.

<sup>276</sup> Paragraph 128 of the Guidelines links the amendment of data protection laws to the improvement of human rights monitoring and advocacy as well as to privacy rights. Data protection and privacy are equally relevant to individuals’ rights vis-à-vis independent monitoring mechanisms and civil society or DPO initiatives. If safeguards in that regard are inadequate, they should be improved with the leadership of DPOs. See also paragraphs 55, 63, 94, and 95(a) on respect for legal capacity and decision-making in the deinstitutionalization process.

<sup>277</sup> DI Guidelines, para 135; see note 198 and accompanying text.

<sup>278</sup> See Basic Principles and Guidelines on Reparations, para 10 (on treatment of victims).

<sup>279</sup> DI Guidelines, paras 138 and 141.

<sup>280</sup> Id, paras 138 and 139.

<sup>281</sup> Id, para 141.

<sup>282</sup> Id, para 140.

an international coordination of efforts aimed ‘to prevent the replication of bad practices, such as promoting a medical model approach and coercive mental health laws.’<sup>283</sup> States are similarly to discourage ‘voluntourism’ that brings tourists to work in institutions.<sup>284</sup>

The use of international cooperation for deinstitutionalization and to prevent bad practices can be reparative if these Guidelines are used to their full extent as an actionable standard and if accountability to survivors, beyond consultation, is built into the resourcing and structuring of these measures.

### 13. Conclusions

This paper has examined the Guidelines on Deinstitutionalization comprehensively, providing commentary that aids in reading the Guidelines as an instrument of reparative justice, particularly for survivors of psychiatric institutionalization. Reparations obligations and the concept of reparative justice should inform all actions undertaken to implement the Guidelines, maintain fidelity to the reparative aims indicated throughout the text, and ensure the cessation of violations and guarantees of non-repetition.

Several themes emerge to highlight for action and further exploration.

First is the value of the Guidelines to carry us forward to the abolition of involuntary psychiatric interventions as a form of deinstitutionalization. Throughout the Guidelines are found obligations that insist on the immediacy of this obligation. Immediate revocation of detentions and release are complemented by the provision of emergency, short-, and medium-term assistance with resettlement to overcome the obstacles of economic and social deprivation faced by people wishing to leave psychiatric institutions (including those mental health settings where they may have only been deprived of liberty for a brief duration).<sup>285</sup>

Second is the need to transform the nature and provision of support services. The Guidelines set out a space for the de-medicalization of services for needs related to distress or unusual perceptions—deliberating using non-diagnostic terminology that avoids referencing mental health discourse and practices. The de-medicalization of law, policy, and practices regarding deinstitutionalization and the creation of new services is enshrined through the limits set on involving perpetrators of institutionalization in these matters, including a specific prohibition on the mental health system running housing.

Third is the explicit invocation of reparations owed to survivors, who include people still in institutionalizations who have survived this far and have a right to have the violations end. In this paper, I have tried to bring a reparative lens to all the obligations in these Guidelines beyond the text, noticing where reparation calls for amplification, additional perspectives, or greater fidelity to the centrality of survivors’ rights over those of third parties with conflicting interests. For advocates seeking to implement reparations, I urge both instrumental use (as in lawsuits for abolition) and careful study and reflection to develop a sound approach in the local context.

Transforming communities is linked to society-wide reparation as well as to the social policy of states. Informal support seems to work best when it is grounded in relationships that are honest and in which each person gets what they need from many sources. Scarcity and stress about meeting basic needs lead us to treat one another as resources, objectifying another person either as a means to an end or as a burden. Neither the support approach of the CRPD nor the care agenda being developed in the United Nations and elsewhere can resolve the root causes of problematic support relationships without fundamental social,

<sup>283</sup> Id, para 143.

<sup>284</sup> Id.

<sup>285</sup> See discussion of paragraph 17 in Section 3 Part A. Even a brief period of detention in a psychiatric setting, especially if it is the latest in a series of such detentions, can result in loss of housing, work, and supportive relationships with family or others in the community. Such deprivations might also happen in a person’s life preceding the detention, and psychiatry is the last blow. Not everyone will need the same assistance to resettle, but it should be made readily available so that economic needs do not pose an obstacle to leaving.

economic, and political change that enshrines both autonomy and collectivism.<sup>286</sup> The Guidelines do not provide a recipe for such change but, as has been implicit in the CRPD and its underlying values from the beginning, constrains the possible solutions to the rights of persons with disabilities and, in so doing, sets out a path forward that leads inescapably to this conclusion.

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<sup>286</sup> TCI Positionality on Community Inclusion (2022) presents a similar view in this discussion of 'Care':

With respect to the 'care' and 'support' debate, 'Care' was one of the earliest notions to be co-opted by health and social service systems. However, if we sever this concept from these services, and place it back within community and human engagements, we can see the importance of the CRPD guidance on individuality within the context of interconnectedness. In the psychosocial support works that TCI has been engaged in, we see a lot of transactions around 'care giving', typically by family members, especially women who carry a double or triple load of work. Hence, there is talk about 'burden of care'. Here, because care is seen as a 'burden', and persons would like to minimize that burden, persons giving care become custodians and guardians offering control rather than determine the nature and quality of support. But we should not throw out the baby with the bathwater. There must be ways of retrieving care as a useful concept not necessarily linked with services, nor a 'burden', but linked with strengthening communities and families, creating broader group support systems, in the context of providing individualized support to persons with disabilities. We in TCI lean on the side of retaining 'care' as a human quality that cements communities together, but delinking it from services.

I would add that providing individualized support entails respecting the separate agency of the person receiving support, whether it is provided by service providers or by friends, neighbors, or family members (see note 140).



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