**Para: Comité CDPD de N.U.**

**De: Prof. María Soledad Cisternas Reyes.**

**A continuación se han copiado los párrafos comentados, indicando con color la observación.**

**Draft Guidelines on Deinstitutionalization, including in emergencies**

**Committee on the Rights of Persons with Disabilities**

38. States Parties should adopt an intersectional approach to tackle discrimination, segregation, isolation, and other forms of ill-treatment of persons with disabilities living in and leaving institutions. The personal identities of persons with disabilities are multifaceted and disability will likely only be one characteristic. Other characteristics include race, sex, gender identity, sexual orientation, gender expression, intersex variation, language, religion, ethnic, indigenous or social origin, migrant or refugee status, age, or impairment group, or other status, and these may intersect to shape a person’s individual identity \*It is suggested to add in the enumeration: “ideology / political tendency”. (Se sugiere adicionar en la enumeración: “ideología / tendencia política”). Intersectionality plays an important role in the lived experiences of all persons with disabilities.

***Women and girls with disabilities***

 40. States Parties should acknowledge that women and girls with disabilities are subject to multiple discrimination on the grounds of gender and disability and they are not a homogeneous group. Women with disabilities are at a heightened risk of violence, exploitation, and abuse compared to other women, and are at high risk of gender-based violence and harmful practices, such as forced contraception and sterilization, during institutionalization.[[1]](#footnote-1) They are denied the right to legal capacity more often than men with disabilities, and more often than women without disabilities, leading to denial of access to justice, choice, and self- control. \*States Parties should consider these risks when designing and implementing deinstitutionalization plans to ensure the fulfilment and protection of the rights of women and girls with disabilities, ensuring gender equality is reflected transversally throughout all process and policies

\*It is suggested to indicate that States are obliged to adopt all appropriate measures to ensure the full development, advancement and empowerment of women and girls with disabilities (art. 6 paragraph 2).(se sugiere indicar que los Estados están obligados a adoptar todas las medidas pertinentes para asegurar el pleno desarrollo, adelanto y potenciación de las mujeres y niñas con discapacidad (art. 6 inciso 2).

***Children with disabilities***

45. Even short-term placement outside a family causes great suffering and trauma, emotional and physical impairments. Preventing institutional placement for children must be a priority. Family-based placements, with financial and other forms of support, should be created for all children with disabilities.

\*Mention can be made: "... considering the participation and the best interest of the girl, boy or adolescent with disabilities." (\*Se puede hacer mención: “… considerando la participación y el interés superior de la niña, niño o adolescentes con discapacidad”).

49. States Parties should develop and ensure access to support services in the community, including personal assistance and peer support, for children and adolescents with disabilities, as necessary.

\*Here you can also mention "... considering the participation and the best interest of the girl, boy or adolescent with a disability" (\*Aquí también se puede hacer mención “… considerando la participación y el interés superior de la niña, niño o adolescente con discapacidad”)

### **Right to access to justice**

54. The right to live independently and be included in the community is closely connected to the right to access to justice for all persons with disabilities, particularly for women and girls living in or leaving institutions who experience gender-based violence. \*Environmental, attitudinal, legal, and procedural barriers to access justice for persons with disabilities, including those placed in institutions, should be removed, across all legal domains. Procedural accommodations, such as Easy Read materials and plain language, should be made available. States Parties should ensure legal standing in courts and tribunals and provision of legal representation for persons with disabilities in the justice system. States Parties should ensure law and judicial procedures recognizing the right of persons with disabilities to provide testimony and stand as witnesses,[[2]](#footnote-2) and ensure persons in institutions have an effective right to call police and file criminal charges while inside an institution.

\*It is suggested to add: “information, communications, and technological barriers” (Se sugiere adicionar: “las barreras informativas, comunicaciones y tecnológicas”).

### **Right to equality and non-discrimination**

57. States Parties should recognize in law that institutionalization on the basis of disability, separately or in combination with other grounds, amounts to a prohibited form of discrimination.

\* It is suggested to add a segment dedicated to universal accessibility, which is an important factor for deinstitutionalization. Universal accessibility facilitates the exercise of human rights and fundamental freedoms. (Se sugiere adicionar un segmento dedicado a la accesibilidad universal que es un factor importante para la desinstitucionalización. La accesibilidad universal facilita el ejercicio de derechos humanos y libertades fundamentales)

## Legal Framework and resources

### **Legislation**

60. Legislation that needs to be brought in line with the Convention includes legal provisions governing legal capacity; disability laws; family laws; health laws; civil laws; laws governing social care provision for children, adults, and older persons; and social protection legislation. Such legislation should be reviewed in line with the Convention and Committee’s general comments. Provisions in mental health laws allowing for institutionalization of persons with disabilities should be abolished.

\*It is suggested to add for the review “criminal laws and procedural laws”. (\*Se sugiere adicionar para la revisión de “leyes penales y leyes procesales”).

### **Workforce analysis**

64. States Parties should map the workforce, including demographic and employment trends, and the impact these may have on deinstitutionalization. States Parties should establish priorities for improvement, assessing the feasibility of transformation of the existing workforce to the provision of services to persons with disabilities that comply with the Convention. They should provide services solely under the direction of persons with disabilities, or their family members in respect of children with disabilities. States Parties should ensure that those responsible for human rights violations are not licensed to provide new services.

\*It is suggested to add “hearing to the girl, boy and adolescent and considering their opinion". (\*Se sugiere adicionar “oyendo a la niña, niño y adolescentes y considerando su opinión”).

**VI. Inclusive community support services, systems, and networks**

## Support systems/networks

69. States Parties should recognize the existence of informal support and ensure communities and families are trained and supported so they can provide support that is respectful of the choices, will and preferences of persons with disabilities. Where persons with disabilities do not wish to be supported by their families or communities, they should have access to other options. \* This applies also when the nuclear family or extended family are not available to support persons with disabilities. (Esto se hace aplicable también cuando la familia nuclear o la familia extendida no están disponibles para apoyar a las personas con discapacidad).

72. States Parties should ensure that persons with disabilities can receive support from their families, should they decide. In such cases, States Parties should provide support to families in order that they fulfil their support roles. Support arrangements can include a multiplicity of supporters acceptable to the person using support, and States Parties should ensure that they can take breaks. Options for families to take breaks through informal supports or through States Parties’ sponsored community-based supports should be made available. This includes the development of respite[[3]](#footnote-3) services, but these should not entail placing children or adults with disabilities in institutions, even for short periods of time.

\*This applies when the person with a disability has high support needs. Not every person with a disability will cause the family to need "rest or respite." (\*Esto se aplica cuando la persona con discapacidad tiene altas necesidades de apoyo. No toda persona con discapacidad producirá que la familia necesite “descanso o relevo”).

## Support services

73. Support services should be developed in accordance with a human rights model that respect the will and preferences of persons with disabilities, ensuring their full participation and that of their broader support network if the person so wishes. States Parties should not use medical criteria when developing new needs assessment tools, and medical professionals should not be involved. Instead, a person-centred process should be used, identifying the range of supports a person may need to live independently and be included in the community.

\*I suggest mentioning “interdisciplinary criteria. (\*Sugiero hacer mención de “criterios interdisciplinarios).

79. Support for older persons with disabilities, including for those with \*dementia, should provide the opportunity for persons to stay in their own homes in the community. Persons with disabilities should not lose access to support, such as personal assistance, once they reach old age. Instead, States Parties should increase community support over time as needed, and never in any institution.

\*It is suggested not to include the word “dementia” due to its pejorative use. It is suggested to use: “older persons with cognitive diversity, by the course of their life cycle”. (\*Se sugiere no incorporar la palabra “demencia” por su uso peyorativo. Se sugiere usar: “personas mayores con diversidad cognitiva, por el transcurso de su ciclo de vida”).

**VII.** **Access to mainstream services on an equal basis with others**

## Preparing to leave the institution

93. Persons leaving institutions should:

e) In preparation to leave the institution, be offered a wide range of experiences to assist with community integration \*Change: “integration” to “inclusion to help build their experience, strengths, socialization, life skills, \*Add. increase your self-esteem (adicionar: aumentar su autoestima), remove fears and gather positive experiences of living well and independently;

94. States Parties should remove all barriers to establishing citizenship status and the provision of official identification documents, including alternative documents for non-citizens (?) \*Do they refer to non-resident foreigners? (¿se refieren a los extranjeros no residentes?), to persons leaving institutions. This shall include all documentation such as national identity cards, residence permits, voter registration, employment numbers, social security cards, disability cards, and passports, as applicable, even where this requires provision of retroactive documentation, by the time of exit. States Parties should ensure that no discriminatory or derogatory identification marker or description of the earlier detainee status of persons leaving institutions exists, and that the highest standards of protection of privacy and confidentiality are ensured for all health documentation.

## Living independently in the community

98. States Parties should actively seek the participation of organizations of persons with disabilities, especially of those whose members live in institutions and/or who are survivors of institutionalization, at every stage of mainstreaming persons into communities. Community-based organizations, individuals, and neighbourhood groups may play a diversified role in providing social support, connecting persons to local resources, or provide support as a member of a broader social capital from the community. States Parties should support large-scale awareness-raising activities on the inclusion of persons with disabilities, through their representative organizations, building the capacity of families, neighbourhoods and communities on the value and practice of inclusion. \*It is suggested to add: “Promoting the recognition of capacities, merits, abilities and contributions (art.8) (\*Se sugiere adicionar: “Promoviendo el reconocimiento de las capacidades, los méritos, habilidades y aportaciones (art.8))

101. States Parties should ensure comprehensive health care, including primary health care, for persons leaving institutions, on an equal basis with others. Health care services should must respect the choice, will and preferences of persons with disabilities leaving institutions, and provide additional health care support as needed, for example, \*to withdraw from psychiatric medication, and to access nutritional and fitness programs, with a view to retrieving their overall health and wellbeing, and always on the basis of their free and informed consent. \*or decrease medication. (o disminuir la medicación).

102. States Parties should ensure that persons leaving institutions have equal access to employment, \*prohibiting sheltered or segregated employment, and shall ensure an inclusive law and policy framework in employment that eliminates barriers faced by persons leaving institutions. A range of choices, allowing time for decision-making and support in decision-making, should be provided for persons leaving institutions to exercise their right to work and employment. \*there may be more gradual forms (pueden existir formas más paulatinas).

103. States Parties should ensure the right to an adequate standard of living while recognizing that the risk of homelessness and poverty is very high for persons leaving institutions. A robust social protection package should be provided to all persons with disabilities leaving institutions to cover immediate and mid-term needs for resettlement. Long-term economic and social support should also be made available. States Parties shall ensure that persons with disabilities can access existing social protection measures on an equal basis as others, for example, child support, unemployment benefits, rent subsidies, food stamps, pensions, public health schemes, subsidized public transport, and tax credits. Being a recipient of social protection should not be tied to treatment conditions, guardianship, nor eligibility criteria related to employment. Social protection schemes related to persons with disabilities should include funding \*for disability-related costs.

\*This part of the sentence can be misunderstood, for example, that labor inclusion is expensive. This is generally not the case. I suggest replacing “for reasonable accommodations and supports, as requested by the worker with disability”.

(\*Esta parte de la frase puede ser malentendida, por ejemplo, que la inclusión laboral es cara. Esto en general no es así. Sugiero reemplazar “por los ajustes razonables y apoyos, según solicitud del trabajador con discapacidad”).

**VIII. Enact emergency deinstitutionalization plans in situations of risk and humanitarian emergencies, including conflicts**

111. States Parties should ensure that institutions and other barriers to inclusion are not rebuilt after emergencies. States Parties should provide adequate financial and human resources to ensure that persons with disabilities are not left behind in response and recovery processes; this could include transfer of funding from institutions to community supports and services. \*Refugees and internally displaced persons should not be returned to institutions after emergencies or when conflict subsides.

\* It would be appropriate to consult the organizations of persons with disabilities and the OHCHR offices in the region of the conflict Russia and Ukraine to determine if this could really be applicable when the military actions decrease (diminution that may be momentary) or when the conflict ends but chaos remains in the affected cities.

(Sería adecuado consultar a las organizaciones de personas con discapacidad y a las oficinas de ACNUDH en la región del conflicto Rusia y Ucrania para determinar si esto podría ser realmente aplicable cuando las acciones bélicas disminuyen (disminución que puede ser momentánea) o cuando el conflicto termina pero queda un caos en las ciudades afectadas).

**IX.** **Remedies, reparations, redress (rezarcimiento o compensaciones)**

117. States Parties should introduce a mechanism for the provision of formal apologies to survivors of institutionalization negotiated with all groups representing persons with disabilities having experienced institutionalization, and providing for further educational, historical, and other cultural measures to raise the status of survivors throughout society. States Parties should introduce the provision of automatic compensation to survivors of institutionalization at levels that \*dignify the pain, suffering, and consequential damages experienced over the course of a lifetime within an institution or as a result of institutionalization. Such financial awards cannot undermine the pre-existing legal rights of individuals to engage in litigation and other forms of access to justice.

\* Can pain be dignified? what really needs to be is a redress. (¿se puede dignificar el dolor? lo que realmente debe haber es una reparación).

119. Truth commissions at the national and international level should be established to investigate and promote public understanding of all forms of institutionalization and the full scope of harms caused to past and present survivors, to lay the groundwork for planning an effective national response.

\*There are states that have mechanisms for the prevention of torture, they should be in charge of this task. The NHRIs and the mechanism of article 33 of the CRPD can also do it, in those countries that have these organisms. At the international level, there is the Committee for the Prevention of Torture in accordance with the optional protocol of the CAT. This body can also be in charge of these actions).

(\*Hay estados que cuenta con mecanismos para la prevención de la tortura, ellos deberían encargarse de esta tarea. También pueden hacerlo las INDH y el mecanismo del artículo 33 de la CRPD, en aquellos países que cuenten con estos organismos. En el ámbito internacional existe el Comité para la Prevención de la Tortura en conformidad al protocolo facultativo del CAT. Este órgano puede ocuparse también de estas acciones).

**XI. Monitoring deinstitutionalization processes**

130. \*States Parties should ensure that independent monitoring mechanisms designated under article 33(2), including National Human Rights Institutions, Ombudspersons, and other equality bodies, have unrestricted access, physical and otherwise, to institutions, documents, and information. States Parties should also ensure independent monitoring activities undertaken by civil society and representative organizations, including those under article 33(3), are facilitated, and barriers to access to institutions, documents and information are removed. States Parties should facilitate open exchange of data on deinstitutionalization.

\* This guarantee should also apply to truth commissions in paragraph 119 of this draft.

(Esta garantía también debería aplicarse a las comisiones de la verdad del párrafo 119 de este borrador).

1. CRPD/C/GC/3, paras. 29, 45. [↑](#footnote-ref-1)
2. CRPD/C/GC/1, para. 38. [↑](#footnote-ref-2)
3. Short-term breaks provided to caregivers. [↑](#footnote-ref-3)