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

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by

the International Disability Alliance (IDA)

The **International Disability Alliance (IDA)** is a network of global and regional organisations of persons with disabilities (DPOs) comprising eight global and six regional DPOs. Established in 1999, each IDA member represents a large number of national organizations of persons with disabilities (OPDs) from around the globe, covering the whole range of disability constituencies. IDA thus represents the collective global voice of persons with disabilities counting among the more than 1 billion persons with disabilities worldwide, the world’s largest – and most frequently overlooked – minority group. IDA’s mission is to advance the human rights of persons with disabilities as a united voice of organisations of persons with disabilities utilising the Convention on the Rights of Persons with Disabilities and other human rights instruments.

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

## Introduction

The International Disability Alliance (IDA) is grateful to the Committee on the Rights of Persons with Disabilities for the opportunity to provide comments on the “Draft Guidelines on deinstitutionalization, including in emergencies.” IDA, including as part of Global Coalition on De-Institutionalisation, has been supportive of this process, and we appreciate the transparent and highly participatory process. We are confident the Guidelines will be an important and useful contribution to accelerating States’ deinstitutionalisation efforts, consistent with international human rights standards.

In general terms, IDA welcomes the purpose, structure, and content of the document. The comments on the next sections are directed to improve clarity, tighten phrases and better delimit the scope of application of the document and of specific recommendations. We stress that States and State officials should be the main, but not exclusive, addressees of this guidance.

## Specific comments (identifying paragraphs)

When providing concrete drafting proposals, added phrasing is indicated bold letters and we use double strikethrough over the words we suggest being removed.

### Paragraph 2:

IDA proposes to reflect that institutionalization impacts on the rights of persons with disabilities:

### “… of institutionalization on the rights and well-being of persons…”

### Paragraph 6:

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

### “6. […] The Human Rights Council has recently expressed that “forced institutionalization is a form of violence that deprives women and girls of liberty on the basis of disability.”[[1]](#footnote-1)

### Paragraph 9:

The last phrase of paragraph 9 should be combined with current paragraph 10 in a new paragraph, as both refer to individual situations of crisis (e.g. distress).

### Paragraph 12:

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

### Proposal for a new paragraph 10

IDA proposes the following paragraph to be added following current para. 12 once placed after para. 8

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

### Paragraphs 14 and a new 15: Scope of the concept of “institutionalization”

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

IDA appreciates the effort to cover all places and situations where persons with disabilities find their rights under article 19 CRPD infringed, whether disability specific or mainstream. Yet, some nuances might prevent confusion, especially when alluding to the criminal and penitentiary system, as persons with disabilities might be detained “when found guilty of a crime, after criminal procedure has been followed, with all the safeguards and guarantees applicable to everyone.”, which would not be contrary to the CRPD.[[2]](#footnote-2)

In addition, IDA believes that, as it stands, the approach to for now called “mainstream institutional settings” is as a minimum confusing. While persons with disabilities might be in practice overrepresented therein, detention is based on other ground and rationale and would not constitute institutionalization for the purpose of these guidelines. Yet, elements from Article 19 of the CRPD remain applicable.

IDA proposes the following amendments:

14. “… and detention **based on disability, alone or in conjunction with other grounds such as “care” or “treatment”. Forms of […] congregated settings. Detention under criminal law is not institutionalization and is compatible with the Convention, as long as it results from procedures followed with all the safeguards and guarantees applicable to everyone and is not based on the persons’ impairment.**

**(new) 15.** **Persons with disabilities are usually overrepresented in** mainstream ~~institutional~~ detention settings such as prisons, […]. **While persons with disabilities detained therein are not addressed by this document,** ~~should also be included in deinstitutionalization efforts~~ **elements of Article 19 CRPD remain applicable to them to the extent compatible with the purpose of the detention. For example, persons with disabilities in prisons should receive support services; persons with disabilities in refugee camps should benefit from accessible services (e.g. water provision, health-care, etc.).**

### Paragraph 18:

IDA proposes the following for clarity purposes:

“**Due to potential conflict of interests,** processes of deinstitutionalization should not be led by **public officials or third parties who have involved in any way, directly or indirectly** in the management and/or **functioning, with relevant decision making power,** maintenance of institutions **(e.g. public official at ministry in charge of institutions, director of an institution…)**.

### Paragraph 19:

### Paragraph 19 would be better placed immediately after current paragraph 16.

### Paragraph 20:

IDA highlights the need to refer to standards under Article 7(3) CRPD when referring to children’s role in decision making:

“20. … requires full **the exercise of** legal capacity, […] Having choice means that persons with disabilities, including women **and** older persons, and children, are respected in their decision-making. **The right of children with disabilities to express their views freely, be provided with disability and age-appropriate assistance to do so, and their views being given due weight in accordance with their age and maturity, is essential for exercising rights under Article 19 CRPD for children (see paras. 42 to 50)** ….”

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

IDA highlights the need to preventing confusing support in decision-making under Article 12 CRPD withs support systems and services under Article 19(b) CRPD, given the different kinds of obligations emanating from them, according to CRPD Committee’s jurisprudence.[[3]](#footnote-3) In addition, the phrase of paragraph 21 would be better place to conclude a new paragraph 22. Thus, the following proposal for para. 22 (and a new 23).

“22. […] networks.[[4]](#footnote-4) **In order to be aligned with the Convention, support services for living independently should be available, accessible, acceptable, affordable, and adaptable**.[[5]](#footnote-5) **States Parties should prioritize the development of a range of individualized supports, while advancing on making mainstream services in the community accessible and inclusive without delay.”**

**23.** Persons with disabilities should be enabled to exercise their legal capacity **in line with General Comment No. 1 on articles 12 CRPD, thus with immediate application,[[6]](#footnote-6)** in choosing, managing and terminating the provision of community-based support. Support in exercising legal capacity can be provided as a service funded by the State,[[7]](#footnote-7) or by a person’s informal networks.”

### Paragraph 31 and 32:

This section under the title “Access to accessible housing” should be placed before the section “Allocation of funding and resources”.

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

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

“33. … in line with articles 4(3) and 33 and General Comment No. 7.[[8]](#footnote-8) **States parties should give priority to the views of organizations of persons with disabilities, as they address issues related to persons with disabilities.[[9]](#footnote-9)** Service providers, …”.

### Paragraph 36:

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

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

### Paragraph 37:

IDA emphasises the need to acknowledge and protect the *de facto* support role family members usually assume due to lack of alternatives, and avoid restrictions to the rights of caregivers in the design and requirements of social protection schemes providing any support, e.g. financial support schemes should not prevent care-givers from engaging in employment compatible with the supportive role. A similar concern is expressed in paragraph 87.[[10]](#footnote-10) For para. 37, IDA proposes:

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

### Paragraph 39:

*De jure* discrimination is discrimination enshrined in law; thus, it cannot depend on factual consideration of the lack of support services. More relevant for para. 39 might be referring explicitly to direct and indirect discrimination. Thus, for para. 39, IDA proposes:

“39. Discrimination on the basis of disability may occur whether or not persons are institutionalized explicitly on the basis of disability. **Direct or indirect discrimination, including multiple** discrimination, and *de jure* or *de facto* discrimination may also …”.

### Paragraph 41:

IDA highlights the relevance of including a subsection on older persons with disabilities after the subsection on women and girls with disabilities.

### Paragraphs 44 and 45: Consideration of harms of institutionalization to all children and prevention of primary impairments.

These two paragraphs lack sufficient clarity on the issue of institutionalization causing primary impairments to children in general and provide, and recommendations related to both children generally and children with disabilities in particular. IDA proposes a **full redrafting** in the following way:

**“44. Children are usually placed in institutions based on their actual or perceived impairment, poverty, ethnicity, among other grounds. This Committee itself has found that institutionalization is dangerous for all children.[[11]](#footnote-11) Institutional placement might be the cause and/or facilitate the acquisition of impairments by children, who then become children with disabilities. Even short-term institutional placement (outside a family) may cause great suffering, trauma, and other harm that can evolve or become impairments. A clear example is acquiring cognitive impairments due to lack of proper nutrition in institutional settings. Avoiding institutionalization of children, including children with disabilities, must then be a State’s priority and serves both primary prevention of impairments on children (as a general matter of public health) and prevention of isolation, segregation and secondary impairments on children with disabilities (as a disability rights matter), favouring inclusion in the community.**

**45. In this vein, specific support measures for children with disabilities and their families should be part of and coordinated with support measures available for all children and their families, with the purpose of avoiding any support gap: support should be available when required to prevent and end institutionalization of children, including children with disabilities. In addition, peer support for children and adolescents can significantly contribute to full community inclusion.”**

### Paragraph 54: broad scope of procedural accommodations

IDA considers it important to portray a broad scope of procedural accommodations through examples not limited to issues of accessibility of information and communication.[[12]](#footnote-12) Hence, IDA proposes:

“54. Procedural accommodations, such as Easy Read materials and plain language, **procedural flexibility, extending or adjusting procedural deadlines and adjusting procedural formalities**,[[13]](#footnote-13) should be made available.”

### Paragraph 56: “security measures” as a violation of article 14 of the CRPD

“Security measures,” and other analogous legal institutions depending on the context, are usually applied to persons with disabilities “found not responsible due to “insanity” and incapacity to be held criminally responsible.”[[14]](#footnote-14) They are a consequence of denying persons with disabilities a fair trial and due process of law, with the guarantees applicable to anyone, based on the impairment of the person, and/or constitute the deprivation of liberty of a person not found guilty of a crime. Even without being found guilty of a crime, many persons with disabilities are deprived of liberty based on impairments, in conjunction with other alleged grounds such as “care,” “treatment” and “dangerousness”, which is contrary to article 14 CRPD. Not being justified under the CRPD, “security measures” would constitute a form of “institutionalization” (see above proposals on paragraph 14). IDA believes it should be outlined more clearly and proposes:

“56. …. **Criminal codes or legislation typically allow for the imposition of “security measures,” or other analogous legal institutions depending on the context, to persons with disabilities “found not responsible due to “insanity” and incapacity to be held criminally responsible.”[[15]](#footnote-15) Such measures consist of depriving persons with disabilities of their liberty on grounds such as “care”, “treatment” or “dangerousness.” They usually follow the diversion of persons with disabilities from a fair trial and due process of law with the guarantees applicable to anyone, based on their impairment and/or are applied to persons with disabilities not found guilty of a crime based on the said grounds. These measures are contrary to article 14 CRPD, provide for a form of institutionalization and legal provisions allowing for them should be repealed**. Guardianship and other forms of substitute decision-making regimes and provisions for forced psychiatric hospitalization, including of children, should **also** be repealed. … .[[16]](#footnote-16)

### Paragraph 59:

Part c) requires more clarity to better reflect the connection between violations of rights and their causes:

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

### Paragraph 72:

Based on the same rationale that the comment and proposal on paragraph 37, IDA proposes:

**“**72. States Parties should ensure that persons with disabilities can receive support from their families, should they decide **to do so**. In such cases, States Parties should provide support to families in order that they fulfil their support roles**, preventing that that support schemes do not restrict automatically and unnecessarily the rights of caregivers (see para. 37).”**

### Paragraph 73:

The second phrase is extremely categorical and prevents the possibility of benefitting from medical expertise:

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

### Paragraph 75:

IDA proposes further clarifying in this way:

**“**75…The use of day-care centres and sheltered employment **that segregate persons with disabilities and impose a routine, in addition to typically infringing labor rights in the second case,** are paternalistic and do not comply with the Convention.”

### Paragraphs 83:

IDA proposes to add the criterion of “affordability”.

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

### Paragraphs 84:

In order to more clearly distinguish concepts and purposes of social protection for persons with disabilities, IDA proposes more recently agreed language for paragraphs 84 and 85.

“84. Persons with disabilities **and other survivors of institutionalization** should receive individualized and direct funding that provides for income replacement and covers disability-related costs **basic income security, coverage of health care cost and disability-related costs,** including […] For persons leaving institutions, **funding** should **suffice and** be tailored to their new living arrangements.”

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1. Human Rights Council, Res. 47/15, PP20. [↑](#footnote-ref-1)
2. CRPD/C/NZL/CO/1, para. 33. [↑](#footnote-ref-2)
3. See CRPD/C/GC/1, para. 26 (stating that “[a]s such, the rights provided for in article 12 apply at the moment of ratification and are subject to **immediate realization**. … Progressive realization (art. 4, para. 2) does not apply to article 12.”); and CRPD/C/GC/5, para. 39 (stating that “Article 19 (b), the right to access individualized, assessed support services, is an economic, social and cultural right.”) [↑](#footnote-ref-3)
4. A/HRC/34/58. [↑](#footnote-ref-4)
5. Brought up from current para. 23 of the draft. [↑](#footnote-ref-5)
6. See CRPD/C/GC/1, para. 26. [↑](#footnote-ref-6)
7. CRPD/C/GC/1, para. 16 [↑](#footnote-ref-7)
8. CRPD/C/GC/7, para. 12(c). [↑](#footnote-ref-8)
9. CRPD/C/GC/7, paras. 13, 14 and 23. [↑](#footnote-ref-9)
10. Current para. 87, in fine, reads: “Family members whose support responsibilities have disadvantaged them in other life paths should be provided with additional support.” [↑](#footnote-ref-10)
11. CRPD/C/GC/5, para. 16(c). [↑](#footnote-ref-11)
12. Current para. 87, in fine, reads: “Family members whose support responsibilities have disadvantaged them in other life paths should be provided with additional support.” [↑](#footnote-ref-12)
13. See A/HRC/37/25, para. 24. [↑](#footnote-ref-13)
14. Committee on the Rights of Persons with Disabilities, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities, para 20 (2015). [↑](#footnote-ref-14)
15. Committee on the Rights of Persons with Disabilities, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities, para 20 (2015). [↑](#footnote-ref-15)
16. A/72/55 (Annex). [↑](#footnote-ref-16)