

# The Committee on the Rights of Persons with Disabilities

Human Rights Treaties Division

Office of the United Nations High Commissioner for Human Rights Palais Wilson – 52 Rue des Pâquis

CH-1201 Geneva Switzerland Dear Jorge and Carla,

Save the Children shares the real concern that large numbers of persons with disabilities, including children, continue to be placed in and kept in institutional care. Any group of children unnecessarily going into any form of alternative care is extremely disturbing.

We therefore welcome the draft ‘Guidelines on Deinstitutionalisation’ developed by the Committee and share the Committee’s vision of a world where institutional care is no longer used and every adult and child with disabilities is seen as a respected and valued member of the community where they are given every opportunity to grow up, live, thrive and fully enjoy their rights. However, as a child rights organisation, we also have some concerns that we respectfully ask the Committee to consider.

# Executive Summary

1. *The specific rights of children and responsibilities of their families:* The rights and needs of children with disabilities are mentioned in different sections and points of the document, but not treated consistently throughout the Guidance. This is problematic for a number of reasons, including underestimating the critical role and legal responsibilities of the primary caregivers of children with disabilities. Children often do not have full autonomy over their lives with many of the fundamental responsibilities and decisions about their care and education come under the responsibility of their caregivers. **We suggest changing the wording “persons with disabilities” to “adults and children with disabilities” throughout the Guidance and more specifically highlighting the fundamental role that caregivers play in decision-making and supporting their children.**

As children have a fundamental right to participate in decisions that affect their lives in line with their evolving capacities and under the CRC, States must provide support and enable caregivers to fulfil their critical role **and we would encourage the Committee to initiate a process to enable disability, child rights and child protection organisations to come together to discuss and strengthen the Guidance to more specifically address the rights of children with disabilities in the context of deinstitutionalisation and the fulfilment of their right to family life.**

1. *The broad definition of institutionalisation:* We share the concern that State Parties and service providers can often focus deinstitutionalisation efforts only on large residential care facilities and disregard small group homes. We agree that small group homes are residential facilities and should not be considered family-based care. However, we do not believe that all residential care settings are necessarily institutional in nature. By broadening the definition of

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institutionalisation, we are concerned that there is not enough focus on the harmful elements of what characterises institutionalisation, especially for children placed in them solely because of their disability. **We recommend using the term “institutional care” to illustrate one form of residential care rather than all forms of residential care.** While the size of the institution should not matter, the way that services are provided, how people are integrated into community life, and the individual way people are treated in those residential care facilities should. This quality element must be highlighted throughout the guidance.

1. *The focus on accelerating deinstitutionalisation without an equal focus on improving access to and quality of community-based services and supports for children and their families.* There are many examples where countries have rapidly deinstitutionalised their childcare institutions without ensuring that support services are available in the community, resulting in significant child rights violations and child protection and other risks, including in response to COVID-19. **We believe this guidance would be strengthened by calling on State Parties to accelerate and scale up child and family centred community based services and support in parallel with deinstitutionalisation. This is particularly an issue in humanitarian settings** where, in the first phase of an emergency, humanitarian actors will be doing everything they can to prevent further separation and institutionalisation of children while also addressing the immediate threats to the rights of children with disabilities already in institutional care. **It is not safe or realistic to call for rapid deinstitutionalisation in these insecure contexts without simultaneous efforts to ensure family-centred community-based services and supports are available to these children and families**.
2. *The lack of focus on preventing persons with disabilities from being placed in institutional care in the first place.* **We believe the Guidance could be strengthened by having a specific section addressing the root causes as to why people with disabilities, including children, are placed in institutional care in the first place.** There are many contexts where poverty, stigma, or lack of access to good education or rehabilitation are the main drivers of institutionalisation and, to effectively create a deinstitutionalisation plan, these drivers must be understood and addressed through concrete action. We think the Guidance could better emphasize how to prevent the common practice of adults and children with disabilities being placed into and kept in institutional care looking at factors due solely on the basis of their impairment as well as the other factors outside of disability which may have contributed.
3. *The lack of concrete recommendation on how to transition services:* State parties do not have indefinite resources. **We believe that the guidance would be strengthened by illustrating how to deinstitutionalise services including more of a focus on transitioning, costing examples, including the reallocation of funding from institutional care to community-based services and the need for efforts to combat stigma and discrimination in the community.** Similarly, many staff members in institutions are well trained and could play a significant role in a transition process in providing accessible community-based support.
4. *The focus on State Parties without sufficient recognition that the majority of institutions worldwide are not State managed or funded.* For State Parties to effectively close institutions, they need to determine where this funding is coming from and engage with including international financial institutions, private donors and faith-based actors. The State has a significant role in helping to bring about the redirection of these funds and many actors could support these efforts by advocating to those funding organisations to do so. **The Guidance should be clearer on how State parties can regulate private donors, faith-based actors and NGOs as the State has direct responsibilities for what their citizens, foundations, faith-based institutions, corporations, and foreign aid support when these lead to human rights and child rights violations**.
5. *The lack of disaggregated disability child data:* **Disaggregated disability data must more strongly refer to age disaggregated data to understand how many children with disabilities are in institutions, the type of institution they are in and how many are leaving institution to move into family-based care in the community. It must be collected across all types of residential care settings and schools where children reside and spend long periods as well as residential rehabilitation centres.** This is key to address family reunification efforts and plan and resource such initiative which must be central within a de-institutionalisation agenda for children alongside looking at family-based alternative care options where reunification is not possible. State parties should take active action to address the data gap and provide reliable statistics to support this. Therefore the **recommendation in the Guidance should not be limited to the Washington Group Short Set, for adults, but also include tools from the Washington Group and UNICEF specifically aimed at collecting data on children**. This includes the CFM modules and teacher version where possible as part of the EMIS system in residential special schools. We advise the Committee to **further elaborate on how data of children under the age of two in residential care should be collected, as this is currently not possible using the CFM modules** and may therefore present a significant data gap.

# Detailed Recommendations and Suggestions:

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| **Section** |  |
| 3 | **Comment:** It is unclear how many women and men, girls and boys participated based on the way the sentence is written.  **Edit**: the harmful impact of institutionalization on **the mental health** and well-being of persons (…) |
| 4 | **Edit:** The impact of the pandemic on persons in institutions has underscored the urgency of immediate action to **scale up community based services and support for persons with disabilities and** end institutionalization. (as these two need to be connected) |
| 7 | **Edit:** and **be** included |
| 8 | **Comment:** We need to distinguish what an institution is – a person with a disability who decides on their own accord to check themselves into a residential mental health facility or support with addiction etc is very different from someone choosing to stay in an institutionalised setting where they have no access to the community or the individual support they need.  **Edit:** should **progressively** abolish |
| 9 | **Comment:** This is part of the reform and speeding up the closure of institutions without scaling up services at the same speed is dangerous. |

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| 11 | **Edit**: in the private, **public and religious** spheres |
| 13 | **Comment:** While we completely support the prohibition of new institutions and new placements, we believe that deinstitutionalisation is a gradual process and there may be times when basic repairs are needed for the health and wellbeing of the individuals within the institution while deinstitutionalisation is taking place**Edit:** Make the second part a separate point and edit to : States Parties should immediately stop new placements in institutions, by adopting a moratorium on new admissions and on the building of **new institutions and wards**, and refrain from repair or maintenance |
| 14 | **Comment:** This definition is far too broad to be useful. It is assumed that these are all forms of residential care and that community rehabilitation services would be where the person returns home and therefore not a form of rehabilitation? There are times when a person may need residential services for a short term intervention even after deinstitutionalization takes place. Even in very wealthy countries with well- functioning systems and support, children may need to travel with their families to receive specific in- patient care that is not available in their community. We do not believe that this constitutes institutionalisation.  **Comment**: A refugee camp is not an institution unless it is classified by institutional settings listed below. |
| 15 | **Comment:** Some of the settings listed in the paragraph above do not necessarily by their very nature constitute an institution and would not be the same level of harm as long term institutional care – grouping them all together makes reform that much more challenging for member states and may have the opposite effect of supporting reform.  **Edit:** sharing of assistants **or caregivers (…)**  **Edit:** certain authority; **discouraging contact between children and their birth or extended families and the lack of the ability for children to form attachment to one or two primary caregivers**, a paternalistic approach in service |
| 16 | **Edit:** actors, **including religious institutions**, should be included i |
| 17 | **Edit:** disabilities **and their families** about how |
| 19 | **Comment:** Just need to clarify if an institution is any residential setting or a residential setting that has any of the characteristics of institutionalisation. |
| 20 | **Edit: For adults** living independently and being included in the community requires full legal capacity, access to housing, support and service options that enable persons to regain control of their lives. **For children, living independently means being cared for in a safe and supportive family environment.** |
| 20-22 | **Comment: stronger** *language needed around children’s right to choose and the application of article 12 to children in de-institutionalisation processes with a focus on supported decision making and accessible information.* |
| Community based support | *We suggest including a section with specific examples relating to children with disabilities to live in family- based care that includes but is not limited to support and services that enable a family to care for a child with disabilities.* |
| 23 | **Edit:** should be help, **supportive caregivers for children in family-based care following an assessment of their individual needs**, and other community-based services, available |
| 28 | **Comment**: We need to better understand why this “choice” is being made and what concerns persons with disabilities may have in their community rather than disregarding their views.  **Edit:** directed **to the creation of community-based services** and support **the safe and gradual release** of residents |
| 30 | **Edit:** cash **and** vouchers, communication devices and information about services immediately upon departure to persons with disabilities leaving institutions **as well as discussions on spending, saving and budgeting**. |
| 31 | **Edit:** Providing adequate housing and a standard of living for persons with disabilities **and for children, including their family members** is a priority (…)  enjoy the **right of freedom of movement as well as the right** to enter into legally binding |
| 33 | **Comment:** From our work on transforming childcare institutions we have found it much more effective to engage those running institutions to transition rather than keeping them out of the process. They should not have undue weight, but they should be part of the discussions.  **Edit:** involve persons with disabilities, **including children with disabilities**, through their representative organizations, |

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| *Involvement of persons with disabilities* | **Comment:** including a specific paragraph on how to involve children with disabilities to have their voices heard and influence any deinstitutionalisation agenda with a child perspective, especially children who have experience of living in institutions or have transited to the community. |
| 34 | **Edit:** Persons with disabilities living in institutions, survivors, and those at a higher risk of institutionalization, **including those in humanitarian contexts**, should be provided with support and information in accessible formats to facilitate their full participation in deinstitutionalization processes. **They should be able to voice their concerns as part of this process and should not be made to feel pressured if they voice opinions about wishing to stay in residential care. These concerns should be understood and measures to address them should be made.** |
| 37 | **Comment**: beneficial to add a child perspective as this would always apply to children with disabilities who often depend on their family for access to services and their wellbeing and healthy development.  Edit: ember with disabilities **or in the case of children their social worker or legal guardian**. |
| 43 | **Edit:** with a committed **primary** adult caregiver |
| After 43 add a new | Children should be treated as individuals with individual assessments to support decision making and the placement of the child back into his or her family or alternative family-based care. |
| 44 | **Comment:** Include citation |
| 45 | **Comment:** This is also true for children who are kept in abusive homes or transferred to many different foster carers – there should be some points including improving the quality family based alternative care options and that sometime the biological family may also cause harm to the child.  There should be a separate section specifically on prevention  **Edit:** Family-based placements, with financial and other forms of support, should be created for all children**, including those with disabilities**. |
| After 45  2 new | 1. Families must be supported to care for their children including being connected to parenting groups, parental education and support, family mediation and case management. When removal of a child from a home is warranted, family-based care options should be made available. 2. When a child must receive residential services, he or she should be accompanied by a primary caregiver and if the child wishes all efforts should be made to keep the child connected to friends and family during the duration of his/her stay. |
| 46 | **Edit:** from being **separated and** placed in institutions. |
| 47 | **Comment:** This is the first time there is a distinction on age of children – it is an important point to distinguish the age of the child  **Edit:** age, **gender**, and disability-appropriate |
| 48 | **Edit:** remove the sentence ‘Children cannot “choose” to live in an institution.’ |
| 49 | **Comment:** it would be beneficial to provide more details to guide regulation and transition from residential special schools or rehabilitation centres which are often preferred by many families and leading to children being removed from family care on the premise that the support they need is not available within the community and they can be better prepared for life by attending special schools or rehabilitation centres.  **Edit:** including **a social worker to follow up with the child and his/her family following reunification,**  personal assistance |
| 50 | **Comment**: There is also a need to fund services that can support prevention. For example, the social service workforce, increasing social safety nets, and referrals to community-based services.  **Edit**: doctors’ offices, **hospitals** and parent resource centres, and religious institutions. **Caregivers should be provided with support on how to care for their child with a newly diagnosed disability**. Training of professionals, **such as doctors and nurses,** on the human (…) |

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| 52 | **Edit:** living independently or **for children the right to family life** and |
| 52& 53 | **Comment:** Elaboration on section 53 and 54 on Right to legal capacity and access to justice how this specifically applies to children with disabilities who are often denied legal capacity both as children and as children with disabilities. Stronger clarification of Article 12 and children would be helpful. |
| 54 | **Edit**: made available. **Children should have legal advocates or guardians who specialise in working with children with disabilities and whom coordinate closely with their social worker.** States |
| 60 | **Edit:** add to the list laws that govern education and schools as well as rehabilitation facilities and centres. |
| 62 | **Edit**: they are **age and gender sensitive**, adequate, |
| 63 | **Edit:** a) developed **including strengthening the social welfare workforce**; c) communication **and that children’s families are equally supported**; |
| 64 | **Edit:** with the Convention. **Existing training and accreditation schemes for health care workers, teachers, and social workers should include training from disability organisations on how to effectively support persons with disabilities and their families**. They should |
| After 69 add a new | For children, State Parties should invest in peer support for family members and their children including financial support and fund access to training in how to care for children with disabilities, parent, understanding networks of child-centred resources and services available and connection to organizations of persons with disabilities and child rights organizations. |
| 69 | **Edit:** Where **adult** persons with disabilities do not wish |
| 70 | **Edit:** Add to end of sentence : **Social workers play an important role in ensuring that family members are acting in the best interests of children and that support persons helping to care for the child are acting on the child’s preferences and thus crucial to promote the right to family, community support and prevention of institutionalisation as well as encouraging family based care if a child is no longer able to safely live with their biological family** |
| 72 | **Edit**: families, **particularly as they pertain to children** in order that they |
| 78 | **Edit:** disabilities **dependent on their age** and should  **Edit**: arrangements ~~where~~ that conform |
| 84 | **Edit**: inflation**. Families of children with disabilities should also be eligible for such support**. |
| 84-87  Income Support | **Comment:** add a section or integrate stronger language about how income support relates to children with disabilities and the family’s ability to support the child with disability effectively and safely to develop and reach its full potential without harm and family separation |
| 86 | **Edit**: with disabilities **or in the case of children, their primary caregiver(s),** ensuring |
| 88 | **Edit:** care, family **life**, employment |
| 90 | **Comment**: Yes, but there is a challenge here – States must be investing in community-based supports and services at the same time as deinstitutionalisation efforts begin. |
| 91 | **Comment:** Children cannot leave without a designated caregiver/legal guardian to support the child, but family members should be able and encouraged to be reunified and take the child out of an institution at any time and emphasis should be on continuous and regular support to the family to care for the child |
| 91-96 | Add a section similar to that of section 93 to list specific considerations for children with disabilities |
| 93 | **Edit:** Add at the end: Children leaving institutions should have access to an individualized assessment that identifies the specific requirements, risks and protective factors in the child’s life to ensure appropriate determination of the care arrangement and prioritise family-based alternative care if reunification with  the biological family is not in the child’s best interest. Assessment should be free from bias and |

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|  | stigmatisation relating to children with disabilities, their ability and their impairments and be rooted in a rights-based model and the right to participation and family life. |
| 94 | **Comment:** add registration card as common in refugee settings, and disability cards where this exist and ensure children are included with the family’s registration to access distributions in humanitarian settings for examples  **Edit:** national identity cards, **registration cards**, residence permits, |
| 96 | **Comment:** On not extend to offering “continuity of care” in the community. This is very challenging as some of the social workers employed by the institution have nothing to do with the type of care provided there and could be a valuable resources if reallocated to community based care instead – this would need to be made on a case by case basis. Perhaps differentiating between those in charge of the institution and those employed to provide specific services and caring for children and ensuring that children with disabilities have their requirements met, both emotional, psychological, physical and otherwise. Many children with disabilities who have lived in institutions do not know the outside world and leaving a familiar residential setting, even if an institution can be very scary and cause trauma. We therefore suggest the Committee provide more direction of how transition from institutions should occur without harm to the individual child as well as how resource personnel and trusted adults from residential care facilities and social workers can play a role in such a transition and support community alternatives and safe environments in family based replacement care. This also applies to where children are reunited with their biological parents who they may not know at all. |
| After 96 add a new one | **Comment:** The social welfare workforce should be trained and supervised by organizations of persons with disabilities on how to work with children and caregivers who were previously institutionalized |
| 97-104  Article 19 | **Comment:** Address Article 19 and living independently in the lens of children with disabilities with specific recommendations |
| 97 | **Edit**: recreation, **education**, and the right to political |
| 98 | **Edit:** persons with disabilities, **including those with a particular specialization of working with children**, especially  **Edit:** persons with disabilities **and combatting stigma and discrimination through** |
| 102 | **Edit:** access to **education or** employment, |
| 103 | **Edit:** disabilities **and the families of children with disabilities** leaving |
| 105 -112 | **Comment:** The section on enacting emergency de-I plans does not mention unaccompanied and separate children with disabilities.  **Edit:** continue and **safely** accelerate efforts to close institutions. During emergencies, immediate efforts are necessary to identify **all those residing in institutions** including people with disabilities, displaced persons with disabilities, **unaccompanied and separated children with disabilities** and refugees with disabilities.  **Edit**: plans for **the** accelerated **support of community based services and** deinstitutionalization |