

Comments on the draft of General Comment No. 5 on article 19 of the Convention on the rights of persons with disabilities on Living independently and being included in the community

This submission represents the views of the Child Rights International Network (CRIN) (www.crin.org) on the proposed draft general comment No. 5 by the UN Committee on the rights of persons with disabilities, on article 19 of the Convention. CRIN is a global research, policy and advocacy organisation. Our work is grounded in the United Nations Convention on the Rights of the Child. Our goal is a world where children's rights are recognised, respected and enforced and where every rights violation has a remedy.

Introduction

These comments focus on the sections of the general comment that specifically address or impact on the rights of children with disabilities in the context of living independently and being included in the community.

All human rights apply to children. They must be allowed to express their views and be heard in all matters that affect their lives, in particular when it comes to deciding about where and with whom and how to live.

CRIN argues that detention of children in institutions is detrimental to their development and that institutionalisation constitute cruel, inhuman and degrading treatment and sometimes amounts to torture.

In the light of the above, CRIN makes the following comments to the draft General Comment (suggested changes have been included below the comments and explanations on the relevant paragraphs):

Paragraph 11

While we acknowledge the mention of the particular relevance of article 9 and 23 of the Convention on the rights of the child (CRC) in this General Comment, we also recommend a specific reference to article 12 of the same convention, on the right of children to express their views and be heard in all matters affecting them, a prerequisite for guaranteeing all their other rights. The CRC does not set a minimum age at which children can express their views; this right applies to all children in all settings. The Committee has recognised that even very young children learn to make choices, communicate their feelings, ideas in various ways before they acquire oral and written language skills.¹ In addition to an active obligation to listen to children, this article asserts that children's views "must be given due weight in accordance with the age and maturity of the child". In deciding how much weight to give to a child's views on a particular matter, age and maturity must be considered (in

¹ Committee on the Rights of the Child, General Comment No. 7, 2005, CRC/C/GC/7, para. 14

accordance with article 5 of the CRC on 'evolving capacities'). This means children must have the ability to understand and assess the implications of a given situation.²

Suggested amendment to paragraph 11:

Article 9 of the Convention on the Rights of the Child enshrines the right of children not to be separated from their parents unless it is necessary for the best interest of the child. Article 23 (1) [also](#) specifies that all children with disabilities should enjoy a life in dignity with conditions that promote self-reliance and facilitates active participation in the community. [Article 12 further enshrines children's right to express their views in all matters affecting them. The extent to which these should be taken into account depends on their age and maturity.](#)

In its General Comment No. 9, the Committee on the Rights of the Child also expresses its concern at the high number of children with disabilities placed in institutions and urges States parties to set up de-institutionalization programs for children with disabilities.

Paragraph 15 (a)

Children are often denied their right to participate in the decision-making process concerning their right to live independently and be included in the community. That's because children are not always viewed as human beings with human rights, but rather as an extension of their parents, guardians or the State. Children certainly require protection and adult guidance as a result of their young age but they should be listened to, irrespective of age; their views should be taken seriously when it comes to making decisions concerning their lives. A reference to the concept of evolving capacities that the CRC uses in article 5 should be made in paragraph 15 (a) of the draft General Comment. Article 5 seeks to encourage respect for children's capacity to exercise their rights and involve them in decisions, while balancing this with their relative lack of experience to protect them from harm. In its General comment No. 7 the Committee on the Rights of the Child explains "Evolving capacities should be seen as a positive and enabling process, not an excuse for authoritarian practices that restrict children's autonomy and self-expression and which have traditionally been justified by pointing to children's relative immaturity and their need for socialisation". Parents (and others) should be encouraged to offer "direction and guidance" in a child-centred way, through dialogue and example, in ways that enhance young children's capacities to exercise their rights.³

Suggested amendment to paragraph 15 (a):

***Independent Living**, which means that individuals with disabilities, [including children in accordance with their evolving capacity](#), are enabled to exercise control over their lives and make all decisions that concern their lives ...*

Paragraph 15 (b)

² For more information about implementing article 12, see the [CRC general comment](#) on the right to be heard.

³ CRC General Comment No. 7, CRC/C/GC/7/Rev.1, September 2006, para. 17

In its General Comment No. 2 on accessibility, the Committee calls on States “to ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system”. A reference to access to playgrounds, libraries and other cultural activities could be made in paragraph 15 (b) to reflect on specific community based services that are specific to children.

Suggested amendment to paragraph 15 (b)

Community living: ...

These services can relate to housing, personal care, transportation, shopping, cinemas and all other facilities and services offered to the public, including children centred services such as play grounds, libraries and other cultural activities. The right to be included in the community also means having access to all measures and events of political and cultural life in the community. These can be elections as well as public meetings of local governments, sports events as well as theatre festivals.

...

Paragraph 15 (c)

Institutionalisation is indeed about losing control over day-to-day decisions, lack of choice over whom to live with, isolation and segregation from community life and we commend the Committee for reminding these realities in paragraph 15 (c), whatever scale the institution may have. However we would recommend your Committee to go even further in the condemnation of the institutionalisation of children. Institutionalisation deprives children with disabilities (and others in other types of institutions) of their human rights. No child should be placed in an institution, large or small, even temporarily as they are detrimental to children’s development. Placement of a child in an institution will never meet their “best interest.” Violations of children’s rights in institutions across the world include: beatings and the use of abusive physical restraints in Russia, sexual violence against girls with disabilities in India, the use of caged beds in Greece, inappropriate use of psychotropic medication in Serbia, shackling of children with disabilities in Ghana and Indonesia.⁴ Furthermore, children in institutions are often denied education, contact with the outside world, privacy, recreation and cultural opportunities. We therefore urge your Committee to recognise that detention of children in institutions constitutes cruel, inhuman and degrading treatment and can sometimes amount to torture.

Suggested amendment to paragraph 15 (c):

*Both concepts, i.e. independent and community living, -- refer to **life settings outside of institutions**, including large or smaller group homes. Institutionalization is not about living in a particular setting, it is, first and foremost, about losing control as a result of the imposition of a certain living arrangement. Therefore, neither large*

⁴ Human Rights Watch, *Children with disabilities: Deprivation of liberty in the name of care and treatment*, in *Protecting children against torture in detention, Global solutions for a global problem*, p. 289/290, March 2017, available at: <https://www.hrw.org/news/2017/03/07/children-disabilities-deprivation-liberty-name-care-and-treatment>

scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals can be called independent living or community living arrangements. Although institutionalized settings can differ in size, name and setup, there are certain defining elements, such as: isolation and segregation from community life, lack of control over day-to-day decisions, lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences, identical activities in the same place for a group of persons under a certain authority, a paternalistic approach in service provision, supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment.[3] Institutional settings may offer persons with disabilities a certain degree of choice and control, however, these choices are limited to specific areas of life and do not change the segregating character of institutions.

No child should be placed in institution, large or small, even temporarily. Any placement of children in institutions is detrimental to their development and will never meet their best interest; detention of children in institutions constitutes cruel, inhuman and degrading treatment and can sometimes amount to torture.

Paragraph 19

Legal capacity in paragraph 19 should be extended to children who have not reached the minimum age to acquire the capacity to act.⁵ No legal capacity nor minimum age should restrict the right to independent and community living.

Suggested amendment to paragraph 19:

Article 19 explicitly refers to all persons with disabilities; thus neither legal capacity issues, including minimum age, nor the level of support required may be invoked in order to deny the right to independent and community living to persons with disabilities.

Paragraph 26

The rights to equal recognition before the law and to legal capacity are very important rights for children and should be referred to in paragraph 26. While children must enjoy legal capacity, this ability is rarely afforded to them. Children must be recognised as subject to the protection offered by the legal system and the responsibilities required by it. Under article 12, the CRC requires that States “assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child”.

This means, for example, that children who are able to form their own views should be allowed to make decisions about their health care. Children with mental health problems are very often held in institutions without their consent and may be victims of human rights abuses such as forced sterilisation and abortion, denial of essential pain relief, and the use of involuntary detention as “treatment”. Children must be allowed to express how they ought

⁵ For more information about CRIN’s approach to minimum ages, see “Age is arbitrary: setting minimum ages”, available at: <https://www.crin.org/en/home/what-we-do/policy/minimum-ages>

to be treated and be able to give an informed consent. Where a child lacks capacity to consent, any decision taken concerning the child must be taken in his or her best interests.

Suggested amendment to paragraph 26:

Legal capacity and equal recognition before the law are the basis of the realization of independent and community living for adults [and children](#) with disabilities. Article 19 is therefore linked to the recognition and exercise of legal capacity as enshrined in article 12 of the Convention and further explained in General Comment No. 1 Legal Capacity (2014) to the Convention. The recognition of choices and decisions of an individual is a precondition for living independently and being included in the community. At the same time, decisions, will and preferences and the exercise of legal capacity, are always bound to social interactions, to others within the respective community where one lives and can freely pursue one's personal development and fulfilment.

Paragraph 40 (a)

Children are entitled to be actively involved in the decisions related to their own life, including to decide where and with whom and how to live. Article 12 of the CRC recognises the value of a child's views and the need to give them weight in accordance with the age and maturity of the child. This approach clearly requires that the individual capacity of the child is taken into account, not just their age. Capacity, based on a range of factors including psychological maturity, experience and context, rather than age alone, should be determining factor in evaluating if a child has the capacity to decide.

Suggested amendment to paragraph 40 (a):

To have legal capacity to decide where and with whom and how to live is a right for all persons with disabilities, irrespective of impairment [and of age, according to the evolving capacity of the child](#);

Paragraph 42

While recognising the importance of this paragraph of the draft General Comment, calling on States to take steps for achieving de-institutionalisation in all its forms, we recommend the Committee to adopt a stronger position urging States to ban any new admission of children to those institutions. The Committee has already made recommendations to States parties to the Convention in that direction, asking for instance Guatemala to abolish the institutionalisation of children of any age.⁶ Institutionalisation of children is never in the best interest of the child. They are at greater risk of being subjected to torture and ill-treatment and require higher levels of protection than adults. Therefore we think that it would be important to reflect on that in paragraph 42, calling for a moratorium of placement in institutions as recommended by Eric Rosenthal when interpreting the thematic report of the

⁶ Committee on the Rights of Persons with Disabilities, Concluding observations to Guatemala, CRPD/C/GTM/CO/1, September 2016, para. 54 (d).

Special Rapporteur on Torture Juan E. Méndez on “torture and ill-treatment of children deprived of their liberty”.⁷

A paragraph could be added to the existing paragraph 42 on the specific question of institutionalisation of children and the responsibility of States parties to ban any new admission of children in the existing institutions while taking steps in the general de-institutionalisation process. This moratorium on new admissions should, however, never be adopted without corresponding effort in carrying out de-institutionalisation reform, which includes provision of services to families/community.

Suggested amendment to paragraph 42:

In order to achieve the realization of social and cultural rights, States parties must take steps to the maximum of their available resources (art. 2 (1) ICESCR). While full realization of the goals may be achieved progressively, steps towards it must be taken immediately or within a reasonably short period of time. Such steps should be deliberate, concrete, targeted and use all appropriate means.[5] The systematic realization of the right to independent and community living requires structural changes. In particular, this applies to de-institutionalization in all its forms. In this regard, States parties have the immediate obligation to enter into strategic planning in close and respectful consultation with representative organizations of persons with disabilities to replace any institutionalized settings with independent living and community-based services that comply with all general principles of article 3 of the Convention. The margin of appreciation of States parties is related to the mode of services but not to the question of replacement.

While taking steps in this de-institutionalisation process, States must immediately stop any new admission of children in institutions, taking into account the greater risks to be exposed to ill-treatment and torture and the higher levels of protection that they must be afforded. Moratorium on new admissions should never be adopted without corresponding effort in carrying out de-institutionalisation reform

Paragraph 43

There are 8 million children detained in orphanages and other institutions around the world⁸ and the number is likely to be higher if we take into consideration unregistered institutions and the lack of data on vulnerable children. As explained above in our comments under paragraph 15 (c), placement of children in institutions is detrimental to children’s development and we are calling the Committee to recognise in this General comment that institutionalisation of children constitutes ill-treatment and torture. Therefore we urge the Committee to acknowledge in the paragraph 43 that the lack of resources must not be accepted as an excuse for its continuation.

⁷ Eric Rosenthal, *A Mandate to End Placement of Children in Institutions and Orphanages: The duty of governments and donors to prevent segregation and torture*, p. 326/327, in *Protecting children against torture in detention, Global solutions for a global problem*, available at: http://srsq.violenceagainstchildren.org/sites/default/files/2017/Protecting_Children_From_Torture_in_Detention.pdf

⁸ Paulo Sergio Pinheiro, UN Study on Violence Against Children – Secretary General’s Study on Violence Against Children, A/61/299, 29 August 2006, available at: <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N06/491/05/PDF/N0649105.pdf?OpenElement>.

Suggested amendment to paragraph 43:

An exemption from progressive realization regarding article 19 (b) and (c) is the “minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights” incumbent upon the States parties.[6] If persons with disabilities are deprived of the core elements of independent and community living as listed in paragraph 40 of this General Comment, this counts as a failure to fulfill States parties’ obligations. States parties can only attribute the failure to meet the obligations to a lack of resources if they demonstrate having made every effort to use all resources at their disposal in order to satisfy those minimum obligations as a matter of priority.[7] Such exception to the State's’ failure to meet the obligations could not be accepted in the case of detention of children in institutions which constitutes inhuman and degrading treatment.

Paragraph 67

Access to justice is a human right, but it is also what makes other rights a reality. For children’s rights to be more than a promise, there must be a way for those rights to be enforced. The legal system must provide children the means to obtain a quick, effective and fair response to protect their rights.⁹ Children with disabilities living in institutions face increased barriers which require additional measures to guarantee their access to justice. Where violations of the rights of children take place in these facilities, the role of the institution as the legal guardian of the child and a violator of rights creates a serious barrier to children accessing justice. The existence of these facilities and children’s placement in them may constitute a rights violation in itself, but where they exist they create additional barriers to children accessing justice for rights violations that occur within them. States must adapt all proceedings to the particular circumstances of the children involved and develop a child friendly justice system that addresses children’s precarious situation in the justice system.

Suggested amendment to paragraph 67:

States parties should ensure access to justice and provide appropriate legal advice, remedies and support, including through reasonable and procedural accommodation for persons with disabilities who seek to enforce their right to independent and community living; additional measures should be taken in order to provide children with disabilities the means to obtain a quick, effective and fair response to protect their rights.

Paragraph 73

We recommend to include in paragraph 73 an explicit reference to article 7 (3) of the Convention on the Rights of Persons with Disabilities (CRPD) as the right for children with disabilities to express their views freely on all matters affecting them, and for their views to be given due weight in accordance with their age and maturity. This provision is of

⁹ CRIN, *Rights, Remedies and Representation: A global report on access to justice for children*, February 2016, available at: <https://www.crin.org/en/library/publications/rights-remedies-and-representation-global-report-access-justice-children>.

particular relevance for instance, for decisions about health care. Children who are able to form their own views should be allowed to make decisions about their health care. As explained in our comments under paragraph 26, children with mental health problems for instance, are very often held in institutions without their consent and may be victims of human rights abuses such as forced sterilisation and abortion, denial of essential pain relief, and the use of involuntary detention as “treatment”. Children must be allowed to express how they ought to be treated and be able to give an informed consent.¹⁰ Where a child lacks capacity to consent, any decision taken concerning the child must be taken in his or her best interest (CRC, art. 3).

Suggested amendment to paragraph 73:

The existence of adequate and age-sensitive support services for girls and boys with disabilities is of vital importance for equal enjoyment of their human rights (art. 7). Respecting the evolving capacities of children with disabilities and supporting them in having a say on choices that impact them, [including in decisions about their health care](#), is critical. It is also important to provide support, information and guidance to families (art. 23) to prevent institutionalization of children with disabilities and to have inclusive policies on adoption to ensure equal opportunities to children with disabilities.

Paragraph 94

As explained in our comments under paragraph 67, access to justice is fundamental in ensuring the realisation of human rights. An explicit reference should therefore be added to paragraph 94 (c) on the implementation by States parties at the national level of the right to living independently and being included in the community.

Suggested amendment to paragraph 94:

The Committee notes that States parties may face challenges at the national level when implementing the right to living independently and being included in the community. However, in line with the normative content and obligations outlined above, States parties should take the following steps to ensure the full implementation of article 19 of the Convention:

...

(c) Provide persons with disabilities with substantive and procedural rights to independent living and community living, [including access to justice and effective remedies when violations occur](#);

¹⁰ UN CRC, General Comment No. 4, paragraph 32, available at: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC%2fGC%2f2003%2f4&Lang=en