## Submission to the CRPD draft General Comment No. 7 on articles 4 (3) and 33 (3), relating to consultation and involvement of persons with disabilities, including children with disabilities in decision-making processes through their representative organizations

## By

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This submission aims to highlight how the participation of children with disabilities is addressed in the draft General Comment (GC) and to provide recommendations on how to strengthen the links with the standards of the UN Committee on the Rights of the Child (CRC) to ensure that the CRPD General Comment reaffirms the agency of children with disabilities, building on the principles and mechanisms already in place.

**Recommendations and analysis**

1. **The GC should recognise the specific challenges faced by children with disabilities**

The recognition of children with disabilities as a specific group that has its own challenges is essential

in order to call for tailored policies and measures to tackle barriers for their empowerment. Like adults with disabilities and children more generally, children with disabilities have not traditionally been viewed as ‘rights holders’. Furthermore, children with disabilities are particularly vulnerable to discrimination and experience what is called “double jeopardy”[[1]](#footnote-1): they suffer violations of their rights on the grounds of age, like other children, as well as on the grounds of their disability. They are commonly overprotected, infantilized, and denied opportunities for their emerging autonomy. Children with disabilities face greater difficulties in gaining recognition of their capacities for independent decision making[[2]](#footnote-2), and they often fall victim of the misuse of the best interests principle by their parents, medical professionals and other service providers. Therefore, it is key that the CRPD Committee highlights these specific challenges in order to promote a shift from the traditional paradigm of protection to one where children with disabilities are seen as rights-holders who are supported to have their views heard and taken into account in decisions that affect them. They should be empowered to believe in themselves, to build strength through collaboration, and to actively engage in the realisation of their rights. Although there has been greater emphasis placed on the participation of children, children with disabilities continue to have fewer opportunities to participate than their non-disabled peers.[[3]](#footnote-3)

In this vein, we recommend the creation of a new item under para 11 of the draft General Comment, highlighting these specific barriers to meaningful and safe participation of children with disabilities.

1. **The GC should promote the creation of child-led organizations and initiatives**

The CRC Committee has called on States to support children “to form their own **child-led organizations and initiatives, which will create space for meaningful participation and representation**.” Furthermore, in connection to adolescents, that Committee has stressed that “[a]dolescents can connect with peers, engage in political processes and increase their sense of agency to make informed decisions and choices, and therefore need to be supported in forming organizations through which they can participate in a variety of means, including digital media, and that “[l]egal recognition should be afforded to adolescents to establish their own associations, clubs, organizations, parliaments and forums…”.

While we appreciate the reference to “organisation of children with disabilities” in para. 22, we believe that the GC needs to go a step further to be in line with international standards on children’s right to **freedom of association** and expression as well as from one of the general principles of the CRC, children’s right to be heard. We strongly recommend that the GC reflects these standards, by including in section II.1 (para. 14) “child-led organisations and initiatives” as an additional type of “representative organisations” in order to both acknowledge children’s role in channelling the views of their constituency and in promoting their development and advocacy.

In line with the recommendation of the Special Rapporteur on the rights of person with disabilities – “States must create an enabling environment for the establishment and functioning of representative organizations of persons with disabilities as part of their obligations to uphold the right of freedom of association” – we suggest the following new text to be included:

***(additional letter): “Organizations and initiatives of children with disabilities*** *is fundamental for their participation in public and community life as well as fulfilment of their right to be heard and their freedom of expression and association. Adults have a key role to play in the creation of an environment that would enable children with disabilities to establish and act within their own organisations and initiatives, formally or informally, including through cooperation with adults and with non-disabled children”.*

1. **The GC should review the role of organisations of parents of children with disabilities and other caregivers**

While recognizing the important role of parents in promoting the participation of children with disabilities and the value of such organizations, by presenting this type of disabled people’s organisation (DPO) as the only organisation specifically related to children with disabilities, the GC does not demonstrate sufficient intent to move away from an adult-centred approach which reinforces past protectionist views, where the interests and lived experience of children with disabilities would always be best articulated by their caretakers[[4]](#footnote-4) and brings along the risk of legitimising the widespread practice of parents acting as gatekeepers, deciding on their own assessment of whether children are sufficiently mature to express themselves.[[5]](#footnote-5)

The Special Rapporteur on the rights of persons with disabilities has highlighted “**the will and preferences of the child always being respected** and their evolving capacities always being taken into account[[6]](#footnote-6)” in the context of parents and relatives organisations. Furthermore, “the role of parents in such organizations should increasingly move towards the provision of support, with self-advocates in full control.”[[7]](#footnote-7) In line with this, we recommend the following changes (in red) to the text in para 14 (e):

“**(e) Organization of parents *and caregivers* of children with disabilities** are key to facilitating, promoting and securing the interests, autonomy and active participation of children with disabilities, with the will and views of the child always being given due weigh and their evolving capacities always being taken into account. Such organisations should be included in the consultation, decision-making and monitoring of process. *The role of parents in such organizations should increasingly move towards the provision of support, with self-advocates in full control.”*

1. **The GC should recognise that children with disabilities need specific participation processes and representative organisations (different from adults’ participation)**

In defining the **concept of child participation**, the CRC has emphasized that “including children should not only be a momentary act, but the starting point for **an intense exchange between children and adults on the development of policies, programmes and measures in all relevant contexts of children’s lives**”[[8]](#footnote-8). The Committee systematically notes the essential role that many different adults (government authorities, parents, guardians, social workers, civil society, etc.) should play to facilitate the participation of children and the States’ obligation to invest in training and awareness-raising, particularly for parents and caregivers, professionals working with and for children, policymakers and decision makers[[9]](#footnote-9).

In GC 12, the CRC Committee has outlined **specific basic requirements** which have to be reached for **effective, ethical and meaningful implementation of article 12**. States parties must integrate these requirements into all legislative and other measures for the implementation of article 12 and all adults facilitating child participation processes have a responsibility in making them compliant with the Committee’s requirements. All processes in which a child or children are heard and participate, must be: (a) Transparent and informative; (b) Voluntary; (c) Respectful; (d) Relevant; (e) Child-friendly; (f) Inclusive; (g) Supported by training; (h) Safe and sensitive to risk; (i) Accountable.

Article 12 of the CRC states that a child should be heard “in any judicial and administrative proceedings affecting the child[[10]](#footnote-10), **either directly, or through a representative or an appropriate body**”. The representative can be the parent(s), a lawyer, or any another person, like for example a social worker. It is up to the child to decide if and how to be heard, although the Committee recommends that, wherever possible, the child must be given the opportunity to be directly heard in any proceedings[[11]](#footnote-11).

Children participate in activities, processes and decision-making at broadly three levels: **consultative** (adult-led), **collaborative** (adult-led but in partnership with the children so that they can influence the process) or **adolescent-led** (children design and implement the process).[[12]](#footnote-12) It is important not to perceive them in terms of a hierarchy of preference. Each level offers differing degrees of empowerment and influence, but they are all legitimate and appropriate in different contexts and can be rights-respecting provided they comply with the Committee’s basic requirements.

To ensure that the GC takes into account the complexity of the measures that different stakeholders need to take to create the opportunities for children with disabilities, including the most vulnerable children who are often left behind, to participate in a safe and meaningful way, we recommend that the GC:

1. **Builds on the features of qualitative child participation** which have beenoutlined by the CRC Committee through the 9 basic requirements for effective, ethical and meaningful participation; the GC should seize the opportunity to elaborate further guidance on how the requirements should be fulfilled by the organisations representing the views of children with disabilities. A good example would be the guidance elaborated by UNICEF in partnership with the CRPD Committee on the participation of children with disabilities, entitled “Take Us Seriously”.[[13]](#footnote-13) The GC should talk about the empowerment of childrenwith disabilities asakey outcome of participation and shouldelaborate on the measures that need to be taken to provide disability and age-appropriate assistance[[14]](#footnote-14), like the provision of sign language interpreter, material in braille, easy to read version as per art. 7(3) CRPD, and adequate support for self-advocacy such as capacity building activities for genuine and meaningful participation [[15]](#footnote-15).Additionally, it should stress the need for children’s representatives to “have sufficient knowledge and understanding of the various aspects of the decision-making process and experience in working with children”[[16]](#footnote-16). It should provide capacity building activities for their family members, teachers, disability workers, etc. to have a right based perspective on participation and for them to provide appropriate support to children with disabilities.
2. **Addresses the direct participation of individual children with disabilities:** paras 13 and 22 ofthe GC consolidate the historical limitation brought by Art. 4.3, according to which children can participate “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” only “through their representative organisations”. This limits the scope of the right to be heard as per Art. 12 CRC and Art. 7(3) of the CRPD, which states the right of children with disabilities to express their views freely on all matters affecting them and for their views be given due weight in accordance with their age and maturity. The lack of reference to children with disabilities in para 26 further weakens the right of individual children to get involved in monitoring, considering that Art. 33.3 requires people with disabilities – including children, even if not explicitly mentioned – to be involved in the monitoring process *alongside*, that is, in addition to, their representative organizations rather than only *through* these organizations.
3. **Acknowledges and elaborates on the role that civil society plays in facilitating child participation**: in defining what constitutes “representative organisations” as referred to in Articles 4.3 and 33.3 of the CRPD, the GC makes the term a synonymous of “disabled persons organisations (DPOs)/organizations of persons with disabilities (OPDs)” by using the expression “or in other words”. It then defines what a DPO/OPD is by enumerating a series of different types of organisations. Child rights organizations who in most of the time work directly with children with disabilities, including those who do not have parental care and those who are not part of child-led organisations and DPOs, do not fall within the category of DPOs but nevertheless play a key role in empowering, defending and promoting the views of children with disabilities themselves in decision making. While it is legitimate to differentiate between DPOs and civil society organisations, and while reinforcing that organisations led by children with disabilities and DPOs are primary representatives, child rights organisations are often in a position to support children with disabilities to represent themselves, like for example when children with disabilities are not in parental care or in absence of child led organisations. It is important to acknowledge that children with disabilities can and may choose such organisations to support “their representation” when it comes to their right to participate, not only in monitoring but also in implementation and other decision-making processes (as the CRPD Committee notes in para 26 “The Committee stresses that article 33.3 requires that persons with disabilities be allowed to participate separate from the participation of DPOs, if they so choose”).
4. **The GC should refer to the principle of the best interests of the child** (Art. 7(2) and elaborate on its interdependence with the right to participate, by building on the CRC standards included in GC 12 and 14. The latter, clearly states that:

“any decision that does not take into account the child’s views or does not give their views due weight according to their age and maturity, does not respect the possibility for the child or children to influence the determination of their best interests.

The fact that the child is very young or in a faces greater risk of discrimination (e.g. has a disability, belongs to a minority group, is a migrant, etc.) does not deprive him or her of the right to express his or her views, nor reduces the weight given to the child’s views in determining his or her best interests. The adoption of specific measures to guarantee the exercise of equal rights for children in such situations must be based on an individual assessment which assures a role to the children themselves in the decision-making process, and the provision of reasonable accommodation and support, where necessary, to ensure their full participation in the assessment of their best interests”.

Given the concept of the best interests being subjected to different interpretation (which is “a primary” consideration in all actions concerning children with disabilities) as well as the challenging practices in determining the best interests of the child or group of children, the GC should recommend measures to ensure that the best interests is not used by adults, especially parents, as a reason to hinder the participation of children with disabilities.

**Suggested changes in the text:**

**Para. 22**

22. The importance of “*including children with disabilities*” in the development and implementation of legislation and policies to implement the Convention, and in other decision-making processes, *through organizations supporting children with disabilities or of children with disabilities* and organizations of parents of children with disabilities is also implied in article 4.3. These organizations are key to facilitating, promoting and securing the individual autonomy and active participation of children with disabilities. *States must create an enabling environment for the establishment and functioning of representative organizations of children with disabilities as part of the States obligations to uphold the right of freedom of association.* Through their DPOs/ODPs, children with disabilities should be able to express their views freely on all matters affecting them, their views should be given due weight in accordance with their age and maturity, on an equal basis with other children, and children with disabilities should be provided with disability and age-appropriate assistance to realize that right. The will and preferences of the child must always be respected, and their evolving capacities always be taken into account. The recognition *and promotion* of the right to individual autonomy is of paramount importance for all persons with disabilities, including children, to be respected as rights holders.

**Para. 56**

Articles 4.3 and 33.3 are fundamental for the implementation of the rights of children with disabilities as stated in article 7 of the Convention. *Children with disabilities suffer double discrimination, due to their condition as a disabled person and the fact that they are children. Therefore, States should take steps to ensure the* participation and the active involvement of children, through their DPOs/OPDs, in all aspects of planning, implementation, monitoring and evaluation *of all relevant legislation, policies, services and programmes affecting their lives, at school and at the community, local, national and international levels. The ultimate goal of participation is empowerment for children with disabilities and recognition by duty-bearers that they are rights holders who can play an active role in communities and society. This takes place at different levels, beginning with the recognition of their right to be heard moving towards their active engagement in the realisation of their own rights.[[17]](#footnote-17) State parties should provide children with disabilities with support in their decision-making, including ‘*equipping children with disabilities with, and enabling them to use, any mode of communication necessary to facilitate the expression of their views’[[18]](#footnote-18), including *child-friendly information, adequate support for self-advocacy as well as to ensure appropriate training for all professionals working with, and for children with disabilities.[[19]](#footnote-19) States should also provide disability and age-appropriate assistance and procedures, and non-conditional support for children with disabilities and, when appropriate, children with disabilities themselves and* their families must be recognized as partners and not merely recipients of education.[[20]](#footnote-20) The participation of their DPOs/OPDs should be considered a requisite in consultations addressing specific issues that concerns them, and their views given due weight in accordance with their age and maturity.

1. Gerison Lansdown, *Th e Evolving Capacities of the Child*, UNICEF/Save the Children, Florence, 2005. [↑](#footnote-ref-1)
2. Gerison Lansdown, Making a case for a dedicated Article for children with disabilities, in Human Rights and Disability Advocacy, Sabatello & Schulze. [↑](#footnote-ref-2)
3. Council of Disabled Children, “A literature review on the participation of disabled children and young people in decision making”. [↑](#footnote-ref-3)
4. Ibid. [↑](#footnote-ref-4)
5. See Byrne, “Minding the Gap? Children with Disabilities and the United Nations Convention on the Rights of Persons with Disabilities” and Sandland, “A Clash of Conventions? Participation, Power and the Rights of Disabled Children”. [↑](#footnote-ref-5)
6. A/HRC/31/62, para. 36. [↑](#footnote-ref-6)
7. Report of the Special Rapporteur on the Rights of Persons with Disabilities (2017), para 37. [↑](#footnote-ref-7)
8. General Comment 12 CRC, para 13. [↑](#footnote-ref-8)
9. General Comment 20 CRC, para 25. [↑](#footnote-ref-9)
10. Including, for example, “decisions about children’s education, health, environment, living conditions, or protection”. General Comment 12 CRC, para 32. [↑](#footnote-ref-10)
11. General Comment 12 CRC, para 35. [↑](#footnote-ref-11)
12. Lansdown G & O’Kane C (2014) A Toolkit for Monitoring and Evaluating Children’s Participation, Save the Children et al, London. [↑](#footnote-ref-12)
13. Take Us Seriously, Available at [www.unicef.org/disabilities](http://www.unicef.org/disabilities). [↑](#footnote-ref-13)
14. Take Us Seriously gives practical suggestions in this regard. [↑](#footnote-ref-14)
15. General Comment 12 CRC, para 34. [↑](#footnote-ref-15)
16. General Comment 12 CRC, para 36. [↑](#footnote-ref-16)
17. UNICEF, “Conceptual framework for monitoring outcomes of adolescent participation”, 2017. [↑](#footnote-ref-17)
18. General comment 12 CRC, para 21. [↑](#footnote-ref-18)
19. General comment 12 CRC, para 34. [↑](#footnote-ref-19)
20. General comment 4 CRPD, para. 7. [↑](#footnote-ref-20)