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**Submission**

**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**

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**1. Comments:**

*"Full and effective participation"* of persons with disabilities and their representative organizations entails that States parties' decision-makers give due weight and consideration to the contribution of persons with disabilities and their representative organizations in deliberations and decision-making processes affecting their lives by explaining how and why (or why not) their contribution was taken into account and how it has influenced outcomes. Following close consultations and active involvement of persons with disabilities and their representative organisations, persons with disabilities and their representative organisations are entitled to this form of reasoning which represents a *conditio sine qua non* for full and effective participation and needs to be seen as part of the normative content of articles 4.3 and 33.3 CRPD.

Full and effective participation can be described as comprising three basic dimensions, (1) an input dimension, (2) a throughput dimension and (3) an output dimension. The input or access dimension concerns the question of how participants gain access to and can be present at deliberations and decision-making processes affecting their lives. The throughput or process dimension concerns the active involvement in deliberations and decision-making processes. The output or impact dimension concerns the question of how the contribution of participants was taken into account and to which extent it influenced the outcome. The third dimension, the output dimension, is necessary to move the participation of persons with disabilities and their representative organisation beyond tokenism. The explanatory reasoning described above is indispensable to validate the impact dimension.[[1]](#footnote-1)

All three dimensions depend on enabling conditions. Socioeconomic and political arrangements are needed that create and sustain spaces and fora for deliberation and public reasoning on legislation and policies affecting the lives of persons with disabilities. Socioeconomic and political arrangements are further required to develop and build up participatory capabilities of persons with disabilities and those of their representative organizations. States parties contribute to the development of such participatory capabilities by meeting their human rights obligations vis-à-vis persons with disabilities.

The model of full and effective participation presented here is summarized in the following Table 1:

**Table 1: Effective and Full Participation**[[2]](#footnote-2)

 *Source:* Bundschuh (2018)

**2. Recommendations:**

**Recommendation 1:**

**Insert letter "A" (in red) between paragraph 12 and paragraph 13:**

II. Normative content of articles 4.3 and 33.3

A. Definition of ‘representative organisations’

**Recommendation 2:**

**Insert new paragraph 24a (in red) after paragraph 24:**

**24a.** Full and effective participation means that participants are entitled to be informed about how their contributions have been taken into account and how they have influenced outcomes of deliberations or decision-making process affecting their lives. Participants should be provided with an opportunity to challenge the justification of any outcomes.[[3]](#footnote-3)

**Recommendation 3:**

**Insert at the beginning of paragraph 25 the phrase in red and keep the remainder of paragraph 25:**

**25**. If and when contributions of persons with disabilities and their DPOs/OPDs are given due weight and consideration, full and effective participation can be a transformative tool for social change, promote agency and empowerment of citizens…..

**Recommendation 4:**

**Insert or change phrases in red in paragraph 34 and keep the rest (in black):**

**34.** Persons with disabilities, through their DPOs/OPDs, can only effectively participate if and when their views are given due weight and consideration, thereby guaranteeing that they are not only heard as a mere formality or as part of a mere tokenistic approach to consultation.[[4]](#footnote-4) [Furthermore, their views should be considered as no less important than other actors, under article 4.3 (see para. …)]. States parties' decision-making actors should "take into account the results of such consultations and reflect them in the decisions adopted,"[[5]](#footnote-5) by duly informing participants of the outcome of the process. This includes that States parties' decision-making actors explicitly explain, in the findings, considerations or reasoning of decisions, how and why participants' views were considered and how their contribution has influenced the outcome and why.[[6]](#footnote-6)

**Recommendation 5:**

**Insert a new paragraph 64a (in red) after paragraph 64:**

**64a**. To ensure the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (art. 25), States parties must consult with and actively involve persons with disabilities, including children with disabilities, through DPOs/OPDs, in all aspects of planning, implementation, monitoring and evaluation of inclusive health legislation, policies and services. Persons with disabilities and, when appropriate, their families, should be recognized as partners and not merely recipients of health care and be ensured their right to be heard and to have their views be given due weight and consideration.

[15 May 2018]

1. In the context of participation, the question of tokenism and the question of impact or control are not new questions. See Arnstein, S. R. (1969). "A Ladder Of Citizen Participation", *Journal of the American Planning Association*, 35 (4): 216 - 224. [↑](#footnote-ref-1)
2. For the concept of participatory capabilities, see Bundschuh, T. (2015). "Enabling Transitional Justice, Restoring Capabilities: The Imperative of Participation and Normative Integrity." *International Journal of Transitional Justice*, 9(1): 10 - 32 [↑](#footnote-ref-2)
3. See CRC/C/GC/12, para. 134(i). [↑](#footnote-ref-3)
4. See CRC/C/GC/12, para. 132. [↑](#footnote-ref-4)
5. See CRPD/C/COL/CO/1, para. 11(a). [↑](#footnote-ref-5)
6. See CRC/C/GC/12, para. 45. [↑](#footnote-ref-6)