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### **Inclusion International and Down Syndrome International Joint Response to Draft General Comment (GC) No.7 on Art. 4.3 + Art. 33.3 CRPD: Participation of Persons with Disabilities in the Implementation and Monitoring of the Convention.**

## **Submitted to the UN Committee on the Rights of Persons with Disabilities**

## **Introduction**

Inclusion International (II) welcomes the strong and comprehensive draft General Comment (GC) on the participation of persons with disabilities in the implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities (CRPD). Inclusion International is the global network of people with intellectual disabilities and their families. Our global network works to advance the human rights and full inclusion of people with intellectual disabilities and their families around the world. With over 200 member organizations in 115 countries throughout five regions, Inclusion International is uniquely positioned to highlight the issues people with intellectual disabilities and their families experience in relation to participation.

CRPD Articles 4.3 and 33.3 create an obligation for States Parties “to *closely* consult with and *actively* involve persons with disabilities through their representative organisations” not only “in the development and implementation of *legislation* and *policies* to implement” the CRPD, but also “*in other decision* – *making* processes concerning issues relating to persons with disabilities.” The draft GC interprets these obligations in a very comprehensive way by stating that there is no space to exclude persons with disabilities from one of the basic principles of the CRPD: to guarantee “full and effective *participation* and inclusion” of persons with disabilities “in society” (Art. 3 c. CRPD). The draft GC reflects that organisations representing persons with disabilities should have the scope to influence the implementation of the CRPD in the fields of law and politics and in all other fields where decisions are made which directly or indirectly affect persons with disabilities.

For Inclusion International and our members, participation of persons with intellectual disabilities and their families in the implementation and monitoring of the CRPD is fundamental to securing the rights and inclusion of persons with intellectual disabilities and their families.

We support the need for this important general comment and its alignment with the demands expressed by the disability community: ***Nothing about us without us!***

We welcome the opportunity to provide some comments and feedback on ways in which the draft GC can be strengthened to better reflect the unique needs of persons with intellectual disabilities and their families.

Inclusion International has contributed to the development of the submission of the International Disability Alliance. Our submission is also intended to complement the submission from Inclusion Europe. We support and endorse the recommendation brought forward in both of those submissions. To avoid duplication of efforts, we restrict our submission to a summary of issues which are of utmost importance for people with intellectual disabilities and their families.

## **Key Messages for the General Comment**

**Inclusive Participation essential for Meaningful Participation**

Too often, persons with intellectual disabilities and their families are marginalized and excluded from having a say. They are voiceless and as a result invisible in legislation, policies and other decision-making processes. Inclusive participation is critical for ensuring that people with intellectual disabilities have meaningful opportunities to be involved. Without the participation of persons with intellectual disabilities and their families, communities CANNOT effectively or adequately organize themselves in ways that are responsive to, and reflective of, their needs. Inclusive participation provides opportunities to ensure that our voices are heard on the issues that matter to us. It is essential that the draft GC reflect the unique needs of persons with intellectual disabilities to have access to information in plain language. **We call on the Committee to demonstrate leadership in this area by committing to undertake inclusive consultations and providing General Comments in plain language.**

**Recognition of Families**

Families are the cornerstone of our communities. For all people, families should be a source of support and strength. For us, “families” refers not only to parents and siblings but to the extended family and those with whom a person chooses to share his or her life. It includes families where the parent is a person with intellectual disability. Around the world, families are the main source of support for persons with intellectual disabilities. Often, it is families that are the key to facilitating their sons’ and daughters’ inclusion in community and securing their rights.

The draft GC’s current definition of “representative organizations” is too narrow and misses the valuable role that families play in the lives of persons with intellectual disabilities and other cognitive impairments like dementia. While the voice of families should never substitute the voice of persons with intellectual disabilities, the existence of self-advocacy organizations does not negate the need to include families. In keeping with the recognition of families in the CRPD preamble and with support from the International Disability Alliance and the European Disability Forum, we ***recommend the GC define the term “representative organisations” by including an additional section after section 14 e as follows:***

***“Organisations of persons with intellectual disabilities composed and governed by persons with intellectual disabilities and family members.”***

Such a section would also be in line with section 17 of the CRPD´s Committee General Comment No.6 on equality and non - discrimination which claims that the protection against discrimination (Art. 5 CRPD) “includes persons with disabilities *and their associates”,* which are not only parents of children with disabilities,but also family members and peers.

### **Specific Comments on the Draft General Comment**

**Definition of the term “representative organisations” in Art. 4.3 CRPD**

In addition to the recommendation to include a specific section on families following 14 e., we call for the committee to reconsider 14 d. on self-advocate organizations.

We welcome the Committee’s efforts to explicitly recognize self-advocacy organizations. In many countries it remains difficult for groups of self-advocates to organize and seek legal status. However, the current paragraph could be interpreted to mean that self-advocacy organizations are separate from DPOs. While the paragraph provides valuable reflection on the need for support, we encourage the committee to include this reflection in a new section under paragraph 14.a to ensure that self-advocacy organizations are recognized as DPOs. A new section should be revised to reflect that self-advocacy groups may take the shape or organizations, networks of platforms. Additionally, the focus should be on groups of persons with intellectual disabilities. We support and emphasize the point from the submission of the International Disability Alliance that: *“****persons with psychosocial disabilities****, currently included in para. 14(d), do not identify themselves as “self-advocates”, providing their rationale.[[1]](#footnote-2) IDA believes that* ***the reference to that particular group in para. 14(d) should be removed*** *in line with the view and self-organisation and identification.”*

ADD: 14(a)(iv):Self-advocacy organisations, networks and platforms are groups of persons with intellectual disabilities who advocate for their rights and the rights of other persons with intellectual disabilities. Self-advocate organisations, platforms and networks are an important part of OPDs/DPOs. In many countries self-advocacy organisations are discriminated against and are refused legal status because of laws which deny the legal capacity of their members or require the fulfilment of criteria such as official registration by a court as a legal entity which due to high registration costs or rather complicated and complex application forms usually cannot be met by self – advocate organisations. They are of fundamental importance to political participation particularly for persons who are denied the right to vote, prevented from exercising legal capacity and/or are institutionalised. Their establishment, with appropriate, sometimes extensive, support to express their opinions, is indispensable to guarantee their participation in decision-making, monitoring and implementation processes. Such support includes any necessary form of reasonable accommodation.

**Umbrella organisations of persons with disabilities**

The recommendation “to support the establishment of preferably one single umbrella DPO/OPD which coordinates and represents the activities *of a number of single* DPOs/OPDs of persons with *different disabilities,* to ensure the inclusion and full participation of persons with *all kinds of disabilities* in the monitoring process” (s. 75 d Draft GC No.7) assumes the umbrella organization will have the capacity and representational authority to speak with one voice. However, as long as persons with intellectual or psychosocial disabilities or persons with dementia are deprived of their right to exercise legal capacity by guardianship laws and comparable laws and practices many of them are not in the position to form a group or organisation to influence the activities of a national umbrella organisation of persons with disabilities. Without effective and meaningful participation by all groups, the umbrella organization will not have the credibility or legitimacy to speak as one voice.

**Consultative status of DPOs representing persons with disabilities.**

Art. 4.3 CRPD is of utmost importance to put pressure behind States Parties to implement the CRPD at global, regional, national and local level, but it should not remain unmentioned that there are limits with regard to the lobbying permissions and capacities of global, regional and national DPOs. Some governments have started to control all kinds of NGOs; some went some steps further and started to prohibit NGOs which receive support from abroad. Even the UN carefully observes which kind of NGO should be allowed to enter the UN – headquarters, to speak up, to organize side events, to send and receive documents etc. by granting so – called *consultative status*. United Nations Economic and Social Council (ECOSOC) is the UN Body responsible to check whether NGOs / DPOs meet the criteria for consultation. As far as global and regional DPOs are concerned ECOSOC seems to be fairly generous, but this can change. The best way to secure DPOs´ influence is the quality and expertise offered by global, regional and national DPOs. NGOs derive their authority not simply from their existence, but from their individual qualities. International decisions taken without the input of NGOs risk remaining unimplemented because they lack the required degree of public support.

**Establishment of legal and regulatory frameworks and procedures across all levels and branches of government to successfully implement Art. 4.3 CRPD.**

According to s.18, s.38 and s.75 e) Draft GC No.7 States Parties are obliged to adopt legislation which guarantees that all public authorities and decision – making bodies closely consult with and actively involve persons with disabilities in the fulfilment of Art. 4.3 CRPD and in the monitoring process under Art. 33.3 CRPD.

It would be worthwhile to add some examples showing that it is necessary, for instance, to provide legal frameworks which prescribe legally binding public hearings of organisations representing persons with disabilities by national parliaments, ministries and public decisions – makers with regard to all draft laws and political issues which directly or indirectly affect persons with disabilities. And it should be mentioned that such an obligation is not limited to federal laws and political activities, but includes the development and implementation of legislation and policies at all levels of state/provincial laws and laws of municipalities with regard to persons with disabilities.

It´s a complex task to establish legal and regulatory frameworks to implement Art. 4.5 + 33.3 CRPD, if States Parties do not act exclusively on the basis of centralized laws and policies, but have to share rights, obligations and public competences with states/province governments and local authorities.

**Effective remedies and complaint mechanisms linked to Art. 5 CRPD (Equality and non – discrimination) to enforce States Parties to implement Art. 4.3 + 33.3 CRPD.**

The Committee is very well aware of the fact that the effective inclusion of organisations representing persons with disabilities in the development and implementation of legislation and policies as prescribed in Art. 4.3 CRPD will work in many countries only, if legal remedies and complaint mechanism are available. It is, therefore, stated in s.29 and s.48 Draft GC No.7 that such legal instruments should be provided by States Parties and “include the effect of *nullification* of decisions in cases where they have been adopted in breach of Art. 4.3 of the Convention by not ensuring close and timely consultation and active involvement of DPOs/OPDs complying with the duties, requirements and features put forward in this General Comment.”

It´s a strong and important demand, but the question is how these remedies and complaint mechanisms should be structured to become effective at all federal, states/provincial and local levels of the States Parties concerned. One solution could be to add such legally enforceable means and appeals to each law (be it a federal, provincial or local one) regarding directly or indirectly persons with disabilities and/or to provide sanctions, if public authorities planning policies which directly or indirectly affect persons with disabilities ignore or neglect to closely consult or actively involve persons with disabilities. But such solutions do not seem to be practical in particular within States with complex structures differing between federal, provincial and local competences.

Another solution could be the development of anti – discrimination laws as mentioned and described under section 72 b of General Comment No.6 on Equality and Non – discrimination adopted by the CRPD Committee on March 9, 2018. According to Art. 2 + Art. 5 CRPD persons with disabilities can claim to be discriminated against and to ask for protection in all cases and situations where the facts presented allow the assumption that the human rights of persons with disabilities as laid down in the CRPD are *not* recognized “on an equal basis with others”. Such anti – discrimination laws should “have a broad personal and material scope and *provide effective legal remedies”* (s.72 b GC No.6). As far as organisations representing persons with disabilities are concerned such laws can be applied only, if not just individuals with disabilities, but also organisations/associations representing these persons are entitled to start legal actions against third parties with reference to the obligation of States Parties to prohibit all forms of discrimination based on disability. So far there are only a few countries allowing so – called class – action lawsuits combining claims of individuals based on identical or similar factual backgrounds. The CRPD Committee expressively supports such actions by stating in its General Comment No. 6 on equality and non – discrimination: “The recognition of legal remedies of a *collective nature or class actions* can significantly contribute to effectively guaranteeing access to justice in situations that affect *groups* of persons with disabilities” (s.72 h GC No.6).

Submitted by Inclusion International and Down Syndrome International, 15 May, 2018

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1. See e.g. submission to this draft general comment by Center for Human Rights of Users and Survivors of Psychiatry and the Absolute Prohibition Campaign. [↑](#footnote-ref-2)