**Submission of COFACE Families Europe to the UN CRPD Committee on the 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 organisations**

# Introduction

1. COFACE Families Europe very much welcomes the draft General Comment (GC) on Articles 4(3) and 33(3) of the UN Convention on the Rights of Persons with Disabilities (CRPD). COFACE Families Europe is a pluralistic network of civil society organisations representing the interests of all types of families. With 59 member organisations in 23 Member States of the EU, COFACE Families Europe represents more than 25 million families. We appreciate the opportunity to share the views and remarks of COFACE Families Europe and its COFACE Disability branch on the consultation and involvement of persons with disabilities, including children with disabilities in decision-making processes through their representative organizations.
2. COFACE Families Europe advocates for policies of non-discrimination and equal opportunities between persons and between family forms, and specifically supports policies aimed at increasing equality between women and men, with a special focus on reconciliation between work, care and family life. COFACE’s focus is essentially on policies and legislation that impact the lives of children and families, in particular in the fields of social protection and inclusion, safeguarding the rights of persons with disabilities and persons with support needs, prevention and fighting child poverty, migration, inclusive education, early childhood education and care, parenting support services to families, information and communications technologies. COFACE holds a special consultative status at the Economic and Social Council of the United Nations. More information is available at: <http://www.coface-eu.org/>

# General comments

1. COFACE Families Europe compliments the CRPD Committee for linking Articles 4(3) and 33(3) in one General Comment. These two provisions interlink and explicitly require the involvement of persons with disabilities and their representative organisations in law and policy‐making, as well as in monitoring the implementation of the CRPD.
2. COFACE Families Europe would like to emphasise that in line with the Preamble of the CRPD, **family members should be empowered and supported to become facilitators of the social inclusion and development of their relatives with disabilities**. Thus, we find very unfortunate the overly negative language used in the draft GC referring to the involvement of family members in consultations that affect the lives of their children and relatives with disabilities. Families should not be considered as third parties (e.g. in Para 37) which people with disabilities deserve protection from. While recognising the need to
* protect persons with disabilities from domestic abuse and violence;
* ensure more independence from families in adulthood and
* the importance of giving priority to the voice of DPOs over the organisations for persons with disabilities on matters affecting their lives,

the current wording of the draft GC may be interpreted in a negative way towards families, enhancing some of the prejudices and discrimination they are subjected to. Moreover, the **right of children to be included in decision-making processes should be better mainstreamed throughout the GC**.

1. Unfortunately, the draft GC does not take into account the diversity of the disability movement and DPOs when detailing States Parties’ obligations to ensure the full consultation and involvement of the representative organisations of persons with disabilities (except listing briefly in para 36 the different groups that face particular challenges). **Disability movements can be fragmented and especially the voice of persons with complex needs, intellectual disabilities, psychosocial disabilities, and people on the Autism spectrum are often missing from the day-to-day advocacy work of umbrella DPOs**. Persons with disabilities with HIV/AIDS, with migrant background, or those belonging to an ethnic group face multiple discrimination and thus should be consulted and involved in decision-making processes in a broader sense. Families of children with intellectual disabilities, or of children with multiple disabilities and complex needs play an extremely important role in bringing the -otherwise neglected- voice of their children to discussions at law and policy-making levels. If umbrella DPOs are not established in a fully inclusive and participatory way, they do not automatically represent the interest of persons with **all types of impairments**. Furthermore, there can be disagreement within the disability movement around certain matters (e.g. on inclusive education, use of assistive devices etc.).
2. Considering the long-term exclusion of persons with disabilities and their families from societies, **DPOs need extensive capacity building to impact successfully more complex decision-making processes** (e.g. legislative reform of the civil code, or revision of the social protection system). The GC should provide detailed analysis on the necessary resources (both financial and other forms), accessibility requirements, as well as the capacity building and human rights training needed to empower all persons with disabilities, so they can participate in policy and decision-making processes in a meaningful way. For instance, it’s not enough to mention easy-to-read format, but it would be necessary to provide details on whether all documents produced in public administration should be published in easy language, or not.
3. It would be useful if, beyond describing the principles of Articles 4(3) and 33(3) of the CRPD in detail, the GC provided **more concrete guidance** to States Parties on how to implement these provisions in a CRPD compliant way and where to put their **funding priorities** when it comes to enhancing the participation of persons with disabilities. Both Articles 4(3) and 33(3) of the CRPD include important provisions to narrow the implementation gap and to stimulate change in the operations of States and the human rights regime. Through these guarantees, the Convention aligns with the domestic level and could become a real instrument for persons with disabilities. The organisations of persons with disabilities are expected to use the participatory provisions for advocacy purposes, as the provisions entitle them to act as a channel between policy-makers and the human rights regime in enforcing Treaty provisions. **The GC should therefore provide a realistic, informative and useful guidance to States Parties on what requirements they should respect in order to involve the representative organisations of persons with disabilities in a meaningful way** in law, policy and decision-making processes, as well as in the monitoring of the implementation of the Convention. Without listing the concrete measures and prerequisites, States Parties will not be able to meet with the complex requirements of Articles 4(3) and 33(3). The draft GC is discussing the issue of participation in a very general manner, referring to ‘all policies and programmes’ and ‘all decision-making processes’. We encourage the Committee to revise the draft GC, shorten it and include parts that provide more concrete information and guidance to States Parties on this very important issue.

# Substantive comments

1. Beyond the already mentioned elements, **Para 11** should include a reference to the lack of mechanisms that would ensure that the participation of persons with disabilities and their representative organisations has an impact on the outcome of policy and decision-making processes and consultations are not tokenistic.
2. It would be useful to mention in **Para 11** the **fragmentation of disability movements as a remaining implementation gap,** because in some States Parties measures would be needed to support the capacity building of umbrella DPOs to ensure their operation is inclusive towards persons with all types of impairment and support needs. Historically, persons with physical and sensory impairments played a greater role in setting up advocacy groups, while other groups (e.g. persons with intellectual, or psychosocial disabilities) would still need additional support to take up an equally active role in the work of DPOs and represent themselves. This can be achieved through the introduction of concrete accessibility measures and reasonable accommodation. Furthermore, members of DPOs may not be automatically aware of the human rights of other marginalised groups, therefore all DPOs should be provided with free, or affordable trainings on the rights of e.g. LGBTQI people, ethnic and minority groups, migrants and refugees, women etc.
3. Under **Para 14 (e**), we appreciate that the Committee acknowledges parents as key actors in facilitating, promoting and securing the interests, autonomy and active participation of their children with disabilities. As a result of the lack of community-based public services, parents, and other relatives very often become family carers and provide unpaid informal care and support to their relatives with complex needs. This situation undermines the social inclusion (poverty risk), health (physical and/or mental exhaustion) and gender equality (most family carers are still women) of these families. Family carers, including siblings and other relatives not only play an important role in supporting children and adult relatives with disabilities, but need support and protection against burnout and poverty themselves. Thus, we suggest to modify the wording of Para 14(e) to the following: **Organisations of** ~~parents of children with disabilities~~ **family members of persons with disabilities** are key to promoting ~~and securing the interests, autonomy and active participation of their children with disabilities~~ and supporting autonomy and active participation of their relative(s), and advocating for their own support needs and should be included in the consultation, decision-making and monitoring processes.
4. It is important to distinguish between organisations ‘of’ and ‘for’ persons with disabilities. We suggest adding to the wording of **Para 15** that ‘organisations “of” persons with disabilities, which are composed of and controlled/led by persons with disabilities **in majority**’. The proposed wording by the Committee would exclude many existing regional and national umbrella DPOs from being considered as DPOs, as they often have persons without disabilities in their membership. The Committee should refrain itself from imposing restrictions on the composition of DPOs that potentially negatively affect the participation of existing representative organisations (where the majority of the membership is composed of persons with disabilities, who are leading the organisation, but there are also some non-disabled members, e.g. parents) at national and local level.
5. We recommend that the organisations of **families of persons with disabilities** should be recognised in **Para 15** of the draft GC as a type of organisation for persons with disabilities along with service providers.
6. The definition to distinguish NGOs from CSOs, provided in the draft GC is inadequate and incorrect, e.g. in **Para 16**: ‘CSOs are very closely related to NGOs and other bodies’. We suggest the Committee to elaborate on the definition. Nevertheless, families are outside of the definition of CSOs, but family organisations are integral part of civil society.
7. It would be useful to include in **Para 30** a list of criteria on what constitutes close and meaningful consultation and active involvement of persons with disabilities.
8. We recommend amending the text in **Para 33** from ‘[In addition, in line with the basic principle of good governance and international law, States parties must **have political commitment to** consult and engage with DPOs/OPDs ~~in good faith~~. Acting truthfully and fairly with each other, should be a foundational stone of all State party actions during processes of dialogue and consultation with DPOs/OPDs.]’.
9. The language used in **Para 37** is very problematic and unhelpful, thus we call the Committee to revise the wording and change it to a more constructive one. Instead of calling States Parties to ‘take measures to prevent family members from directly or indirectly interfering with DPOs’, the GC should call States Parties **to provide accessible, affordable and good quality community-based services and family support to families of persons with disabilities**. Family support is key to allow persons with severe, complex disabilities to live in the community and to prevent their institutionalisation. Furthermore, families play an important role as facilitators of the social inclusion and development of their relatives with disabilities, especially for children with disabilities, therefore they should have good relation and active collaboration with DPOs to work together towards the protection of the rights of persons with disabilities. In our view, it’s neither realistic, nor helpful that the CRPD Committee is calling for legislation and policies that would ‘prevent persons with disabilities from being undermined by their family members’. Persons with disabilities, just like anyone else should be empowered to enjoy autonomy and to be able to have choice and control over their lives. People should be protected from all forms of violence and abuse, including domestic violence and oppression. Thus, persons with disabilities and their family members should have **access to human rights awareness training** to be able to live in dignity.
10. The CRPD Committee should clarify that **Para 40** reflects directly to the monitoring and evaluation of the CRPD in line with Article 33(3) and in this case, indeed, priority should be given to the voice of DPOs. Otherwise, the Committee should be careful calling policy makers for giving priority in monitoring ‘all policies and programmes’ to the voice of persons with disabilities over other marginalised groups, e.g. ethnic minorities, women, children etc., as the voice of different target groups should be equally taken into account.
11. In **Para 42**, the distinction between the participation of DPOs and the involvement of citizens with disabilities in civil society organisations should be strengthened. Persons with disabilities may want to get involved in civil society organisations, or to be consulted on matters that do not closely relate to their impairment. They should receive support and be provided with accessibility, or reasonable accommodation in those cases too. A separate paragraph should discuss the issue of **representativity** and the right of persons with disabilities to participate in decision-making, outside of DPOs, as the voice of persons with disabilities who wish to be associated with mainstream CSOs (e.g. advocating for sexual and reproductive rights), should also be considered by policy makers.
12. **Para 42 and 44** refer to ‘non-conditional funding’ to be provided to DPOs. We would be careful calling States Parties to provide non-conditional funding to certain civil society organisations. Civil society organisations, including DPOs do not necessarily carry out work that fully complies with human rights standards, therefore conditions in accessing funding can serve the purpose of increasing accountability, quality of work and compliance with human rights. Non-conditional funding could potentially also create inequalities within the civil society sector which would hinder the intention of creating strong and accountable civil society in all States Parties representing the interest of all citizens in marginalised situations. Funding should be adequate, accessible and independent (i.e. do not impose any limitations in the work plan and output of DPOs/NGOs).
13. In **Para 62**, it would be useful to include a reference to the involvement of persons with disabilities in planning, implementing and monitoring deinstitutionalisation projects, and in the development of community-based services, with special regards to those people, who are currently living in institutional settings in some States Parties.
14. We compliment the Committee for including more detailed and useful information on how to implement Articles 4(3) and 33(3) successfully in **para 75.** However, we recommend re-phrasing point a) of this paragraph as it refers to the 'right not to be confined as a form of isolation in the family’, which implies that living with one’s family would automatically result in isolation. COFACE Families Europe is a strong supporter of ensuring that persons with disabilities can choose where and with whom to live and be included in the community. However, in reality, many persons with disabilities have nowhere else to live, but with their family, as a result of the lack of supported housing, or due to economic reasons (e.g. challenges in accessing the open labour). Some persons with disabilities prefer to live with their family, be their parents, or their own partners, children and that choice must be respected too. In these cases, families also play an important role in preventing the institutionalisation of persons with disabilities. Family carers who have to quit their jobs often face poverty and various burdens, due to the lack of community-based support services for persons with disabilities. The text of the GC should reflect on **the need to provide support for persons with disabilities and their families, so they can live in dignity where and with whom they want.**
15. It would be useful to add to **Para 75** the following elements:
	1. Persons with disabilities and their representative organisations should be **involved from very early stages of the policy process to be able to influence decisions from the beginning**. It’s tokenistic to consult with them on draft proposals only at later stages in the policy process.
	2. The work of the CRPD monitoring framework until Article 33(2) should be **continuously monitored to ensure that the involvement** of persons with disabilities and their representative organisations **is meaningful**.
	3. **Political commitment** of policy and decision-makers and other actors involved in monitoring the CRPD is key to ensure the active and effective participation of persons with disabilities and their representative organisations. This should happen through building good personal relations between DPOs and actors in the State, NHRIs as well as civil society organisations.

# Conclusions

1. Once again, we would like to thank the Committee for drafting the General Comment on Article 4(3) and 33 of the CRPD and hopefully the Committee will find our comments and feedback useful. We are looking forward to reading and using the final version of the General Comment.

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