

## Annex DOC 11-18-11

### EDF Communication on General Comment No. 7 on the participation of persons with disabilities in the implementation and monitoring of the Convention

In September 2018, the UN Committee on the Rights of Persons with Disabilities (CRPD Committee) adopted “General Comment No. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organizations”. The General Comment elaborates on articles 4.3 and 33.2 of the UN Convention on the Rights of Persons with Disabilities (CRPD) by challenging exclusion of persons with disabilities and their representative organisations from decision-making processes and the implementation and monitoring of the Convention.

This EDF communication aims at providing guidance to organisations of persons with disabilities on the content of the General Comment and obligations it creates on countries party to the CRPD.

#### Who are organisations of persons with disabilities?

Organisations of persons with disabilities are organisations that are **led, directed and governed by a majority of persons with disabilities, with the aim** to promote or defend the rights of persons with disabilities, **in compliance with** the principles and rights recognised in the CRPD.

They can be local, national, regional or international, but should be **independent** from public authorities and any other non-governmental organisations of which they might be part of. They do **not have to be formally registered** at the national level.

The General Comment identifies different types of organisations of persons with disabilities:

- **Umbrella organisations of persons with disabilities:** coalition of representative organisations of persons with disabilities, organised, led and controlled by persons with disabilities. They speak on behalf of their members on matters **previously agreed on**.
- **Cross-disability organisations:** organisations composed of persons representing all, or many, types of impairment, thus representing a wide diversity of disability (e.g. physical, sensory, psychosocial, intellectual).

- **Self-advocacy organisations:** often loosely and/or locally formed networks and platforms representing persons with disabilities, especially persons with intellectual disabilities, and advocating for their rights.
- **Organisations including both persons with disabilities and family members and/or relative with disabilities:** organisations or network composed of persons with intellectual disabilities, children with disabilities or persons with dementia, and their family members and/or relatives. The role of the parents, relatives and caregivers in these organisations should be to assist and empower persons with disabilities to have a voice and take full control of their own life. They should use and promote supported decision-making.
- **Organisations of women and girls with disabilities:** organisations representing women and girls with disabilities as a diverse group, including all types of impairment.
- **Organisations and initiative of children and young persons with disabilities:** organisations composed and representing the voice of children and young persons with disabilities, with adults acting in a supportive role in promoting an environment empowering them to establish organisations and initiatives and act within them.

Organisations for persons with disabilities (not composed of a majority of persons with disabilities), organisations of service providers (including families providing support services), research organisations/institutes, and other civil society organisations, are **not** organisations of persons with disabilities.

#### What are the obligations of States parties under article 4.3 and 33.2 CRPD?

Under the CRPD States parties have the obligations to consult and involve persons with disabilities and their representative organisations in the development and implementation of legislation and policies to implement the CRPD, and in other decision-making processes concerning issues relating to persons with disabilities (article 4.3) and in the monitoring of the CRPD (article 33.2).

“Issues relating to persons with disabilities” covers any acts adopted by the State that may directly and indirectly impact the rights of persons with disabilities. For instance, issues directly affecting persons with disabilities are deinstitutionalization, social insurance and disability pensions, personal assistance, accessibility requirements or reasonable accommodation policies, among others. Measures indirectly affecting persons with disabilities might concern electoral rights, constitutional law and access to justice and transport, as well as public policies in the field of education, health, work and employment. It is interpreted broadly and in case of dispute, it is for the

**Commenté [DV1]:** Si on vise les aidants proches : OK. Bcp plus réservés pour les accompagnants en soins et soutien qui peuvent être des individus « assistants personnels » (Flandre) ou des sociétés commerciales ....

**Commenté [DV2]:** Cette précision vient atténuer l'affirmation précédente. néanmoins, quel service d'accompagnement ne se revendiquera pas de prodiguer un accompagnement pour soutenir la PH dans son choix de vie. Je pense bien évidemment à EASPD et Luk Zelderlo...

**Commenté [DV3]:** Ok ; cela clarifie. en même temps, gardons en même temps les réflexions plus haut car à contrario de cette définition, certaines organisations composées partiellement de services providers peuvent donc être considérées comme OPH (organisations de PH)

**Commenté [DV4]:** Dans les exigences qui suivent, il manque un aspect quant au contenu des obligations de l'Etat : donner les moyens aux OPH (en l'occurrence les conseils d'avis en BE) pour assurer leurs missions de suivi, participation... : Cfr situ du CSNPH et BDF qui ne suivent pas dans les demandes et qui ne reçoivent pas le personnel nécessaire

States to prove that the issue under discussion would not have a disproportionate effect on persons with disabilities and that, therefore, no consultation is required.

**Commenté [DV5]:** Argument intéressant pour le CSNPH lorsqu'un ministre prétend que sa réforme qu'il n'y pas d'impact pour les PH

States Parties should **support organisations of persons with disabilities through sufficient and independent funding and technical capacity-building**, for instance with the provision of **training** on the human rights model of disability. They should also ensure that organisations of persons with disabilities can **register and exercise** their rights to participate, providing free and accessible registration systems and facilitating their registration. In any case, registration cannot be a pre-requisite for taking part in consultation.

States parties should **ensure transparent and accessible consultation processes**, including by establishing mechanisms and procedures at the different branches and levels of government and by adopting legal and regulatory framework and procedures to ensure full and equal involvement of persons with disabilities, through their representative organisations, in decision-making processes. Persons with disabilities and their representative organisations should be consulted **early and continuously** in these processes, allowing for reasonable and realistic timeline. All facilities and procedures related to public decision-making and consultation should be accessible, for instance through **the provision of meeting assistants and support persons, information in accessible formats, sign language interpretation**, etc. States should **cover the costs** related to the consultation **processes** for representative organisations of persons with disabilities, including transport and other expenses incurred to attend meetings and technical briefings.

**Commenté [DV6]:** C'est ici que cela coince : pas de procédure prévue et structurée pour impliquer le CSNPH et autres conseils PH

States parties should ensure **consultation and involvement of organisations of persons with disabilities which represent all persons with disabilities and their views should be considered in good faith and being given due weight**. States should guarantee that representative organisations of persons with disabilities are not **only heard as a mere formality**. They must **take the result of consultations and reflect them in the decision adopted**. Participants should be informed of the outcome of the consultation process.

**Commenté [DV7]:** Ce sont ces 2 étapes qui manquent par rapport au suivi des avis du CSNPH

Finally, States Parties should **develop mechanisms and procedures ensuring effective sanctions for non-compliance** with the obligations under article 4.3 and 33.2. **Compliance should be monitored by independent bodies**, for instance the ombudsperson or parliamentary commissions, with the authority to initiate investigation and confront the non-compliant authorities. They should also recognise **effective remedies to enforce compliance with the rights of persons with disabilities to participate**. For instance, effective remedies could be the suspension of the procedure, returning to an earlier stage to ensure the consultation and involvement of organisations of persons with disabilities, delaying implementation of the decision until appropriate consultation take place, or even cancelling totally or partially the decision.

**Commenté [DV8]:** Ici aussi inexistant en BE