EDF input to the draft General Comment no. 7 on articles 4.3 and 33.3 of the Convention on the participation of persons with disabilities in the implementation and monitoring of the CRPD

# Background

The **European Disability Forum** (EDF) is a European umbrella organisation representing the interests of 80 million persons with disabilities in Europe. The mission of EDF is to ensure that persons with disabilities have full access to their human rights through their active involvement in policy development and implementation in Europe.

EDF has vocally advocated for the adoption of a General Comment on articles 4.3 and 33.3 of the Convention on the participation of persons with disabilities in the implementation and monitoring of the Convention. We acknowledge the ambition of the Committee on the Rights of Persons with Disabilities (CRPD Committee) to adopt this as soon as possible. It is fundamental to every aspect of the Convention and yet we have seen that its implementation is seriously lacking. Global trends in decreasing civic space and lack of financing of civil society, including budget cuts and retrogressive measures, are making the situation of Organisations of Persons with Disabilities (OPDs) even more precarious than they were. Some governments have started to control NGOs and OPDs; some even started to prohibit NGOs and OPDs which receive support from abroad. In addition, inadequate attention has been giving by States Parties to the autonomy and legal capacity of persons with disabilities. Instead of strengthening of the disability movement, we see the opposite. It is for all these reasons that the General Comment is timely and critically important.

The approach taken by the Committee to interpret and comment articles 4.3 and 33.3 of the Convention is warmly welcomed by EDF. Central to the CRPD’s implementation is autonomy of persons with disabilities themselves, central to transforming legislation and policy is their close consultation and active involvement. Moreover, it is in line with the demands of, for instance, the International Disability Caucus during the negotiations of the draft text of the Convention at the UN and summarized by the slogan of the international disability movement: ‘**Nothing about us without us!**’

We believe that it is important to define the implementation of these key articles of the Convention in the light of the principle of non-discrimination as enshrined in article 5 of the Convention. Article 5 of the Convention does not only apply to individuals, but also to organisations of persons with disabilities. As individuals with disabilities are discriminated against to participate fully and on an equal basis with others in all areas of life, representative organisations of persons with disabilities face a collective exclusion and discrimination to be fully involved and participate in all spaces of public decision making and decisions that affect their lives. Paragraph 5 of the draft General Comment highlights that ‘persons with disabilities, whether as groups, organisations or as individuals, have experienced and continue to experience exclusion’.

Currently, representative organisations of persons with disabilities in Europe do not have the necessary capacity nor resources to be equal partners in decision-making processes in their countries, and at EU and international levels. They are not considered social partners nor have they been granted a place in decision-making as other stakeholders and civil society organisations have.

Representative organisations of persons with disabilities are usually severely and profoundly underfunded, and many struggle to survive. To build their strength, capacity and unity, as well as to fulfil their responsibilities under the CRPD, public resources are needed.

The CRPD Committee has on several occasions called on States Parties “to take measures to set up a structured dialogue with an independent budget line and sufficient funding for meaningful consultation with and the participation of persons with disabilities, through their representative organisations”. This recognises the close relationship between Article 4.3 of the Convention, and the need for adequate resourcing of OPDs.

Adequate resources are the only way for representative organisations of persons with disabilities to build their capacity, exist independently and be involved and consulted in the implementation and monitoring of the Convention on equal basis with others.

Representative organisations of persons with disabilities play a crucial role not only in defending the human rights of persons with disabilities, but also of all individuals living in their societies. As they represent rights-holders, they should receive with priority public funding to play this crucial role as enshrined in the articles 4.3 and 33.3 of the Convention.

EDF hopes that, with our input, the draft General Comment will be strengthened and will provide an excellent basis for a strong and ambitious interpretation of articles 4.3 and 33.3 of the Convention.

This submission follows the structure of the draft General Comment and provides comments and suggestions for specific paragraphs that it considers important to be included in the final version of the General Comment.

# Introduction

# Throughout the draft General Comment, the following terms are used “disabled persons organisations (DPOs) / organisations of persons with disabilities (OPDs)”, followed by the abbreviation “DPOs/OPDs”. There is no definition describing the difference between DPOs and OPDs. Based on context and the equal use of those terms in the document, it seems evident that DPOs and OPDs are seen as the same organisations, without any significant difference in their mission, structure and members.

# EDF is concerned that this duality may cause misunderstandings mainly when the general comment will be translated and used in different languages. We recommend to use only one of those terms with an explanation covering both of them. Because in our view, the term “organisations of persons with disabilities” reflects better the text and the spirit of the CRPD, EDF refers solely to OPDs in this document.

# Normative content of articles 4.3 and 33.3

## Paragraph 14 (a) – Definition of ‘representative organisations’

We are concerned that the draft General Comment does not mention families of, among others, persons with intellectual disabilities, persons in need of a high level of support, persons with dementia and persons with autism. **EDF encourages the Committee to strengthen and increase the consultation of organisations composed by family members of persons with disabilities.** While the voice of family members should never substitute the one of persons with disabilities, the consultation and participation of family members is important, especially in countries allowing arbitrary deprivation of liberty and institutionalisation on the basis of impairment.In such cases family members may not only disclose violations of the Convention but also assist in advancing its implementation at the national levels, regional and international levels, for instance in the development of policies on independent living.

Therefore, EDF recommends when defining the term “representative organisations” to include a paragraph which would **allow for the inclusion of organisations composed and governed by persons with disabilities and family members, to ensure that organisations of parents or family members of persons with intellectual disabilities, autism, dementia and those in need of a high level of support, are fully included in the disability movement**. EDF believes that the unity of the disability movement is strengthened when people are representing themselves alongside family members.

This is in line with paragraph 24 of the Preamble of the Convention[[1]](#footnote-1) and paragraph 17 of the CRPD’s Committee General Comment No 6 on Article 5 on equality and non-discrimination.[[2]](#footnote-2) It is also important to recall that family members may be facing **discrimination by association**, an example being when a family member is requesting to his or her employer reasonable accommodations such as additional leave or part-time schedule to support a relative with disabilities.

Finally, EDF agrees with the need for OPDs to reflect a broad range of persons with disabilities, **including children, young people, older people, women, LGBTIQ people, refugees and indigenous people**, and that these organisations should seek to provide a collaborative and coordinated voice of persons with disabilities in the decision-making processes. This is crucial as to ensure that OPDs represent a **united and diverse voice** of the disability movement.

## Paragraph 14 (b) and (c) – Cross disability vs umbrella organisations

Under paragraphs 14 (b) and (c), we understand that cross disability organisations represent individuals with disabilities, whereas umbrella organisations of persons with disabilities are a federation or confederation of organisations of persons with disabilities.

We recommend the Committee to clarify these two definitions, and to move the last sentence of paragraph 14 (c) to paragraph 14(b): “There is usually only one or perhaps two umbrella DPOs/OPDs in a given State party”.

## Paragraph 14 (e) – Organisations of self-advocates

EDF would like to stress that persons with psychosocial disabilities do not identify themselves as “self-advocates”, and thus we would prefer that the reference to this particular group be removed from this paragraph.

## Paragraph 14(f) – Organisations of women with disabilities

Under paragraph 14 (f), it is important to include ‘girls’ in the organisations of women with disabilities.

## Paragraph 14(h) – Organisation of children and youth with disabilities

EDF recommends adding a paragraph 14 (h) on organisations of youth with disabilities as ensuring the participation of young people with disabilities should also be a prerequisite in consultation addressing specific issues, for instance access to education, employment and cultural life, recreation, leisure and sport.

Moreover, we encourage the Committee to include organisations and initiatives led by children with disabilities. This would include children-led unregistered associations, informal groups, school-based student’s forums, parliaments, etc. States parties should acknowledge these organisations and initiatives, and promote their close consultation and active involvement on issues concerning them.

## Paragraph 15 and 16 – Distinction between organisations of persons with disabilities, and organisations for persons with disabilities and civil society organisations

EDF welcomes the important distinction the Committee makes between organisations of persons with disabilities, and organisations for persons with disabilities and other civil society organisations.

EDF supports the view that ODPs should be recognised as having unique inputs **as rights-holders**. We suggest to add “as rights holders”, in line with the human rights based approach to disability, at the end of the sentence of paragraph 15[[3]](#footnote-3) and to also include the same sentence at the end of paragraph 16 as to ensure that the views of OPDs are given specific priority in the implementation and monitoring of the Convention.

Under these two paragraphs, we would also include that States parties should ensure that CSOs and other stakeholders consult and involve organisations of persons with disabilities in their work on implementing the Convention, and align themselves with their views.

# Scope of article 4.3

## Paragraph 18 – Legal and regulatory frameworks and procedures

EDF agrees fully with the need to adopt legal and regulatory frameworks and procedures across all levels and branches of the government that explicitly require public authorities to consult with and actively involve persons with disabilities in the development and implementation of decision making processes. This paragraph could include some examples of legal frameworks that prescribe the involvement of OPDs 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.

The consultation and involvement should not be limited to the federal or national level, but also includes the involvement in the development and implementation of legislation and policies at all regional, provincial and municipal levels.

EDF wants to add that at each level of public decision-making, there should be a corresponding representation of persons with disabilities, also including regional integration organisations, such as the European Union or others. It is important that both at the local, national, regional and international level representative organisations of persons with disabilities are consulted, and that this is stipulated in the legal and regulatory frameworks.

## Paragraph 20 – Concerning issues relating to persons with disabilities

## EDF suggests to include that persons with disabilities and their representative organisations should be consulted in all decisions on measures that have an impact on people’s lives, which include the lives of persons with disabilities.

## Paragraph 21 – To closely consult with and actively involve persons with disabilities

EDF is concerned that consultation is too often viewed by States parties and decision-makers as a simple exchange of information, without the views of OPDs being taken into account. We consider that consultation should be understood as a **requirement** in all matters that directly and indirectly affect persons with disabilities, from the first input to the final product, in order to ensure their active involvement in all decision-making processes. Under the right to be actively involved, States parties should have the duty to ensure that persons with disabilities, through their representative organisations, can **actively and systematically** take part in **all spaces of public decision-making** on an equal basis with others, including national funds and all relevant public decision-making bodies, and in every aspect related to the implementation and monitoring of the Convention. A systematic and strong involvement of persons with disabilities would contribute to building strong consensus prior to the adoption of legislations and public policies, thus fostering their legitimacy and effectiveness.

It is crucial that States parties ensure that consultation and involvement are fully **accessible** to all persons with disabilities. For instance, when conducting online consultations, States parties must ensure that they are accessible to all persons with disabilities.

States parties should also provide **reasonable accommodation** and necessary support to OPDs and their representatives to ensure they can take part in consultation and participate in all relevant decision-making processes.

## Paragraph 22 - Importance of “including children with disabilities”

Under this paragraph, EDF suggests striking a **balance between the inclusion of children with disabilities and their parents**. We would like to highlight that it is our members experience that parents and children have very different focuses. Both the focus of children and of parents are relevant, and contribute to inclusion, participation and wellbeing of children with disabilities and their parents, and both perspectives should be reflected in policies and programmes. This can only happen if children with disabilities are properly included in consultations and their opinions are taken seriously. Parents should be consulted **as the advocates of children with disabilities** and their families.

While this paragraph explicitly mentions that “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”, we find that **the general comment should focus more on the importance of, and opportunities to, include children with disabilities more systematically**. Moreover, States parties should ensure that children with disabilities are provided with age-appropriate assistance to express their views.

Regarding the last sentence of paragraph 22 “the recognition of individual autonomy is of paramount importance for all persons with disabilities, including children, to be respected as rights holders”, EDF suggests moving this sentence up to paragraph 21 as the requirement to ‘closely consult with and actively involve’ also implies to persons who are deprived of their legal capacity. It is important to stress the requirement of ‘recognising the person’s individual autonomy and legal capacity’ in consultation and involvement in public decision-making processes. All persons with disabilities, including the ones deprived of their legal capacity should be consulted and involved in all decisions that affect their lives, as is also mentioned in paragraph 60.

## Paragraph 25 – Full and effective participation

EDF suggests to include that the full and effective participation of OPDs also enables them in bringing a **united and diverse voice** to the table.

# Article 33.3: the involvement of civil society

## Paragraph 26 – Nothing about us, without us

EDF supports the States parties’ obligation to consult and involve OPDs when deciding and/or reviewing the establishment of focal points and coordination mechanisms under article 33.1 and of independence mechanisms under article 33.2. However, we are concerned of the common confusion between the obligation to undertake broad consultation with persons with disabilities through their representative organisations under article 4.3, and the obligation to establish focal points and/or coordination mechanisms under article 33.1.

We suggest the Committee to bring more clarity regarding the relationship between the two articles **under the section on “Scope of article 4.3”** of the General Comment. It should explicitly mention that while focal points and/or coordinating mechanisms potentially contribute to article 4.3, their existence and consultation with OPDs do not exhaust the obligation to undertake **broad consultation** required by this article.

## Paragraph 27 – National human rights institutions and the Paris Principles

EDF suggests including in the General Comment the text between brackets in the last sentence of paragraph 27: “the Paris Principles require that DPOs/OPDs should be either represented in the independent mechanism, or be able to cooperate closely with these mechanisms, and preferable be appointed to their board”. It is important to stress here that the views of OPDs in this board should be given specific priority: OPDs are rights-holders whose voices have a unique position in relation to the Convention.

#  Obligations of the States parties

## Paragraph 31 – Accessibility for persons with disabilities to all facilities and procedures

EDF fully agrees that all relevant communication, information, meetings and its contents should be accessible to all persons with disabilities. We suggest the Committee to further stress the importance of accessible procedure for consultation and to provide more details on what accessibility entails in practice.

Planning of surveys, meetings and other methods should allow sufficient time for response and consider in their organisation the access needs of all groups. Meetings held should follow accessibility and design for all standards and encourage participation by all. Organisers should monitor attendance and note gaps in representation. There should be a requirement to make public bodies’ websites accessible, as is obliged by the EU Directive 2016/2102 on the accessibility of the websites and mobile applications of public sector bodies.

EDF would also like to stress that the growing reliance on online method excludes large numbers of people with intellectual disabilities. States parties should always provide alternative methods of consultation in accessible formats for all persons with disabilities, including persons with intellectual disabilities.

More generally, we recommend adding ‘accessible digital formats’ to paragraphs 21, 38 and 63 of the draft general comment, where the use of braille is mentioned. Accessible digital formats are widely used via assistive technologies. Those formats also serve as a source code for Braille, large print, text-to speech translation and other accessible formats.

## Paragraph 36 – Protection against discrimination from third parties

As we mentioned under paragraphs 15 and 16, EDF suggests including that States parties should ensure that third parties closely consult OPDs in the work they undertake in relation to the Convention.

## Paragraph 41 – Support to establish single representative umbrella group

EDF recommends adding the words ‘united and diverse’ to the phrase “the establishment of a single, united and diverse representative umbrella group”.

Moreover, we suggest the Committee to encourage States parties to ensure the diversity of groups and opinions are represented and resources are available to guarantee that the most excluded groups also have a voice in umbrella organisations.

## Paragraph 42 – Non-conditional and sufficient funding and technical capacity building

As mentioned in the introduction, representative organisations of persons with disabilities at EU level and in Europe have **limited or no financial resources**, and are thus not able to independently monitor the actions of their State on the implementation of the Convention.

We recommend the Committee to stress that States parties should provide **adequate funding** to representative organisations of persons with disabilities and ensure **long term capacity building support** to increase their capacity and enable them to be meaningfully involved and participate as partners on an equal basis with others in the development and implementation of the CRPD. In addition, **reasonable accommodation** and **necessary support** should always be provided to enable persons with disabilities to participate in capacity building, to be a representative of an OPD and to take part in the work of an umbrella organisation.

It is crucial to develop mechanisms to **ensure that funding coming directly or indirectly from governments cannot be withdrawn on the basis of disagreement between the government and ODPs**.

At its Board meeting in February 2016, EDF adopted the following recommendations on funding to OPDs that should be taken into account in this draft General Comment under the chapter on obligations of States parties:

• Ensure that funding mechanisms such as national civil society participation programmes, lottery funds for good causes, corporate and private contributions, are preserved and expanded for social inclusion of persons with disabilities;

• Ensure that the existing funding mechanisms are not used for fiscal consolidation of general State budgets;

• Funding to representative organisations of persons with disabilities should not hinder their autonomy, and their inclusion in all related decision-making processes as per UN CRPD and disability movement’s motto “Nothing About Us Without Us”;

• Fund advocacy and capacity building activities of representative organisations of persons with disabilities to ensure that sound policies can be implemented based on acceptance of the disability movement;

• Support equally regional, national and local organisations of persons with disabilities.

• Secure adequate funding for and encourage local, national and regional organisations of persons with disabilities to be formed and fulfil their mission of connecting, promoting and representing the interests of persons with disabilities. All State mandated decision-making bodies, for instance standardisation bodies, should provide adequate funding and resources, accessibility and reasonable accommodation to ensure ODPs’ participation.

## Paragraph 48 – Complaint mechanism

EDF **firmly supports** paragraph 48 according to which States parties should establish complaint mechanisms and remedies for persons with disabilities in cases of breach of article 4.3 of the CRPD.

EDF suggests to include in this paragraph that these complaint mechanisms should be part of the legal frameworks establishing the consultation and involvement of representative organisations of persons with disabilities, or in the national anti-discrimination legislation (as prescribed in paragraph 72 of the General Comment No. 6 of the Committee on article 5 of the Convention), at all levels of decision-making. The legislation should specify that **sanctions** are provided when public authorities plan laws and policies which ignore or neglect to closely consult or actively involve persons with disabilities in all matters that affect them.

These laws should entitle representative organisations of persons with disabilities (and not just individuals) to start legal actions against third parties, with a reference to the obligation of States parties to prohibit all forms of discrimination based on disability, as prescribed in General Comment No. 6 on article 5 of the Convention.

# Relationship with other provisions of the Convention

EDF highly recommends adding a **new paragraph on the monitoring required by Article 16.3** of the Convention on the right to freedom from exploitation, violence and abuse. The Committee should require States parties to ensure that civil society, including ODPs, are actively involved in the monitoring of facilities and programmes designed to serve persons with disabilities, regardless of whether the “independent authority” assigned the task under article 16.3 coincides with the independent monitoring mechanism under article 33.2. In light of well-documented grave violations of the rights of persons with disabilities in facilities aimed to “serve” them (such as psychiatric and/or residential institutions), it is crucial that the Committee addresses the issue in this General Comment.

Moreover, EDF suggests adding under paragraph 55 that women with disabilities have a right to represent and organise themselves. They should be fully part of the leadership of ODPs and be given space and power within umbrella organisations of persons with disabilities through equal representation, women’s committees, empowerment programmes, etc.

# Paragraph 75 – Implementation at the national level

Under paragraph (a), EDF suggests including that all laws denying legal capacity be repealed, and that all persons with disabilities, regardless of their legal capacity be guaranteed the right to be consulted and involved in decision-making processes.

Under paragraph (b), EDF recommends mentioning the importance of the right of freedom of association. In particular, the Committee should mention that unregistered organisations must receive equal protection and opportunity to be consulted and involved in public decision-making processes. The General Comment should also explicitly mention that ODPs have the right to “operate free from State interference in their affairs; their members should be free to determine their statutes, structure and activities and to make decisions without State intrusion”.[[4]](#footnote-4)

Under paragraph (d), EDF suggests that the single umbrella organisation ensures inclusiveness and diversity and represent all groups of persons with disabilities. In addition, this paragraph should mention persons with brain injuries and persons with dementia, as there is a growing number of older people who face cognitive impairments, such as Alzheimer and other forms of dementia. As long as persons with intellectual or psychosocial disabilities, or persons with dementia, are deprived of their right to exercise legal capacity, many of them are not in the position to form an organisation and/or to join the activities of a national umbrella organisation of persons with disabilities.

Under paragraph (i), EDF stresses that it is important to support the creation and funding of representative organisations of persons with disabilities **at all levels of decision-making**, whether local, national, regional (including within a regional integration organisation) or international.

Under paragraph (l), we would add the accessibility of ‘communication’ related to public decision-making, consultation and monitoring.

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1. Paragraph 24 states: “Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.” [↑](#footnote-ref-1)
2. Paragraph 17 states that that the protection against discrimination (article 5 of the Convention) “includes persons with disabilities and their associates”, which are not only parents of children with disabilities, but also **family members and peers**. [↑](#footnote-ref-2)
3. This would read: “States parties should give priority to the views of OPDs and their members **as** **rights holders**” [↑](#footnote-ref-3)
4. A/HR/31/62, para. 42; and IDA’s submission on the draft general comments on Article 4.3 and 33.3 of the CRPD. [↑](#footnote-ref-4)