**International Disability Alliance (IDA)**

Member Organisations:

Down Syndrome International, Inclusion International, International Federation for Spina Bifida and Hydrocephalus, International Federation of Hard of Hearing People, World Blind Union, World Federation of the Deaf, World Federation of the DeafBlind, World Network of Users and Survivors of Psychiatry, Arab Organization of Disabled People, African Disability Forum, ASEAN Disability Forum, European Disability Forum, Red Latinoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus familias (RIADIS), Pacific Disability Forum

**IDA submission on the draft general comment on** **Articles 4.3 and 33.3**

**of the Convention on the Rights for Persons with Disabilities**

The International Disability Alliance (IDA) is a unique international network of global and regional organisations of persons with disabilities. Established in 1999, each IDA member represents a large number of national organisations of persons with disabilities (OPDs) from around the globe, covering the whole range of disability constituencies. IDA thus represents the collective global voice of persons with disabilities counting among them more than 1 billion persons with disabilities worldwide, the world’s largest –and most frequently overlooked– minority group. Currently comprising eight global and six regional OPDs, IDA’s mission is to advance the human rights of children and adults with disabilities as a united voice of organisations of persons with disabilities utilising the Convention on the Rights of Persons with Disabilities (CRPD) and other human rights instruments. IDA also aims to promote the effective implementation and compliance with the CRPD within the UN system and across the treaty bodies.

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**INTRODUCTION**

IDA warmly welcomes the opportunity to provide comments to the draft general comment no 7 on Article 4.3 and 33.3 of the CRPD on the right to participate of persons with disabilities, through their representative organisations, in the implementation and monitoring of the CRPD. The development of this general comment by the CRPD Committee (hereinafter ‘the Committee’) addresses the demands of the movement of persons with disabilities, expressed since the negotiations of the CRPD,[[1]](#footnote-1) and stands for the motto “Nothing about us without us!”

While the draft includes innovative elements, IDA believes that there are aspects that could be clarified and tightened. This submission will try to address them hoping to provide the Committee with elements for further improvement of the draft towards its adoption.

**I – PARTICIPATION TO BUILD LEGITIMACY OF PUBLIC DECISIONS AND THE KEY ROLE OF PERSONS WITH DISABILITIES AS RIGHT HOLDERS FOR CRPD IMPLEMENTATION AND MONITORING**

Participation of individuals is a core principle of international human rights law,[[2]](#footnote-2) and a key element of democratic societies and governance. It is also a requisite of a human rights-based approach.[[3]](#footnote-3) Participation of different groups and stakeholders in public decision making allows for the vast diversity of views to be considered and contributes to **build strong consensus** prior to the adoption of legislations and public policies, fostering their legitimacy and effectiveness. States should be encouraged to develop far reaching participatory mechanisms, including all interested actors.

**Yet,** specifically, persons with disabilities have traditionally been marginalised from decision making on issues concerning their lives, notably under the prevalence of the medical model of disability. In line with the unprecedented involvement of organisations of persons with disabilities described in para. 2 of the draft, Article 4.3 came to reflect the motto “Nothing about us without us!”, providing **persons with disabilities** **with the right (a legal entitlement) to be close consulted and actively involved, and the consequent State obligation**.**[[4]](#footnote-4)**

IDA encourages the Committee to **explicitly promote broad participatory mechanisms**, including of course OPDs and other interested stakeholders, in order to build strong and sustainable consensus for legislations and policies compliant with the human rights standards enshrined in the CRPD. But, as the Committee very well states in the draft,[[5]](#footnote-5) it must be absolutely clear that, however broad participatory mechanisms might be, the **entitlement** under Article 4.3 is exclusive for “persons with disabilities, through their representative organisations,” and consistently, they are their views and insights which need to be prioritised when discussing and deciding on issues concerning their rights.[[6]](#footnote-6)

**I-A) STRESSING ON “MEANINGFUL INVOLVEMENT” OF ORGANISATIONS OF PERSONS WITH DISABILITIES**

In connection to our previous section, and while acknowledging the efforts done by the Committee, IDA believes the Committee should further highlight the idea of **“meaningful involvement”**, putting more stress on the phrase **“actively involved”** of Article 4.3 of the CRPD. “Consultation”, “consult with”, “participation”, etc., are often perceived by States as vague ideas requiring some dissemination of information and gathering of opinions, to validate decisions already projected, in some kind of tokenistic approach. Article 4.3 must be interpreted meaning that OPDs should be regularly involved by States Parties and its bodies, leading to building up constant relations with public authorities at all levels.

In these lines, the Committee should send a very strong message to States stating that “**systematic** consultation and **systematic** involvement” is a **mandatory requirement** **from the very first input to the final product** in all decision-making processes on matters that directly and indirectly affect persons with disabilities. Further, it demands access to all spaces of public decision-making on an equal basis with others, including national funds and all relevant public decision-making bodies, in connection with every aspect related to the implementation and monitoring of the Convention.

**It is very important that the Committee explicitly call States to give up passive attitudes and behaviours with regard to the rights, claims and requests articulated by organisations of persons with disabilities, and to instead openly, constantly and actively approach OPDs to facilitate their meaningful involvement**.

**I-B) CONCEPTUAL AND TERMINOLOGY ISSUES**

***a) A broad understanding of “development of policies”***

While the “development of legislations” is addressed in section V from a procedural perspective, IDA would like to highlight that the term **“development of policies” for implementing the CRPD** covers a broader field than the term “development of legislation.”

It should be established as a general rule that all public bodies, including those that exercise political power or try to influence the government or the legislative decisions such as Unions and Trade Chambers, should regularly consult with and involve OPDs in all issues linked to the CRPD and its implementation before adopting policy decisions.

***b) Preference for “organisations of persons with disabilities”***

In a **digression on terminology**, IDA would like to clarify that the term “organisations of persons with disabilities” should be preferred over “disabled persons’ organisations,” as it is the alternative consistent with the language of the CRPD, in **Articles 29(b)(ii) and 32(1)**. Further, this language prevents misinterpretations and translations in tension with the concept of disability and the human rights model of disability.

**II- COMMENTS ON THE DIFFERENT KIND OF REPRESENTATIVE ORGANISATIONS OF PERSONS WITH DISABILITIES AND RELATED ISSUES**

IDA welcomes the Committee efforts to illustrate States on the different kind of representative organisations of persons with disabilities. In our diversity, we constitute the movement of persons with disabilities, at the local, national and international levels. IDA constitutes a key example at the international level. This example lead us to a very concrete suggestion on the draft: it should be added in the chapeau of paragraph 14, that OPDs may be national, regional or local, and may be members of international or regional coalitions.

In line with our comments in the **section I**, while States should further develop participatory mechanisms to inform public decision making, including the perspectives of all relevant actors, the State’s obligation under Article 4.3 of the CRPD pertains to “persons with disabilities, through their representative organisations”. Thus, we are the key **institutional vehicles in place** **to reach the views of persons with disabilities as right holders**, on the issues that concern them. This conception is important particularly for contexts where not all groups of persons with disabilities are organised, as well as to consider the role of relatives.

**II-A) UMBRELLA ORGANIZATIONS VIS-A-VIS ENSURING THE RIGHT TO PARTICIPATE OF ALL CONSTITUENCIES AMONG PERSONS WITH DISABILITIES**

IDA welcomes the conceptualisation of “umbrella organisations”, as a way in which OPDs may operate and notes that the draft reads “an umbrella DPO/OPD **can** and **should** ensure the participation of persons with all types of disabilities in the consultation, decision-making and monitoring processes”. IDA encourages the development “umbrella organisations,” inclusive of all constituencies of persons with disabilities and of diverse intersectional identities, and respectful of equality of views and rights among them, as a vehicle of a unified voice of the disability movement.

However, we do acknowledge that, in many contexts, “umbrella organisations” do not necessarily include all constituencies within their membership in consistency with Article 1 of the CRPD. Moreover, sometimes, while formally included, internal dynamics may marginalise the views of some groups among persons with disabilities. Further, in occasions, the State itself precludes some constituencies to form their organisations and be able to influence the “umbrella organisation”, as is the case of persons with disabilities deprived of legal capacity. Finally, in some contexts, not all constituencies are represented by existing organisations, becoming essential to consult and involve groups of activists or even individual activists.

This call us to reflect on what message is sent to State Parties. We understand that the Committee is only providing a concept of “umbrella organisation,” and not suggesting they have any particular entitlement over other organisations (e.g. being “the” interlocutor with State officials).[[7]](#footnote-7) Nevertheless, it seems important to prevent misinterpretations, and **to explicitly state that**, in complying with Article 4.3 of the CRPD, **States must not restrict the right to participate to any specific kind of actor nor compel individuals or organisations to be part of larger coalitions, but to undertake broad consultations and actively involving persons with disabilities, in line with our previous comments**, to ensure the great diversity of views informs the public decision making process.[[8]](#footnote-8)

**II-B) OGANISATIONS OF “SELF-ADVOCATES” WITH INTELLECTUAL DISABILITIES AND THE ROLE OF “RELATIVES” OF PERSONS WITH DISABILITIES**

IDA notes the inclusion of organisations of self-advocates in para. 14(d). As stated by the Special Rapporteur on the Rights of Persons with Disabilities, “[t]he CRPD has accelerated the process of establishing organizations **of self-advocates** with intellectual disabilities, of autistic persons and of other individuals who may need extensive support to express their positions.”[[9]](#footnote-9) This is a promising path, which hopefully will develop further.

However, IDA observes that not necessarily all organisations representing the groups mentioned in para. 14(d) identify themselves under the term of “self-advocates”.[[10]](#footnote-10) In this line, IDA believes that the conceptualisation of “organizations of self-advocates” should comprise the **key element of self-identification** to prevent misunderstandings of the intention of the Committee describing this kind of organisation.

In addition, it must be said that **families of persons with intellectual disabilities, autistic persons and persons with dementia,** play a highly constructive role supporting and empowering self-advocates. Many relatives are even key members of their organisations by the side of “self-advocates.” While we completely agree that “the role of parents [or better “relatives”][[11]](#footnote-11) in such organizations should increasingly move towards the provision of support, with self-advocates in full control”,[[12]](#footnote-12) being this last point stressed in current paragraph 14(d) of the DGC, IDA would like to suggest the inclusion of **“organisations of persons with intellectual disabilities composed and governed by persons with intellectual disabilities and family members”** after current section 14(d), as a case of “representative organisations” entitled by Article 4.3.[[13]](#footnote-13)

In connection to the last point, IDA would like to propose a slight modification on paragraph 37. While the concern of the Committee in para. 37 is important, IDA believes that referring explicitly to “family members” projects a rather negative image of relatives that, in the area of intellectual disability, might be the only trustful support to foster empowerment and autonomy of persons with intellectual disabilities. It might be better simply to delete the reference, or harmonise the text with the previous points in this section.

**II-C) PARTICIPATION OF CHILDREN WITH DISABILITIES**

***a) Promotion of children with disabilities-led organisations and of specific processes for ensuring children participation***

IDA notes the attempt of the CRPD Committee of highlighting the importance of including children with disabilities (para. 22). Yet, it might have fallen short from international standards on children rights’ to freedom of association and to express their views, providing with an adult-centred approach of definitions of organisations (see notably para. 14 e). In this vein, IDA believes that the section II.1 (para. 14) should include **organizations and initiatives led by children with disabilities**, before those of relatives, in order to both acknowledge their role to channel the views of their constituency and promote their empowerment for advocacy.

The CRC Committee has called States to support children “to form their own child-led organizations and initiatives, which will create space for meaningful participation and representation.”[[14]](#footnote-14) Furthermore, in connection to adolescents, that Committee has stressed that “[a]dolescents can connect with peers, engage in political processes and increase their sense of agency to make informed decisions and choices, and therefore need to be supported in forming organizations through which they can participate in a variety of means, including digital media,”[[15]](#footnote-15) and that “**[l]egal recognition** should be afforded to adolescents to establish their own **associations**, **clubs**, **organizations**, **parliaments** and **forums**…”[[16]](#footnote-16) Furthermore, “[a]dolescents with disabilities should, in addition, be provided with opportunities for **supported decision-making** in order to facilitate their active participation in all matters concerning them.”[[17]](#footnote-17)

The list highlighted above gives account of an issue that may particularly impact children with disabilities. As children may not be allowed to register associations, groups, etc., States must both acknowledge and promote that children-led **unregistered** associations, informal groups, schools-based student forums, parliaments, etc., are closely consulted and actively involved on issues that concerns them.[[18]](#footnote-18)

Further, in line with Article 7(3) of the CRPD, States must ensure children with disabilities are able to express themselves **freely** and count with disability and age-appropriate assistance to realize that right. IDA believes that States should foresee **specific processes** for them to participate, different from adult-oriented processes, in order to avoid any constraint in the expression of their views. Consequently, it is important to recall, and incorporate in the text of the draft, **the mandatory requirements established by the CRC Committee** for “[a]ll processes in which a child or children are heard and participate […]: “(a) Transparent and informative; (b) Voluntary; (c) Respectful; (d) Relevant; (e) Child-friendly; (f) Inclusive; (g) Supported by training; (h) Safe and sensitive to risk; (i) Accountable.“[[19]](#footnote-19)

***b) Organisations of “relatives” of children with disabilities and their supportive role***

Highlighting the pressing need to give voice and prominence to organisations of children with disabilities does not preclude the important acknowledgement of **organisations of relatives[[20]](#footnote-20) of children with disabilities**. They play a key role worldwide in advancing the rights of children with disabilities and promoting their autonomy and participation, notably in connection with children with intellectual disabilities, autistic children and other marginalised groups of children.

However, it must be stressed that, according to Article 7(3) of the CRPD, applied to the context of these organisations, “children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.” This particular element, together with children-led organisations, is key for ensuring that the views of children with disabilities make their way through the particular institutional setting towards the public decision making process, as an input from specific right-holders.

**II)-D) CONFLICT OF INTERESTS**

IDA welcomes that the Committee addressed the issue of “conflict of interests” in paragraph 15, in connection with “organizations ‘**for’** persons with disabilities” (service providers), which allegedly advocating for the rights of persons with disabilities, might be actually advocating for their own gain. Nevertheless, we believe this issue should be dealt with also in a more general manner, as other cases of conflict of interests could eventually take place, especially in the context of larger consultations where OPDs participate together with other stakeholders. An example could be the case of a OPD representative who is also a public servant or has political ties to his government. Other examples could be imagined.

A specific paragraph could address this issue before paragraph 15. The Committee could request that mechanisms to detect and/or denounce conflict of interests of representatives of OPDs or other stakeholders are put in place to prevent their negative impacts, be it both in connection with larger consultations where OPDs participate and with consultations that might be undertaken only with OPDs, under Articles 4.3 of the CRPD.

In addition, this should also be included under the section III of the draft regarding obligations of States parties, our suggestion is to include the issue of protecting the right to be consulted by clearly setting legal or administrative standards to prevent the possible conflict of interests, under the draft’s paragraph 36.

**III - ENABLING ENVIRONMENT FOR INDEPENDENT ORGANISATIONS OF PERSONS WITH DISABILITIES: ADRESSING RESTRICTIONS ON THE RIGHT TO FREEDOM OF ASSOCIATION. REGISTRATION AND INDEPENDENCE.**

IDA welcomes that the draft refers to States duty to develop an “enabling environment for the establishment and functioning of DPOs/OPDs,”[[21]](#footnote-21) in line with Article 29(b)(ii) of the CRPD and previous Concluding Observations.[[22]](#footnote-22) However, IDA suggests that the draft would benefit from a stronger approach, including issues related to the right of freedom of association.

In many contexts, civil society actors currently operate within restricted legal boundaries[[23]](#footnote-23) and/or face several restrictions to their freedom of association, operational capacities, freedom of expression, and their right to participation, including by fear of reprisals by governments, limitations or prohibition of advocacy activities when relying on foreign funding, and alike. Registration is often mandatory but interposes administrative, bureaucratic, accessibility and cost-related **barriers** and even arbitrary rejections. Furthermore, pervasive violations of Article 12 of the CRPD through deprivation of legal capacity prevent many persons with disabilities from developing and registering their own organisations.

These factors provoke that “numerous organizations representing persons with disabilities remain unregistered.”[[24]](#footnote-24) IDA believes that the draft general comment should be more straightforward in addressing this kind of issues, most likely under the section on State obligations adding a specific paragraph. We feel that by providing clear-cut definitions in para. 14 and not referring to these issues might give room to the wrong impression that the CRPD Committee only considers legally registered organisations.

**III-A) THE RIGHT OF FREEDOM OF ASSOCIATION VIS-À-VIS OFFICIAL REGISTRATION SYSTEMS**

In our view, the Committee should **begin by clearly stating** that “the right to freedom of association **equally protects associations that are not registered**”[[25]](#footnote-25) and that States must not require “a legal entity to be established or an organization for persons with disabilities to be registered as a precondition to the exercise of freedom of association.”[[26]](#footnote-26) Secondly, it should stress that any regulation of the right of freedom of association should be “prescribed by law and […] necessary to protect a legitimate interest in a democratic society,”[[27]](#footnote-27) requiring this standard to be construed narrowly as it impacts on the exercise of human rights. Furthermore, individuals involved in unregistered associations should be able to undertake activities and be free from criminal sanctions,[[28]](#footnote-28) or any other arbitrary persecution by the State, directed to discourage or constraint their activities, as well as be entitled to participate in broad consultations under Article 4.3 of the CRPD.

That said and ensured, and in order to ensure OPDs are able **to register and exercise their right to participate** under Articles 4.3 and 33.3, States should also provide with “registration systems that are simple, flexible, expeditious, fully accessible, non-onerous and/or even free of charge, to facilitate the registration of organizations of persons with disabilities.”[[29]](#footnote-29) In this sense, the Special Rapporteur on the rights to freedom of peaceful assembly and of association has referred to the issue of delays in registration stating that, regardless of the scheme adopted, “registration bodies must be bound to act immediately and laws should set short time limits to respond to submissions and applications respectively.”[[30]](#footnote-30)

In occasions, access to funds is prevented by lack of registration. However, **both registered or unregistered organizations** should be “able to seek and secure funds and resources from domestic and international donors, including private individuals, private companies, CSOs, States and international organizations.”[[31]](#footnote-31) In this sense, States should not impose any requirement that obstruct access to resources.

**III-B) THE RIGHT OF FREEDOM OF ASSOCIATION AND INDEPENDENCE OF ORGANISATIONS**

The draft general comment refers to “guaranteeing the independence [of organisations] and autonomy from the State party.”[[32]](#footnote-32) Nevertheless, IDA believes that the text should address the notion of independence in more concrete terms throughout the general comment, in connection with the right of freedom of association, and related issues.

Experience shows, in many contexts, that organisations politically aligned with the government, and even intertwined institutionally, have a privileged position as interlocutors with the authorities and may monopolize State funding, leaving very limited space, or none, for independent organisations to flourish and participate in the public sphere putting forward their views. Further, governments make use of different mechanisms to silent dissident views, such as reprisals, funding cuts, interventions under the guise of investigations for transparency and accountability, and alike. In occasions, even organisations that have fluent interaction with and receive funding from the State might find themselves in a situation that curtails their autonomy to express disagreement, both at the national or international levels.

In this regard, the CRPD Committee should send a **strong message to States** to ensure by law and in practice the independence of organisations of persons with disabilities. In this even, the general comment should explicitly mention that OPDs 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.”[[33]](#footnote-33) In particular, to address possible internal disputes, organisations’ representatives should have “unfettered access to an independent and impartial judicial body.”[[34]](#footnote-34)

In connection with **“non-conditional public funding,”**[[35]](#footnote-35) IDA believes it might be good to provide **more concrete guidance**, as to ensure mechanisms are put in place to ensure independence[[36]](#footnote-36) and prevent potential funding cuts as reprisals. The draft should first suggest that funding schemes **should be set up in legislation**, regulating mechanisms to ensure **equitable distribution** among different organisations, to prevent arbitrary favouritisms and practices (e.g. prioritising service providers) by the government branch. In this vein, mechanisms should ensure that funding coming directly or indirectly from governments cannot be withdrawn on the basis of disagreement between the government and OPDs. Secondly, the legislative framework should foresee **sustainable core institutional funding**, instead of limiting to project-based funding, as to provide for OPDs’ autonomy in deciding their advocacy agenda. Thirdly, States must ensure that funding comes together with **long term capacity building support** to increase the capacity of OPDs and enable them to duly exercise their right to be closely consulted and actively involved. Finally, **reasonable accommodation and necessary support** should always be provided to enable persons with disabilities to participate in capacity building, as well as to be a representative of an OPD and to take part in the work of an umbrella organisation.

**IV- COMMENTS ON STATE OBLIGATIONS REGARDING THE RIGHT TO PARTICIPATION OF PERSONS WITH DISABILITIES UNDER 4.3 AND 33.3**

**IV-A) IMMEDIATE REALISATION OF THE RIGHT TO BE CONSULTED AND ACTIVELY INVOLVED**

IDA welcomes that the draft explicitly characterises the right to participation as a civil and political right of immediate realisation,[[37]](#footnote-37) including also the required provision of support for its exercise.[[38]](#footnote-38) As these elements are key, IDA believes that they should be drafted in a more straightforward manner in the beginning of para. 29, to leave no space to weaker interpretations.

In connection to this, and while implied in the previous point, IDA considers important to include an explicit statement clarifying that lack of resources cannot be put forward not to undertake close consultations with and actively involve OPDs. Regarding the placement of these points, it might be better to mention them as well in paragraphs 18 and 19, under “Scope of Article 4.3”.

**IV-B) INTERACTIONS OF ARTICLES 4.3 AND 33.3 WITH 33.1 AND 33.2**

IDA believes that paragraph 26 of the draft general comment has a confusing drafting and might be mixing different elements of the Articles considered. Further, the placement of some elements under the title “**Article 33.3: The involvement of civil society**” would be inadequate. If we may, we would like to provide our version of the points that are sought to be addressed, and we would like to suggest that the Committee reflects on the adequate placing of the different elements.

***a) Consultation and involvement under Article 4.3 prior to implement articles 33.1 and 33.2.***

IDA strongly support that the State must consult with and actively involve organisations of persons with disabilities when deciding and/or reviewing the establishment of focal points and coordination mechanisms under Article 33.1, and of independent monitoring mechanism under Article 33.2. OPDs’ experience and views can contribute in identifying weaknesses and challenges to overcome when reflecting upon the more effective institutional frameworks for national implementation and monitoring.

***b) Establishing focal points and/or coordination mechanisms under Article 31.1 must not be confused with obligations under 4.3 of the CRPD***

IDA believes there is a pervasive confusion between the obligation to undertake **broad consultations** with and actively involve organisations of persons with disabilities under Article 4.3, and the obligation to establish focal points and/or coordination mechanisms under Article 33.1. In April 2018, IDA undertook an online consultation to gather information and views by OPDs representative and allies. It was astonishing to note that, when asked about the realisation of broad consultations with persons with disabilities, respondents tended to reply focusing on the existence of disability agencies or advisory bodies that sometimes include some representatives of OPDs and other CSOs related to disability issues.

The Special Rapporteur on the Rights of Persons with Disabilities has addressed this interaction, explaining that “[w]hile disability lead agencies can be effective for strengthening the relationship between the State and civil society, they should be **complementary to direct consultations and dialogue through other formal mechanisms** as their structure usually limits the number and diversity of representative organizations of persons with disabilities.”[[39]](#footnote-39) Further, “[S]tates must promote the participation of representative organizations of persons with disabilities **beyond** disability-specific consultative bodies and mechanisms,”[[40]](#footnote-40) in other forums where wider civil society participates.

IDA believes that focal points and/or coordination mechanisms must of course be established throughout the State, at all level of governments, and be open to gather views from representative organisations of persons with disabilities, but, **while potentially contributing**, **they do not at all exhaust in themselves the obligation to undertake broad consultations and actively involve OPDs under Article 4.3.** This point, which by now is only reflected on paragraph 73 of the draft, could be better placed either in the section “Scope of Article 4.3” **to be absolutely clear from the outset that the existence of those kinds of bodies do not imply compliance with Article 4.3 of the CRPD**.

***c) Articles 33.2 and 33.3 on participation of civil society in monitoring processes***

Article 33.2 requires the existence of an independent monitoring mechanism, respectful of the Paris Principles,[[41]](#footnote-41) and well resourced.[[42]](#footnote-42) Meanwhile, **article 33.3** requires that “civil society, in particular persons with disabilities and their representative organisations, [are] involved and participate fully in the monitoring process”.

Some key points follow. Firstly, the independent monitoring mechanism must involve “civil society” in the monitoring. Secondly, these includes OPDs, **but also** other CSOs, such as Human Rights Organisations, whose expertise can contribute in terms of monitoring. Thirdly, and consequently, an independent monitoring body can meet the requirements of Art. 33(2) and (3) only if it is structured in such a way that OPDs are actively involved in the monitoring process by asking them for their advice and by securing that their voice is heard and recognized in the reports and analysis undertaken by the monitoring body.

**IV-C) THE OBLIGATION TO ENSURE ACCESSIBILITY TO ALL PERSONS WITH DISABILITIES OF ALL THE INFORMATION, FACILITIES AND PROCEDURES TO ENSURE THE RIGHT TO PARTICIPATION OF PERSONS WITH DISABILITIES**

IDA welcomes the effort of the CRPD Committee to highlight the obligation of ensure accessibility in connection to Articles 4.3 and 33.3. However, we call the Committee to further stress this key obligation and provide more detailed guidance on what it would entail in practice, in particular to face current trends that may exclude some constituencies.

The right to participation of persons with disabilities requires to highlight firstly, and broadly, that all means of communication, dissemination of information and interaction between public agencies and citizens are made accessible to all persons with disabilities in line with Articles 3(f), 9 and 21 of the CRPD, by ensuring physical accessibility of all public facilities and the provision of alternative formats and means of communication, including Braille, sign language interpretation, audio-description, Easy to Read format, tactile communication, among many others. In particular, it should be stressed that **websites of public bodies** must comply with accessibility standards.[[43]](#footnote-43)

More specifically related to Articles 4.3 and 33.3, it would be essential that the general comment elaborates, referring concrete practices, on the need that **planning** of public meetings for consultation, surveys and online consultations, **comply with accessibility standards and** explicitly foresee sufficient time for responses, to take into consideration the time connected to the diverse accessibility needs. **Very importantly, States must proactively and constantly seek involvement of all constituencies among persons with disabilities**. Monitoring attendance of meetings and online participation needs to be stressed as key to identify deficits on accessibility and gaps in representation of different constituencies and evaluate alternatives to continue fostering involvement.

Nowadays, there is **increased reliance on online methods**, e.g. online consultations through specialised websites (e.g. GoogleForms, SurveyMonkey, etc.) and online meetings through specialised platforms (e.g. Google Hangout, CISCO WebEX, GoToMeeting, accompanied by the increased use of ICTs. While these elements allow for remote participation, IDA believes that **shortcomings on accessibility that exclude persons with disabilities must be stressed.** For instance, many tools are not accessible to blind persons, and persons with intellectual disabilities might be excluded, be it for the complexity of the tool being used or because of the way information is presented (not in Easy to Read format).

We kindly ask the Committee to request States to: a) encourage service providers of these tools, mostly private sector, to undertake research to improve accessibility of their products and, b) to make sure that their own online tools are accessible and/or to provide alternative methods of consultation in accessible formats for all persons with disabilities, including persons with intellectual disabilities, and reasonable accommodation when required. In addition, concrete references to “accessible digital formats” should be added in the general comment, including in paras. 21, 38 and 63.

**IV-D) PARTICIPATION OF CIVIL SOCIETY, INCLUDING ORGANISATIONS OF PERSONS WITH DISABILITIES, IN MONITORING UNDER ARTICLE 16(3)**

IDA notes with concern that the draft general comment does not at all address explicitly the participation of civil society, including organisations of persons with disabilities, in the monitoring required by Article 16(3), regarding the right to freedom from exploitation, violence and abuse. This should be remedied.

Article 16(3) provides that “[i]n order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are **effectively monitored by independent authorities**.” It is well documented that pervasive grave violations of rights of persons with disabilities occur in facilities to “serve” persons with disabilities, such as psychiatric and/or residential institutions. In line with Article 33(3), IDA believes that, regardless of whether the “independent authority” assigned the task under Article 16(3) coincides or not with the independent monitoring mechanism under Article 33(2), civil society including OPDs should be actively involved in monitoring of those facilities and services.

**V- PRACTICAL ALTERNATIVES FOR CONSULTATION AND INVOLVEMENT OF ORGANISATIONS OF PERSONS WITH DISABILITIES**

While very much appreciative of the guidance given to States, IDA believes that the draft general comment could provide concrete examples of close consultation and active involvement of persons with disabilities in public decision making. It has to be considered that, while many State Parties already developed participatory mechanisms, either on rights of persons with disabilities or in other areas, many other States Parties might have not.

As a first step, the adoption of legislations that recognise the right to participation and involvement[[44]](#footnote-44) and regulations that establish clear procedures for consultations is key to ensure clarity for all relevant stakeholders. Peru, for instance, counts with Article 14 of the Act 29.973 establishes the **right to consultation** of representative organisations of persons with disabilities,[[45]](#footnote-45) which is complemented by a decree that foresees timeframes (30 days for providing comments), provides for accessibility of consultations and obliges to provide reasonable accommodation and support.[[46]](#footnote-46)

In the same vein, legislations and regulations should provide for the **mandatory realisation of public hearings** prior to the adoption of decisions, especially regarding the main functions of the executive and legislative branches of government, but also the judiciary in its administrative function (regulation and administration of the justice system). This would include, e.g., all draft laws and draft regulations and policies which directly or indirectly affect persons with disabilities, at all levels of government. Additional mechanisms could be suggested, such as “round tables, participatory dialogues, […] or online consultations.”[[47]](#footnote-47) This last example stresses the relevance of innovative means, both in order to ensure participation when in person participation is not possible for OPDs and accessibility of information via Internet, taking in account our previous comments under IV-C.

A major example that should be explicitly addressed in detail is the **development and implementation of legislation that affect persons with disabilities directly and indirectly**. Both governments and legislators usually develop draft legislations to submit to the plenary legislative body for debate, amendments and adoption. The general comment should put forward as a **general rule of procedure** that the relevant ministry/ies involved and/or the parliamentarian/s developing a draft proposal must involve OPDs from the outset of the discussions, before officially submitting their proposal. We insist: involving OPDs should not be at discretion of the expert ministry or government or the parliamentarian/s involved, but **a full-fledged obligation established in Acts on Administrative Procedural Law and on Parliamentarian Procedural Law,** bylaws / guidelines within the governments, and alike, complying with all accessibility duties, ensuring provision of support and of reasonable accommodation. Similarly, the same obligation should be established for and discharged by the bodies entrusted to enforce the legislation.

Regarding the exercise of the judicial function, mainly by the judiciary but sometimes by the other branches of government, procedures should provide for **public** **calls for consultation** whenever the implementation of the CRPD is at stake (e.g. public calls for **third party interventions** by OPDs when a judicial procedure may create jurisprudence on the interpretation of the CRPD).

**RECOMMENDATIONS**

For the upcoming review of the draft general comment, IDA would like to propose to the CRPD Committee to:

- Call States to develop broad consultation mechanisms, including notably organisations of persons with disabilities, in order to build legitimacy of public decisions, fostering democratic principles and governance and active citizenship participation, while stressing that Articles 4.3 establishes **the right (legal entitlement) of persons with disabilities, through OPDs**, to be consulted and actively involved in CRPD implementation and monitoring, and on other decision making processes concerning the rights of persons with disabilities. Stress should be put on the idea of “meaningful involvement” to prevent weak interpretations of this right.

- Explicitly call States to give up passive attitudes and behaviours with regard to the rights, claims and requests articulated by organisations of persons with disabilities, and to instead openly, constantly and actively approach OPDs to facilitate their meaningful involvement, as a mandatory requirement from the first input to the final product in all decision-making processes on matters that directly and indirectly affect persons with disabilities.

- Review the draft general comment utilising “organisations of persons with disabilities” as preferred terminology, and adopting a broad concept of “development of policies”, as suggested in section I-B of the submission.

- Review section II-1 of the draft general comment, incorporating our suggestions put forward in section II of this submission. In particular:

a) to stress that States must not restrict the right to participate to any specific kind of actor nor compel individuals or organisations to be part of larger coalitions, but to undertake broad consultations and actively involving persons with disabilities, through their OPDs;

b) to include the category “organisations of persons with intellectual disabilities composed and governed by persons with intellectual disabilities and family members”, considering the comments done on the role of relatives of persons with intellectual disabilities;

c) to incorporate the international standards related to children´s freedom of association and right to express their views, in line with section II-C of this submission.

- To uphold the standards referred to the right to freedom of association addressed in section III of this submission, in particular by calling States to:

a) to ensure non-registered organisations of persons with disabilities are protected by the law;

b) to ensure that registration systems are simple, flexible, expeditious, fully accessible, non-onerous and/or even free of charge, to facilitate the registration of organizations of persons with disabilities;

c) to ensure that organisations of persons with disabilities **to operate independently**; and can access non-conditional public funding, distributed equitably and focused on sustainable core institutional funding rather than project based, to ensure autonomy in deciding their advocacy agenda,

d) to ensure that organisations of persons with disabilities **are provided with long term capacity building support** to increase their capacity and enable them to duly exercise their right to be closely consulted and actively involved in public decision making, implementation and monitoring.

- To incorporate the suggestions put forward in section IV of this submission, including by explicitly stating that lack of resources does not excuse non-compliance with the State obligation to consult and involve OPDs, and by reorganising the elements highlighted related to interaction between Articles 4(3), 33(1), (2) and (3).

- To further elaborate on State obligation related to accessibility in the implementation of Articles 4(3) and 33(3), explicitly referring concrete elements to consider, such as the duty to ensure physical accessibility to facilities, accessibility to information and communication, including through Braille, sign language interpretation, audio-description, Easy to Read format, tactile communication, and accessible digital formats, among others; accessibility of procedures and provision of reasonable accommodation and support when required; and to promote research to improve innovative online based means of disseminating information and holding consultations.

**ANNEX I – Additional drafting proposals**

**Paragraph 11, sub-para (a)**

Change “best practices” by “good practices”.

**Paragraph 11, sub-para (b)**

“On the basis of certain impairments” should be substituted by “due to restrictions on their legal capacity”.

**Paragraph 11, sub-para (d)**

It should also include persons with multiple disabilities, and those living in rural, remote and isolated regions, and, in particular, persons with disabilities who are committed into forced institutionalization

**Paragraph 11**

It should also include “coalitions.”

**Paragraph 16**

It should also be included that OPDs may be part of mainstream umbrella CSO that do not necessarily advocate for the rights of persons with disabilities, but that can be helpful in mainstreaming the rights of persons with disabilities. For instance, organizations of women with disabilities may be part of a broader women’s umbrella organization advocating for sexual and reproductive health and rights, and that organization of WWD could brings the disability rights perspective into that advocacy effort and into the umbrella organization

IDA suggests to adopt the common use as synonyms of CSOs and NGOs, to prevent confusing in the readers. Below our proposed version of paragraph 16:

**"16. Distinction should also be made between DPOs/OPDs and civil society organizations (CSO). The term CSOs comprises different kind of organisations, including research organisations/institutes, organizations of service providers, families and other private stakeholders. DPOs/OPDs are a specific type of CSOs. OPDs may be part of mainstream umbrella CSO and/or coalitions that do not necessarily advocate specifically for the rights of persons with disabilities, but that can be helpful in mainstreaming the rights of persons with disabilities. In line with Article 33.3, all CSOs, including OPDs have a role to play in monitoring the Convention.”**

**Paragraph 30**

“30. States parties have an obligation to respect the right of persons with disabilities, through their **~~DPOs/~~**OPDs to be closely and meaningful consulted and actively involved in decision-making processes by ensuring transparency of consultation and early involvement. States parties should not withhold information, or condition or prevent DPOs/OPDs from freely expressing their views in the consultation and involvement in decision-making, implementation and monitoring processes. **States must not discriminate nor exclude persons with disabilities and on the basis of kind of disability, age, sex, gender identity, sexual orientation, nationality, ethnic, indigenous and/or rural background, asylum-seeking and refugee status.”**

**Paragraph 34 (to consider jointly with para. 35, as it might be useful to merge)**

34. **~~Persons with disabilities, through their DPOs/OPDs, can only effectively participate whether~~ T**he views **of persons with disabilities, through their OPDs,** **~~are~~** must be given due weight guaranteeing that they are not only heard as a mere formality or as part of a mere tokenistic approach to consultation. [Furthermore, their views should be **~~considered as no less important~~** **given priority over those from** **~~than~~** other actors, under article 4.3 (see para. …)]. …

**Paragraph 35**

“As a legal duty, States parties should “give priority” to views of DPOs/OPDs, **take into account the results of such consultations and reflect them in the decisions adopted,** and refrain from adopting measures that would openly contradict the result of close consultations.”

**Paragraph 36 (and 38, 46, 57, 61, 62 and 63)**

IDA would like to suggest to avoid the use of “persons with intellectual **and/or** psychosocial disabilities” and to replace it with “persons with intellectual **and persons with** psychosocial disabilities”. This proposal seeks to prevent any confusion of two different constituencies by lay readers of the general comment.

**Paragraph 44**

“Funds should not only be intended for service providers, but rather be aimed at existing and potential DPOs/OPDs focusing primarily on advocacy, **be distributed equitably among different organizations including sustainable core institutional funding, instead of limited to project-based funding, as to provide for OPDs’ autonomy in deciding their advocacy agenda.”**

**Paragraph 50**

the entire article 4 is about States’ general obligations and under this article the provision of 4.3 is included; the nature of this entire article is cross-cutting to all the other articles, but 4.3 must apply, first and before the rest of articles, to other paras in this article, most fundamentally, paras 4.1 and 4.2.

“50. As part of the States parties’ general obligations, article 4.3 of the Convention applies to the entire Convention and is of particular importance for implementing all other **obligations**. **~~Articles~~ …**.”

**Paragraph 53 and 54:**

“Young persons”, as referred to paragraph 54, should also be included in paragraph 53.

**Paragraph 56**

This paragraph is somehow repetitive of para 64. IDA suggests deleting the following sentence: “Children with disabilities and, when appropriate, their families, must be recognized as partners and not merely recipients of education“.

**Paragraph 60**

“…and participation in decision-making processes should be guaranteed to all persons with disabilities, including persons with intellectual and/or **persons with** psychosocial disabilities as well as children with disabilities…”

**Paragraph 62**

“…DPOs/OPDs must be consulted and involved, especially those representing children, women and persons with intellectual and/or **persons with** psychosocial disabilities. **In particular, deinstitutionalisation processes require the close consultation and active involvement of persons currently living in institutions**”

**Paragraph 66**

“When taking, developing and reviewing measures, strategies, programs, policies and legislation in relation to the implementation of article 28, as well as in the monitoring process thereof, States parties **should ~~partner up~~** **closely consult and actively involve** with **~~DPOs/~~**OPDs representing all kinds of disabilities to ensure the mainstream of disability and that the requirements and views of all persons with disabilities are duly taken into consideration.”

**Paragraph 68 / Paragraph 69**

These paragraphs could be merged into only one.

“… The system should be established to enable the formulation and implementation of policies to give effect to the Convention, through close collaboration with DPOs/OPDs, and **~~guided by~~** **utilising[[48]](#footnote-48)** the Washington Group on Disability Statistics.”

**Paragraph 71**

IDA believes that this paragraph might be repetitive. We refer to our comments in **section IV-B**, observing paragraph 26 of the draft general comment.

**Para 75, subparagraphs:**

**(a)** Repeal all laws that prevent any person with disabilities, **including legislation that fully or partially restricts legal capacity”**

**(d)** “to ensure the inclusion and full participation of persons with all kinds of disabilities, **including the most underrepresented groups of persons with disabilities**”

**(m)** at the beginning of the paragraph, instead of “Provide”, the proposal is **“Ensure the provision of”**

**Add a subparagraph:**

**“Promote and ensure participation and involvement of persons with disabilities, through their representative DPOs/OPDs in international human rights mechanisms”**

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1. E.g. by the International Disability Caucus between 2004 and 2006. [↑](#footnote-ref-1)
2. See e.g., Universal Declaration of Human Rights, Article 21; and International Covenant on Civil and Political Rights, Article 25. [↑](#footnote-ref-2)
3. Office of the United Nations High Commissioner for Human Rights (OHCHR), Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies, para. 64. [↑](#footnote-ref-3)
4. In occasions, consultations, foreseen through disability related bodies which may include OPDs and NGOs representatives (see section IV-B-b), are merely “consultative” implying that ministries and public authorities ***might*** consult them, not necessarily being obliged to do so. See e.g. France, Code de l'action sociale et des familles, Article L146-1 : Le Conseil national consultatif des personnes handicapées assure la participation des personnes handicapées à l'élaboration et à la mise en œuvre des politiques les concernant. Il **peut être consulté** par les ministres compétents sur tout projet, programme ou étude intéressant les personnes handicapées. Il **peut se saisir** de toute question relative à la politique concernant les personnes handicapées.» [↑](#footnote-ref-4)
5. CRPD Committee, Draft General Comment no. 7, para. 15. [↑](#footnote-ref-5)
6. A/HRC/31/62, op. cit. para. 36. [↑](#footnote-ref-6)
7. The use of the verbs “can” and “should” are illustrative of this. [↑](#footnote-ref-7)
8. Further, if well received, this comment should also impact **paras. 41 and 75(d)** of the draft. [↑](#footnote-ref-8)
9. A/HRC/31/62, para. 37. [↑](#footnote-ref-9)
10. 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-10)
11. While we will deal with the case of children with disabilities in the following section, IDA believes that it is more appropriate to always use the more neutral term of “relatives”, instead of “parents” or “family members”. [↑](#footnote-ref-11)
12. A/HRC/31/62, para. 37. [↑](#footnote-ref-12)
13. This is the case within IDA itself. Article 8 of its Statutes read: “Organisations of persons with intellectual disabilities composed and governed by persons with intellectual disabilities and family members.” (preamble x). [↑](#footnote-ref-13)
14. CRC/C/GC/12, para. 128. Throughout this general comment, there are several references to children-led organisations in different areas of life (e.g. education, prevention of violence, etc.) [↑](#footnote-ref-14)
15. CRC/C/GC/20, para. 24. [↑](#footnote-ref-15)
16. CRC/C/GC/20, para. 54. [↑](#footnote-ref-16)
17. CRC/C/GC/20, para. 32. [↑](#footnote-ref-17)
18. See below, section III on the right to freedom of association. [↑](#footnote-ref-18)
19. CRC/C/GC/12, para. 134. [↑](#footnote-ref-19)
20. See previous suggestion to replace “parents” by “relatives”. [↑](#footnote-ref-20)
21. CRPD Committee, Draft General Comment no. 7, para. 75(b). [↑](#footnote-ref-21)
22. CRPD/C/OMN/CO/1, para. 10 (recommending to adopt concrete measures, including amending the “Civil Associations Act (2000) to create and ensure an enabling environment in which civil society organizations may be established and freely conduct their activities“). [↑](#footnote-ref-22)
23. See e.g., CRPD Committee’s Concluding Observations on Oman stating that “NGOs including Disabled People Organizations operate within restricted boundaries established by Oman Civil Associations Act (2000).” [↑](#footnote-ref-23)
24. A/HRC/31/62, para. 37. [↑](#footnote-ref-24)
25. A/HRC/20/27, para. 56. [↑](#footnote-ref-25)
26. A/HRC/31/62, para. 44. [↑](#footnote-ref-26)
27. A/HRC/31/62, para. 45. [↑](#footnote-ref-27)
28. A/HRC/20/27, para. 56. [↑](#footnote-ref-28)
29. A/HRC/31/62, para. 40. [↑](#footnote-ref-29)
30. A/HRC/20/27, para. 60. See also the ECHR’s rulling cited stating that „significant delays in the registration procedure, if attributable to the Ministry of Justice, amounts to an interference with the exercise of the right of the association‟s founders to freedom of association” (Ismayilov v. Azerbaijan, application No. 4439/04, 17 January 2008, para. 48) [↑](#footnote-ref-30)
31. A/HRC/31/62, para. 51. [↑](#footnote-ref-31)
32. CRPD Committee, Draft General Comment no. 7, para. 75(b). [↑](#footnote-ref-32)
33. A/HRC/31/62, para. 42. [↑](#footnote-ref-33)
34. A/HRC/31/62, para. 45. [↑](#footnote-ref-34)
35. CRPD Committee, Draft General Comment no. 7, paras. 38, 42, 44, 46, 47, etc. [↑](#footnote-ref-35)
36. See also CRPD/C/RUS/CO/1, para. 12. [↑](#footnote-ref-36)
37. DGC 7, paras. 29. [↑](#footnote-ref-37)
38. DGC 7, paras. 23. [↑](#footnote-ref-38)
39. A/HRC/31/62, para. 68. [↑](#footnote-ref-39)
40. A/HRC/31/62, para. 70. [↑](#footnote-ref-40)
41. Develop footnote based on paragraphs 10 and 11 of the Guidelines on IMF. [↑](#footnote-ref-41)
42. See e.g. CRPD/C/NPL/CO/1, para. 50; CRPD/C/OMN/CO/1, para. 60(b); CRPD/C/SVN/CO/1, para. 58(b), among many others. [↑](#footnote-ref-42)
43. E.g. EU Directive 2016/2102 on the accessibility of the websites and mobile applications of public sector bodies. [↑](#footnote-ref-43)
44. See e.g., Spain, Real Decreto Legislativo 1/2013, Article 54 (2). [↑](#footnote-ref-44)
45. Perú, Act 29.973, article 14: “The authorities of the different sectors and levels of government have the obligation to consult with the organizations that represent people with disabilities, prior to the adoption of legislative and administrative norms, policies and programs on issues related to disability.“ [↑](#footnote-ref-45)
46. Decreto Supremo Nº 002-2014-MIMP, Article 12 - Right to consultation of persons with disabilities. [↑](#footnote-ref-46)
47. A/HRC/31/62, para. 68. [↑](#footnote-ref-47)
48. The Committee has recently used this language in CRPD/C/NPL/CO/1, para. 46; and CRPD/C/OMN/CO/1, para. 56. [↑](#footnote-ref-48)