



Convention on the Rights of Persons with Disabilities

Committee on the Rights of Persons with Disabilities

General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention *

I. Introduction

1. Persons with disabilities were fully involved and played a decisive role in the negotiation, development and drafting of the Convention on the Rights of Persons with Disabilities. The close consultation and active involvement of persons with disabilities, through organizations of persons with disabilities and their partners, had a positive impact on the quality of the Convention and its relevance for such persons. It also showed the force, influence and potential of persons with disabilities, which resulted in a groundbreaking human rights treaty and established the human rights model of disability. The effective and meaningful participation of persons with disabilities, through their representative organizations, is thus at the heart of the Convention.

2. The active and informed participation of everyone in decisions that affect their lives and rights is consistent with the human rights-based approach in public decision-making processes, and ensures good governance and social accountability.

3. The principle of participation in public life is well established in article 21 of the Universal Declaration of Human Rights and reaffirmed in article 25 of the International Covenant on Civil and Political Rights. Participation, as a principle and a human right, is also recognized in other human rights instruments, such as under article 5 (c) of the International Convention on the Elimination of All Forms of Racial Discrimination, article 7 of the Convention on the Elimination of All Forms of Discrimination against Women, and articles 12 and 23 (1) of the Convention on the Rights of the Child. The Convention on the Rights of Persons with Disabilities recognizes participation as both a general obligation and a cross-cutting issue. In fact, it enshrines the obligation of States parties to closely consult and actively involve persons with disabilities (art. 4 (3)) and the participation of persons with disabilities in the monitoring process (art. 33 (3)) as part of a wider concept of participation in public life.

4. Often, persons with disabilities are not consulted in the decision-making about matters relating to or affecting their lives, with decisions continuing to be made on their behalf. Consultation with persons with disabilities has been acknowledged as important in the last few decades, thanks to the emergence of movements of persons with disabilities demanding recognition of their human rights and their role in determining those rights. The motto “nothing about us without us” resonates with the philosophy and history of the disability rights movement, which relies on the principle of meaningful participation.

5. Persons with disabilities still face significant attitudinal, physical, legal, economic, social and communication barriers to participate in public life. Before the entry into force of the Convention, the views of persons with disabilities were dismissed in favour of those of third-party representatives, such as organizations “for” persons with disabilities.

6. The participatory processes and the involvement of persons with disabilities, through their representative organizations, in the negotiation and drafting of the Convention proved to be an excellent example of the principle of full and effective participation, individual autonomy and the freedom to make one’s own decisions. As a result, international human rights law now recognizes unequivocally persons with disabilities as “subjects” of all human rights and fundamental freedoms.

7. Based on its jurisprudence, the Committee aims to clarify States parties’ obligations under articles 4 (3) and 33 (3) and their implementation in this general comment. The Committee notes the progress made by States parties to implement the provisions under articles 4 (3) and 33 (3) over the past decade, such as granting financial or other assistance to organizations of persons with disabilities, including persons with disabilities in independent monitoring frameworks established pursuant to article 33 (2) of the Convention, and in monitoring processes. Moreover, some States parties have consulted with organizations of persons with disabilities in the preparation of their initial and periodic reports to the Committee in accordance with articles 4 (3) and 35 (4).

8. The Committee, however, continues to observe an important gap between the goals and the spirit of articles 4 (3) and 33 (3) and the degree to which they have been implemented. This is due, among other things, to the absence of meaningful consultation with and involvement of persons with disabilities, through their representative organizations, in the development and implementation of policies and programmes.

9. States parties should acknowledge the positive impact on decision-making processes and the necessity of involving and ensuring the participation of persons with disabilities, through their representative organizations, in such processes, notably because of their lived experiences and knowledge of the rights to be implemented. States parties should also consider the general principles of the Convention in all measures taken for its implementation and monitoring, and in advancing the 2030 Agenda for Sustainable Development and its goals.

II. Normative content of articles 4 (3) and 33 (3)

A. Definition of “representative organizations”

10. The involvement and participation of persons with disabilities through “representative organizations”, or organizations of persons with disabilities, is inherent in both articles 4 (3) and 33 (3). For proper implementation, it is important for States parties and the relevant stakeholders to define the scope of organizations of persons with disabilities and recognize the different types that often exist.

11. The Committee considers that organizations of persons with disabilities should be rooted, committed to and fully respect the principles and rights recognized in the Convention. They can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves. Organizations of women with disabilities, children with disabilities and persons living with HIV/AIDS are organizations of persons with disabilities under the Convention. Organizations of persons with disabilities have certain characteristic aspects, including the fact that:

- (a) They are established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities and should be generally recognized as such;
- (b) They employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves;
- (c) They are not affiliated, in the majority of cases, to any political party and are independent from public authorities and any other non-governmental organizations of which they might be part/members of;
- (d) They may represent one or more constituencies based on actual or perceived impairment or can be open to membership of all persons with disabilities;
- (e) They represent groups of persons with disabilities reflecting the diversity of their backgrounds (in terms of, for example, sex, gender, race, age, or migrant or refugee status). They can include constituencies based on transversal identities (for example, children, women or indigenous people with disabilities) and comprise members with various impairments;
- (f) They can be local, national, regional or international in scope;
- (g) They can operate as individual organizations, coalitions or cross-disability or umbrella organizations of persons with disabilities, seeking to provide a collaborative and coordinated voice for persons with disabilities in their interactions with, among others, public authorities, international organizations and private entities.

12. Among the different types of organizations of persons with disabilities that the Committee has identified are:

- (a) Umbrella organizations of persons with disabilities, which are coalitions of representative organizations of persons with disabilities. Ideally, there should be only one or two umbrella organizations at each level of decision-making. To be open, democratic and represent the full and wide diversity of persons with disabilities, they should accept all organizations of persons with disabilities as members. They should be organized, led and controlled by persons with disabilities. They only speak on behalf of their member organizations and solely on matters that are of mutual interest and collectively decided upon. However, they cannot represent individual persons with disabilities because they often lack detailed knowledge of personal backgrounds. Individual organizations of persons with disabilities representing specific communities are in a better position to play such a role. However, persons with disabilities should be able to decide for themselves which organizations they want to represent them. The existence of umbrella organizations within States parties should not, under any circumstances, hinder individuals or organizations of persons with disabilities from participating in consultations or other forms of promoting the interests of persons with disabilities;
- (b) Cross-disability organizations, which are composed of persons representing all or some of the wide diversity of impairments. They most frequently organize at the local and/or national levels, but can also exist at the regional and international levels;
- (c) Self-advocacy organizations representing persons with disabilities in different, often loosely and/or locally formed, networks and platforms. They advocate for the rights of persons with disabilities, especially persons with intellectual disabilities. Their establishment, with appropriate, sometimes extensive, support to enable their members to express their opinions, is of fundamental importance to political participation and participation in decision-making, monitoring and implementation processes. This is particularly relevant for persons who are prevented from exercising their legal capacity, institutionalized and/or denied the right to vote. In many countries, self-advocacy organizations are discriminated against through the refusal of a legal status because of laws and regulations that deny the legal capacity of their members;
- (d) Organizations including family members and/or relatives of persons with disabilities, which are pivotal in facilitating, promoting and securing the interests and supporting the autonomy and active participation of their relatives with intellectual disabilities, dementia and/or children with disabilities, when these groups of persons with disabilities want to be supported by their families as united networks or organizations. In such cases, these organizations should be included in consultation, decision-making and monitoring processes. The role of parents, relatives and caregivers in such organizations should be to assist and empower persons with disabilities to have a voice and take full control of their own lives. Such organizations should actively work to promote and use supported decision-making processes to ensure and respect the right of persons with disabilities to be consulted and to express their own views;
- (e) Organizations of women and girls with disabilities, which represent women and girls with disabilities as a heterogeneous group. The diversity of women and girls with disabilities should include all types of impairments. Ensuring the participation of women and girls with disabilities is indispensable in consultations addressing specific issues that exclusively or disproportionately affect women and girls with disabilities, and issues related to women and girls in general, such as gender equality policies;
- (f) Organizations and initiatives of children and young persons with disabilities, which are fundamental for the participation of children in public and community life and for their right to be heard and their freedom of expression and association.

Adults have a key and supportive role to play in promoting an environment that enables children and young persons with disabilities to establish and act, formally or informally, within their own organizations and initiatives, including through cooperation with adults and other children and young persons.

B. Distinction between organizations of persons with disabilities and other civil society organizations

13. Organizations of persons with disabilities should be distinguished from organizations “for” persons with disabilities, which provide services and/or advocate on behalf of persons with disabilities, which, in practice, may result in a conflict of interests in which such organizations prioritize their purpose as private entities over the rights of persons with disabilities. States parties should give particular importance to the views of persons with disabilities, through their representative organizations, support the capacity and empowerment of such organizations and ensure that priority is given to ascertaining their views in decision-making processes.

14. A distinction should also be made between organizations of persons with disabilities and civil society organizations. The term “civil society organization” comprises different kinds of organizations, including research organizations/institutes, organizations of service providers and other private stakeholders. Organizations of persons with disabilities are a specific type of civil society organization. They may be part of a mainstream umbrella civil society organization and/or coalitions that do not necessarily advocate specifically for the rights of persons with disabilities, but can support in mainstreaming their rights in the human rights agenda. In accordance with article 33 (3), all civil society organizations, including organizations of persons with disabilities, have a role to play in monitoring the Convention. States parties should give priority to the views of organizations of persons with disabilities when addressing issues related to persons with disabilities, and develop frameworks to request civil society organizations and other stakeholders to consult and involve organizations of persons with disabilities in their work related to the rights enshrined in the Convention and other topics, such as non-discrimination, peace and environmental rights.

C. Scope of article 4 (3)

15. To implement their obligations under article 4 (3), States parties should include the obligation to closely consult and actively involve persons with disabilities, through their own organizations, in legal and regulatory frameworks and procedures across all levels and branches of Government. States parties should also consider consultations with and the involvement of persons with disabilities as a mandatory step prior to the approval of laws, regulations and policies, whether mainstream or disability specific. Therefore, consultations should begin in the early stages and provide an input to the final product in all decision-making processes. Consultations should include organizations representing the wide diversity of persons with disabilities, at the local, national, regional and international levels.

16. All persons with disabilities, without any form of exclusion based on the type of impairment, such as persons with psychosocial or intellectual disabilities, can effectively and fully participate without discrimination on an equal basis with others. The right to participate in consultations, through their representative organizations, should be recognized on an equal basis for all persons with disabilities, irrespective of, for example, their sexual orientation and gender identity. States parties should adopt a comprehensive anti-discrimination framework to ensure the rights and fundamental freedoms of all persons with disabilities, and withdraw legislation criminalizing individuals or organizations of persons with disabilities on grounds of sex, gender or the social status of its members and denying them their rights to participate in public and political life.

17. The legal obligation of States parties to ensure consultations with organizations of persons with disabilities encompasses access to public decision-making spaces and also other areas of research, universal design, partnerships, delegated power and citizen control. Furthermore, it is an obligation that includes global and/or regional organizations of persons with disabilities.

1. Issues relating to persons with disabilities

18. The phrase “concerning issues relating to persons with disabilities”, as referred to in article 4 (3), covers the full range of legislative, administrative and other measures that may directly or indirectly impact the rights of persons with disabilities. The broad interpretation of issues relating to persons with disabilities allows States parties to mainstream disability through inclusive policies, ensuring that persons with disabilities are considered on an equal basis with others. It also ensures that the knowledge and life experiences of persons with disabilities are considered when deciding upon new legislative, administrative and other measures. This includes decision-making processes, such as general laws and the public budget or disability-specific laws, which might have an impact on their lives.

19. Consultations under article 4 (3) prevent States parties from engaging in any act or practice that may be inconsistent with the Convention and the rights of persons with disabilities. In cases of dispute about the direct or indirect impact of the measures under discussion, it falls to the public authorities of the States parties to prove that the issue under discussion would not have a disproportionate effect on persons with disabilities and, therefore, that no consultation is required.

20. Examples of issues directly affecting persons with disabilities are deinstitutionalization, social insurance and disability pensions, personal assistance, accessibility requirements and reasonable accommodation policies. Measures indirectly affecting persons with disabilities might concern constitutional law, electoral rights, access to justice, the appointment of the administrative authorities governing disability-specific policies or public policies in the field of education, health, work and employment.

2. “Closely consult with and actively involve”

21. To “closely consult with and actively involve” persons with disabilities through their representative organizations is an obligation under international human rights law that requires the recognition of every person’s legal capacity to take part in decision-making processes based on their personal autonomy and self-determination. Consultation and involvement in decision-making processes to implement the Convention, and in other decision-making processes, should involve all persons with disabilities and, when necessary, supported decision-making regimes.

22. States parties should systematically and openly approach, consult and involve, in a meaningful and timely manner, organizations of persons with disabilities. This requires access to all relevant information, including the websites of public

bodies, through accessible digital formats and reasonable accommodation when required, such as the provision of sign language interpreters, Easy Read text and plain language, Braille and tactile communication. Open consultations provide persons with disabilities with access to all the spaces of public decision-making, on an equal basis with others, including national funds and all the relevant public decision-making bodies relevant to the implementation and monitoring of the Convention.

23. Public authorities should give due consideration and priority to the opinions and views of organizations of persons with disabilities when addressing issues directly related to persons with disabilities. Public authorities leading decision-making processes have a duty to inform organizations of persons with disabilities of the outcomes of such processes, including an explicit explanation in an understandable format of the findings, considerations and reasoning of decisions on how their views were considered and why.

3. Including children with disabilities

24. Article 4 (3) also acknowledges the importance of systematically “including children with disabilities” in the development and implementation of legislation and policies to give effect to the Convention, and in other decision-making processes, through organizations of children with disabilities or supporting children with disabilities. These organizations are key in facilitating, promoting and securing the individual autonomy and active participation of children with disabilities. States parties should create an enabling environment for the establishment and functioning of representative organizations of children with disabilities as part of their obligation to uphold the right to freedom of association, including appropriate resources for support.

25. States parties should adopt legislation, regulations and develop programmes to ensure that everyone understands and respects the will and preferences of children and considers their personal evolving capacities at all times. The recognition and promotion of the right to individual autonomy is of paramount importance for all persons with disabilities, including children, to be respected as rights holders. Children with disabilities are themselves best placed to express their own requirements and experiences, which are necessary in developing appropriate legislation and programmes in accordance with the Convention.

26. States parties can organize seminars/meetings in which children with disabilities are invited to express their opinions. They could also make open invitations to children with disabilities to submit essays on specific topics, encouraging them to elaborate on their first-hand experiences or life expectations. The essays could be summarized as inputs from the children themselves and directly included in decision-making processes.

4. Full and effective participation

27. “Full and effective participation” (art. 3 (c)) in society refers to engaging with all persons, including persons with disabilities, to provide for a sense of belonging to and being part of society. This includes being encouraged and receiving appropriate support, including peer support and support to participate in society, and being free from stigma and feeling safe and respected when expressing oneself in public. Full and effective participation requires that States parties facilitate participation and consult with persons with disabilities representing the wide diversity in impairments.

28. The right to participate is a civil and political right and an obligation of immediate application, not subject to any form of budgetary restriction, to be applied to decision-making, implementation and monitoring processes related to the Convention. By guaranteeing the participation of organizations of persons with disabilities at each of these stages, persons with disabilities would be able to better identify and point out measures that could either advance or hinder their rights, which ultimately yields better outcomes for such decision-making processes. Full and effective participation should be understood as a process, not as an individual one-time event.

29. The participation of persons with disabilities in implementing and monitoring the Convention is possible when such persons can exercise their rights to freedom of expression, peaceful assembly and association as enshrined in articles 19, 21 and 22 of the International Covenant on Civil and Political Rights. Persons with disabilities and their representative organizations engaging in public decision-making processes to implement and monitor the Convention should be recognized in their role as human rights defenders, and be protected against intimidation, harassment and reprisals, particularly when expressing dissenting opinions.

30. The right to participate also encompasses obligations related to the right to due process and the right to be heard. States parties that closely consult with and actively involve organizations of persons with disabilities in public decision-making also give effect to the right of persons with disabilities to full and effective participation in public and political life, including the right to vote and stand for elections (article 29 of the Convention).

31. Full and effective participation entails the inclusion of persons with disabilities in different decision-making bodies, both at local, regional, national and international levels, and in national human rights institutions, ad hoc committees, councils and regional or municipality organizations. States parties should recognize in their legislation and practice that all persons with disabilities can be nominated or elected to any representative bodies: for example, ensuring the nomination of persons with disabilities to disability councils at the municipal level, or as specific disability-rights office-holders in the composition of national human rights institutions.

32. States parties should strengthen the participation of organizations of persons with disabilities at the international level, for instance at the high-level political forum on sustainable development, and regional and universal human rights mechanisms. The participation of persons with disabilities, through their representative organizations, will thus result in greater effectiveness and equal use of public resources, leading to improved outcomes for such persons and their communities.

33. Full and effective participation can also be a transformative tool for social change, and promote agency and empowerment of individuals. The involvement of organizations of persons with disabilities in all forms of decision-making strengthens the ability of such persons to advocate and negotiate, and empowers them to more solidly express their views, realize their aspirations and reinforce their united and diverse voices. States parties should ensure the full and effective participation of persons with disabilities, through their representative organizations, as a measure to achieve their inclusion in society and combat discrimination against them. States parties that ensure full and effective participation and engage with

organizations of persons with disabilities improve transparency and accountability, making them responsive to the requirements of such persons.

D. Article 33: involvement of civil society in national implementation and monitoring

34. Article 33 of the Convention establishes national implementation mechanisms and independent monitoring frameworks and provides for the participation of organizations of persons with disabilities therein. Article 33 should be read and understood as supplementing article 4 (3).

35. Article 33 (1) requires States parties to establish one or more focal points and/or coordinating mechanisms to secure implementation of the Convention and facilitate related action. The Committee recommends that States parties' focal points, and/or coordinating mechanisms, include the representatives of organizations of persons with disabilities, and formal procedures of engagement and liaison with such organizations, in consultation processes related to the Convention.

36. In accordance with article 33 (2), the Committee has recognized the importance of establishing, maintaining and promoting independent monitoring frameworks, including national human rights institutions, at all stages of the monitoring process. Such institutions play a key role in the monitoring process of the Convention, in promoting compliance at the national level and in facilitating the coordinated actions of national actors, including State institutions and civil society, to protect and promote human rights.

37. Article 33 (3) emphasizes the obligation of States parties to ensure that civil society is involved and can participate in the independent monitoring framework established according to the Convention. The involvement of civil society should include persons with disabilities, through their representative organizations.

38. States parties should ensure that independent monitoring frameworks allow for, facilitate and ensure the active involvement of organizations of persons with disabilities in such frameworks and processes, through formal mechanisms, ensuring that their voices are heard and recognized in its reports and the analysis undertaken. The inclusion of organizations of persons with disabilities in the independent monitoring framework and the work thereof can take several forms, for example, through seats on the board of or advisory bodies to the independent monitoring frameworks.

39. Article 33 (3) implies that States parties should support and fund the strengthening of capacity within civil society, in particular organizations of persons with disabilities, to ensure their effective participation in the processes of the independent monitoring frameworks. Organizations of persons with disabilities should have appropriate resources, including support through independent and self-managed funding, to take part in the independent monitoring frameworks and ensure that reasonable accommodation and accessibility requirements for its membership are met. The support and funding of organizations of persons with disabilities in relation to article 33 (3) complement States parties' obligations under article 4 (3) of the Convention and do not preclude them.

40. Both the Convention and the related strategies for implementation should be translated and made accessible and available to persons representing the wide diversity of impairments. States parties should provide persons with disabilities with access to information that allows them to understand and evaluate the issues in the decision-making process and provide meaningful inputs.

41. To implement article 33 (3), States parties should ensure that organizations of persons with disabilities have easy access to the focal points within Government and/or the coordination mechanism.

III. Obligations of States parties

42. In its concluding observations, the Committee has reminded States parties of their duty to closely and timely consult with, and actively involve, persons with disabilities, through their representative organizations, including those representing women and children with disabilities, in the development and implementation of legislation and policies to implement the Convention and in other decision-making processes.

43. States parties have an obligation to ensure the transparency of consultation processes, the provision of appropriate and accessible information and early and continuous involvement. States parties should not withhold information, condition or prevent organizations of persons with disabilities from freely expressing their opinions in consultations and throughout decision-making processes. This includes both registered and unregistered organizations, in accordance with the right to freedom of association, which should be prescribed by law and protect associations that are not registered on an equal basis.

44. States parties should not require an organization of persons with disabilities to be registered as a prerequisite for taking part in broad consultation processes. They should, however, ensure that organizations of persons with disabilities are able to register and exercise their right to participate under articles 4 (3) and 33 (3), providing free and accessible registration systems and facilitating the registration of such organizations.

45. States parties should ensure accessibility for persons with disabilities to all facilities and procedures related to public decision-making and consultation. States parties should take appropriate measures to provide persons with disabilities, including persons with autism, with access, on an equal basis with others, to the physical environment, including buildings, transportation, education, information and communications in one's own language, including new information technologies and systems, and the websites of public bodies, and other facilities and services open or provided to the public, in both urban and rural settings. States parties should also ensure that consultation processes are accessible — for example, by providing sign language interpreters, Braille and Easy Read — and must provide support, funding and reasonable accommodation as appropriate and requested, to ensure the participation of representatives of all persons with disabilities in consultation processes, as defined in paras. 11, 12 and 50.

46. Organizations of persons with sensory and intellectual impairments, including organizations of self-advocates and organizations of persons with psychosocial disabilities should be provided with meeting assistants and support persons, information in accessible formats (such as plain language, Easy Read, alternative and augmentative communication systems and pictograms), sign language interpretation, guide interpreters for deafblind persons and/or captioning during public debates. States parties should also allocate financial resources for covering expenditures related to the consultation processes

for representatives of organizations of persons with disabilities, including transport and other expenses necessarily incurred to attend meetings and technical briefings.

47. Consultations with organizations of persons with disabilities should be based on transparency, mutual respect, meaningful dialogue and a sincere aim to reach a collective agreement on procedures that respond to the diversity of persons with disabilities. Such processes should allow for reasonable and realistic timelines taking into account the nature of the organizations of persons with disabilities, which often depend on the work of “volunteers”. States parties should undertake periodic evaluations of the functioning of their participation and consultation mechanisms, with the active involvement of organizations of persons with disabilities.

48. The views of persons with disabilities, through their representative organizations, should be given due weight. States parties should guarantee that they are not only heard as a mere formality or as a tokenistic approach to consultation. States parties should take into account the results of such consultations and reflect them in the decisions adopted, by duly informing participants of the outcome of the process.

49. States parties should in close and effective consultation and with the active involvement of organizations of persons with disabilities establish proper and transparent mechanisms and procedures, at the different branches and levels of Government, to explicitly consider the views of such organizations when motivating a public decision.

50. States parties should ensure the close consultation and active involvement of organizations of persons with disabilities, which represent all persons with disabilities, including but not limited to women, older persons, children, those requiring high levels of support, victims of landmines, migrants, refugees, asylum seekers, internally displaced persons, undocumented and stateless persons, persons with actual or perceived psychosocial impairments, persons with intellectual disabilities, neurodiverse persons, including those with autism or dementia, persons with albinism, permanent physical impairments, chronic pain, leprosy and visual impairments and persons who are deaf, deafblind or otherwise hearing-impaired and/or those living with HIV/AIDS. The obligation of States parties to involve organizations of persons with disabilities also encompasses those persons with disabilities with a specific sexual orientation and/or gender identity, intersex persons with disabilities, and persons with disabilities belonging to indigenous peoples, national, ethnic, religious or linguistic minorities, and those living in rural areas.

51. States parties should prohibit discriminatory and other practices by third parties, such as service providers, directly or indirectly interfering with the right of persons with disabilities to be closely consulted and actively involved in decision-making processes related to the Convention.

52. States parties should adopt and implement laws and policies to ensure that persons with disabilities can exercise their right to be consulted and not deterred from involvement by others. These measures include raising awareness among family members, service providers and public employees on the rights of persons with disabilities to participate in public and political life. States parties should put in place mechanisms to denounce the conflicts of interests of representatives of organizations of persons with disabilities or other stakeholders, to prevent their negative impacts on the autonomy, will and preferences of persons with disabilities.

53. To fulfil their obligations under article 4 (3), States parties should adopt legal and regulatory frameworks and procedures to ensure the full and equal involvement of persons with disabilities, through their representative organizations, in decision-making processes and the drafting of legislation and policies concerning issues related to persons with disabilities, including disability-related legislation, policies, strategies and action plans. States parties should adopt provisions granting organizations of persons with disabilities seats on, for example, standing committees and/or temporary task forces by giving them the right to nominate working members to these bodies.

54. States parties should establish and regulate formal consultation procedures, including the planning of surveys, meetings and other methods, setting up proper time frames, early engagement of organizations of persons with disabilities, and prior, timely and broad dissemination of relevant information for each process. States parties should, in consultation with organizations of persons with disabilities, design accessible online tools for consultations and/or provide alternative methods of consultation in accessible digital formats. To ensure that no one is left behind in relation to consultation processes, States parties should appoint persons with the role of following up on attendance, noticing underrepresented groups, and ensuring that accessibility and reasonable accommodation requirements are met. Similarly, they should ensure that organizations of persons with disabilities representing all such groups are involved and consulted, including by providing information on reasonable accommodation and accessibility requirements.

55. States parties should include consultation and engagement with organizations of persons with disabilities when conducting preparatory studies and analysis for formulating policy. Public forums or processes for reviewing policy proposals should be fully accessible for persons with disabilities to participate.

56. States parties should ensure that the participation of organizations of persons with disabilities in monitoring processes, through independent monitoring frameworks, is based on clear procedures, proper time frames and previous dissemination of relevant information. Monitoring and evaluation systems should examine the level of engagement of organizations of persons with disabilities in all policies and programmes and ensure that the views of such persons are given priority. To fulfil their primary responsibility for service provision, States parties should explore partnerships with organizations of persons with disabilities to gain inputs from the users of services themselves.

57. States parties should, preferably, encourage the establishment of a single, united and diverse representative coalition of organizations of persons with disabilities that is inclusive of all the disability constituencies and respectful of their diversity and parity, and ensure its involvement and participation in the monitoring of the Convention at the national level. Civil society organizations in general cannot represent or replicate organizations of persons with disabilities.

58. The promotion of advocacy by and empowerment of persons with disabilities are key components of their participation in public affairs; they call for the development of technical, administrative and communication skills, and the facilitation of access to information and tools concerning their rights, legislation and policymaking.

59. The barriers faced by persons with disabilities in accessing inclusive education compromise their opportunities and undermine their capacities to be involved in public decision-making, which, in turn, have an impact on the institutional capacities of their organizations. The barriers in accessing public transport, the lack of reasonable accommodation, and low

or insufficient income and unemployment among persons with disabilities also restrict the capacity of such persons to engage in civil society activities.

60. States parties should strengthen the capacity of organizations of persons with disabilities to participate in all phases of policymaking, by providing capacity-building and training on the human rights model of disability, including through independent funding. States parties should also support persons with disabilities and their representative organizations in the development of the competencies, knowledge and skills required to independently advocate for their full and effective participation in society, and in developing stronger democratic governance principles, such as respect for human rights, the rule of law, transparency, accountability, pluralism and participation. In addition, States parties should provide guidance on how to access funding and diversify their sources of support.

61. States parties should ensure that organizations of persons with disabilities are able to register easily and freely, and seek and secure funds and resources from national and international donors, including private individuals, private companies, all public and private foundations, civil society organizations, and State, regional and international organizations. The Committee recommends that States parties adopt criteria to allocate funds for consultation, including by:

- (a) Providing funds directly to organizations of persons with disabilities, avoiding third-party intermediation;
- (b) Prioritizing resources to organizations of persons with disabilities that focus primarily on advocacy for disability rights;
- (c) Allocating specific funds for organizations of women with disabilities and of children with disabilities to enable their full and effective participation in the process of drafting, developing and implementing laws and policies and in the monitoring framework;
- (d) Distributing funds on an equal basis among different organizations of persons with disabilities, including sustainable core institutional funding, instead of being limited to project-based funding;
- (e) Ensuring the autonomy of organizations of persons with disabilities in deciding their advocacy agenda, despite the funding received;
- (f) Distinguishing between funding for the running of organizations of persons with disabilities and the projects carried out by such organizations;
- (g) Making funding available to all organizations of persons with disabilities, including for self-advocate organizations and/or those that have not gained a legal status due to laws that deny the legal capacity of their members and hinder the registration of their organizations;
- (h) Adopting and implementing application processes for funding in accessible formats.

62. States parties should ensure that organizations of persons with disabilities have access to national funds to support their activities to avoid situations in which they have to rely only on external sources, which would limit their ability to establish viable organizational structures. Organizations of persons with disabilities that have support from public and private financial resources, supplemented by membership fees, are better able to secure the participation of persons with disabilities in all forms of political and administrative decision-making, provide them with support and create and run individual and different group-oriented social activities.

63. States parties should guarantee appropriate and sufficient funding for organizations of persons with disabilities, through the establishment of a responsible legally recognized formal mechanism, for example trust funds at the national and international levels.

64. States parties should increase public resources for the establishment and strengthening of organizations of persons with disabilities that represent all kinds of impairments. They should also ensure their access to national funding, including through tax exemptions and freedom from inheritance taxes, and the national lottery. States parties should promote and facilitate the access of organizations of persons with disabilities to foreign funding as part of international cooperation and development aid, including at the regional level, on the same basis as other human rights non-governmental organizations.

65. States parties should develop strong mechanisms and procedures ensuring effective sanctions for non-compliance with the obligations under articles 4 (3) and 33 (3). Compliance should be monitored by independent bodies, for example the office of the ombudsperson or a parliamentary commission, which have the authority to initiate investigations and hold the responsible authorities to account. At the same time, organizations of persons with disabilities should be able to initiate legal actions against entities when they find that the latter have failed to comply with articles 4 (3) and 33 (3). Such mechanisms should be part of the legal frameworks governing the consultation and involvement of organizations of persons with disabilities, and national anti-discrimination legislation, at all levels of decision-making.

66. States parties should recognize effective remedies, including of a collective nature, or class actions to enforce compliance with the right of persons with disabilities to participate. Public authorities can significantly contribute to effectively guaranteeing persons with disabilities' access to justice in situations that negatively affect their rights. Effective remedies could include: (a) suspending the procedure; (b) returning to an earlier stage of the procedure to ensure the consultation and involvement of organizations of persons with disabilities; (c) delaying implementation of the decision until appropriate consultations take place; or (d) quashing, totally or partially, the decision, based on non-compliance with articles 4 (3) and 33 (3).

IV. Relationship with other provisions of the Convention

67. Article 3 identifies a set of overarching principles that guide the interpretation and implementation of the Convention. It includes "full and effective participation and inclusion in society", which means that the participation of persons with disabilities, through their representative organizations, cuts across the entire text and applies to the whole Convention.

68. As part of the general obligations of States parties, article 4 (3) applies to the entire Convention and is significant in implementing all of its obligations.

69.Paragraphs 1, 2 and 5 of article 4 are of the utmost importance in implementing paragraph 3 of the same article, as they include the primary obligations of States parties, extending to all parts of federal States without any limitations or exceptions, related to establishing the necessary structures and frameworks and taking measures to comply with the Convention.

70.Policies to promote the equality and non-discrimination of persons with disabilities, as stipulated in article 5, should be adopted and monitored in compliance with articles 4 (3) and 33 (3). The close consultation and active involvement of organizations of persons with disabilities, which represent the diversity of society, is a key component for success in adopting and monitoring legal frameworks and guidance material to promote de facto and inclusive equality, including affirmative action measures.

71.Consultation procedures should not exclude persons with disabilities nor discriminate on grounds of impairment. Procedures and related materials should be inclusive of and accessible to persons with disabilities and include time frames and technical assistance for early involvement in consultation processes. Reasonable accommodation should always be provided in all dialogue and consultation processes, and reasonable accommodation legislation and policies must be developed in close consultation with and the active involvement of organizations of persons with disabilities.

72.Article 6 of the Convention requires measures to ensure the full development, advancement and empowerment of women and girls with disabilities. States parties should encourage and facilitate the establishment of organizations of women and girls with disabilities, as a mechanism for enabling their participation in public life, on an equal basis with men with disabilities, through their own organizations. States parties should recognize the right of women with disabilities to represent and organize themselves and facilitate their effective involvement in close consultations under articles 4 (3) and 33 (3). Women and girls with disabilities should also be included on an equal basis in all branches and bodies of the implementation and independent monitoring framework. All consultation bodies, mechanisms and procedures should be disability-specific, inclusive and ensure gender equality.

73.Women with disabilities should be part of the leadership of organizations of persons with disabilities on an equal basis with men with disabilities and be given space and power within umbrella organizations of persons with disabilities through parity representation, women's committees, empowerment programmes, etc. States parties should ensure the participation of women with disabilities, including women who are under any form of guardianship or institutionalized, as a prerequisite in the design, implementation and monitoring of all measures that have an impact on their lives. Women with disabilities should be able to participate in decision-making processes addressing issues that have an exclusive or disproportionate impact on them, and on women's rights and gender equality policies in general, for example, policies on sexual and reproductive health and rights, and all forms of gender-based violence against women.

74.Articles 4 (3) and 33 (3) are fundamental in the implementation of the rights of children with disabilities as stated in article 7. States parties should take steps to ensure the participation and the active involvement of children with disabilities, through their representative organizations, in all aspects of planning, implementation, monitoring and evaluation of relevant legislation, policies, services and programmes affecting their lives, at school and at the community, local, national and international levels. The goal of participation is empowerment for children with disabilities and recognition by duty bearers that they are rights holders who can play an active role in their communities and society. This takes place at various levels, beginning with the recognition of their right to be heard, moving towards their active engagement in the realization of their own rights.

75.States parties should provide children with disabilities with support in their decision-making, by, among other things, equipping them with, and enabling them to use, any mode of communication necessary to facilitate the expression of their views, including child-friendly information, and adequate support for self-advocacy, and ensure appropriate training for all professionals working with and for such children. States parties should also provide disability and age-appropriate assistance and procedures, and support for children with disabilities. The participation of their organizations should be considered as indispensable in consultations addressing specific issues that concern them, and their views should be given due weight in accordance with their age and maturity.

76.Article 4 (3) is of particular importance in raising awareness (art. 8). The Committee recalls its recommendations to States parties to implement, with the participation of organizations of persons with disabilities, systematic awareness-raising programmes, including media campaigns through public radio stations and television programmes, aimed at portraying persons with disabilities in all their diversity as rights holders. Awareness-raising campaigns and training programmes aimed at all public sector officials must be in conformity with the principles of the Convention, and based on the human rights model of disability to overcome entrenched gender and disability stereotypes in society.

77.For organizations of persons with disabilities to be able to properly participate in the consultation and monitoring processes of the Convention, it is essential to have optimal accessibility (art. 9) to the procedures, mechanisms, information and communication, facilities and buildings, including reasonable accommodation. States parties should develop, adopt and implement international accessibility standards and the universal design process, for example in the area of information and communications technology to ensure close consultation with and the active involvement of organizations of persons with disabilities.

78.In situations of risk and humanitarian emergencies (art. 11), it is important for States parties and humanitarian actors to ensure the active participation of and coordination and meaningful consultation with organizations of persons with disabilities, including those at all levels representing women, men and children with disabilities of all ages. This requires the active involvement of organizations of persons with disabilities in the development, implementation and monitoring of emergency-related legislation and policies, and the establishment of priorities for aid distribution, in accordance with article 4 (3). States parties should promote the establishment of organizations of internally displaced persons or refugees with disabilities that are enabled to promote their rights in any situation of risk, including during armed conflicts.

79.Equal recognition before the law (art. 12) ensures that all persons with disabilities have the right to exercise their full legal capacity and have equal rights to choose and control decisions affecting them. Equal recognition before the law is a prerequisite for direct and effective consultations and the involvement of persons with disabilities in the development and implementation of legislation and policies to implement the Convention. The Committee recommends that the lack of compliance with article 12 should, under no circumstances, preclude the inclusive implementation of articles 4 (3) and 33 (3). Laws and policies should be amended to address this barrier to participation based on denial of legal capacity.

80.The Committee recalls its general comment No. 1 (2014) on equal recognition before the law, in which it states that legal capacity is the key to accessing full and effective participation in society and in decision-making processes and should be guaranteed to all persons with disabilities, including persons with intellectual disabilities, persons with autism and persons with actual or perceived psychosocial impairment, and children with disabilities, through their organizations. States parties should ensure the availability of supported decision-making arrangements to enable participation in policymaking and consultations that respect a person's autonomy, will and preferences.

81.The right of persons with disabilities to have access to justice (art. 13) implies that persons with disabilities have the right to participate on an equal basis with others in the justice system as a whole. This participation takes many forms and includes persons with disabilities assuming the roles of, for example, claimants, victims, defendants, judges, jurors and lawyers, as part of the democratic system that contributes to good governance. Close consultation with persons with disabilities through their representative organizations is key in all processes to enact and/or amend laws, regulations, policies and programmes addressing the participation of such persons in the justice system.

82.To prevent all forms of exploitation, violence and abuse (art. 16), States parties should ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities. The Committee has observed that violations of the rights of persons with disabilities continue to occur in facilities that "serve" persons with disabilities, such as psychiatric and/or residential institutions. In accordance with article 33 (3), this means that regardless of whether the independent monitoring authority, which is assigned the task under article 16 (3), coincides with the independent monitoring framework under article 33 (2), civil society, including organizations of persons with disabilities, should be actively involved in monitoring those facilities and services.

83.Recalling its general comment No. 5 (2017) on living independently and being included in the community, consultations with and the active involvement of persons with disabilities, through their representative organizations, are critical for the adoption of all plans and strategies, and for follow-up and monitoring, when implementing the right to independent living and being included in the community (art. 19). The active involvement and consultation at all levels in the decision-making process should include all persons with disabilities. Persons with disabilities, including those who are currently living in institutional settings, should be involved in the planning, implementing and monitoring of deinstitutionalization strategies, and in the development of support services, with special regard to those people.

84.Access to information (art. 21) is necessary for organizations of persons with disabilities to be involved and to fully participate and freely express their opinions in the monitoring process. Such organizations need to receive the information in accessible formats, including digital formats, and technologies appropriate to all forms of disabilities, in a timely manner and without additional cost. This includes the use of sign languages, Easy Read, plain language and Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of choice by persons with disabilities in official interactions. Sufficiently prior to any consultation, all relevant information, including specific budgetary, statistical and other relevant information necessary for an informed opinion, should be made available.

85.To ensure the right to inclusive education (art. 24), in accordance with the Committee's general comment No. 4 (2016) on the right to inclusive education, States parties should consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations, in all aspects of planning, implementation, monitoring and evaluation of inclusive education policies and legislation. Inclusive education is essential to the participation of persons with disabilities as described within articles 4 (3) and 33 (3). Education enables people to flourish and increases the likelihood of participation within society, which is needed to ensure the implementation and monitoring of the Convention. States parties should ensure that public and private education institutions consult with persons with disabilities and ensure that their opinions are given due consideration within the education system.

86.The adoption of all policies regarding the right of persons with disabilities to work and employment (art. 27) should be taken in consultation with and the involvement of representative organizations of persons with disabilities. Policies should seek to guarantee access to employment; promote work in open, inclusive, non-discriminatory, accessible and competitive employment markets and environments; ensure equal opportunities and gender equality; and provide for reasonable accommodation and support for all persons with disabilities.

87.The realization of the right to an adequate standard of living and social protection (art. 28) is directly interrelated with article 4 (3). The participation of organizations of persons with disabilities in public policies is crucial to ensure that specific situations of exclusion, inequality and poverty among persons with disabilities and their families living in poverty are addressed by the authorities of the States parties. States parties should, in particular, seek to engage with organizations of persons with disabilities and persons with disabilities who are unemployed, who do not have a fixed income or who cannot work because of the implied loss of entitlements or allowances, those in rural or remote areas, and indigenous peoples, women and older persons. When taking and reviewing measures, strategies, programmes, policies and legislation in relation to the implementation of article 28, and in the monitoring process thereof, States parties should closely consult and actively involve organizations of persons with disabilities representing all persons with disabilities to ensure the mainstreaming of disability and that their requirements and views are duly taken into consideration.

88.The right of persons with disabilities to participate in political and public life (art. 29) is of extreme importance in ensuring the equality of opportunity for persons with disabilities to fully and effectively participate and be included in society. The right to vote and be elected is an essential component of the right to participate, as elected representatives decide on the political agenda and are key in ensuring implementation and monitoring of the Convention, advocating for their rights and interests.

89.States parties should pass regulations, in close consultation with organizations of persons with disabilities, to allow persons with disabilities requiring assistance to be able to cast their vote on their own. This may require making aids available for persons with disabilities in voting booths (on election day and at advance voting) at national and local elections and national referendums.

90.Persons representing all or some of the wide diversity of impairments should be consulted and involved, through their organizations of persons with disabilities, in the process and implementation of data and information collection (art. 31).

91.States parties should establish a unified data-collection system to collect quality, sufficient, timely and reliable data, disaggregated by sex, age, ethnicity, rural/urban population, impairment type and socioeconomic status, regarding all

persons with disabilities and their access to the rights under the Convention. They should establish a system to enable the formulation and implementation of policies to give effect to the Convention, through close collaboration with organizations of persons with disabilities and by utilizing the Washington Group on Disability Statistics. Additional data-collection tools should also be pursued to obtain information on perceptions and attitudes and include those constituencies that the Washington Group leaves out.

92. When deciding upon and implementing international cooperation (art. 32), the close partnership, cooperation and involvement of persons with disabilities, through their representative organizations, is crucial in adopting development policies in accordance with the Convention. Organizations of persons with disabilities should be consulted and involved at every level of development, implementation and monitoring of international cooperation plans, programmes and projects, including the 2030 Agenda and the Sendai Framework for Disaster Risk Reduction 2015–2030.

93. Article 34 (3) is important in respecting the relevant criteria for membership of the Committee. It requires States parties to give due consideration to the provision set out in article 4 (3) when nominating candidates. Therefore, States parties should closely consult and actively involve organizations of persons with disabilities prior to nominating candidates for the Committee. National legislative frameworks and procedures should be adopted for transparent and participatory procedures that involve organizations of persons with disabilities and consider the results of consultations, reflecting them in the final nomination.

V. Implementation at the national level

94. The Committee acknowledges that States parties face challenges when implementing the right of persons with disabilities to be consulted and involved in the development, implementation and monitoring of legislation and policies to implement the Convention. States parties should, among others, take the following measures to ensure the full implementation of articles 4 (3) and 33 (3):

(a) Repeal all laws, including those denying legal capacity, that prevent any person with disabilities, regardless of type of impairment, from being closely consulted with and actively involved, through their organizations of persons with disabilities;

(b) Create an enabling environment for the establishment and functioning of organizations of persons with disabilities, by adopting a policy framework favourable to their establishment and sustained operation. This includes guaranteeing their independence and autonomy from the State, the establishment, implementation of and access to adequate funding mechanisms, including public funding and international cooperation, and the provision of support, including technical assistance, for empowerment and capacity-building;

(c) Prohibit any practices of intimidation, harassment or reprisals against individuals and organizations promoting their rights under the Convention at the national and international levels. States parties should also adopt mechanisms for protecting persons with disabilities and their representative organizations against intimidation, harassment and reprisals, including when they cooperate with the Committee or other international bodies and human rights mechanisms;

(d) Encourage the establishment of umbrella organizations of persons with disabilities, which coordinate and represent the activities of its members, and individual organizations of persons with disabilities with different impairments to ensure their inclusion and full participation, including those who are most underrepresented, in the monitoring process. If a State party faces obstacles in involving every individual organization of persons with disabilities in decision-making processes, they could include representatives of such organizations in permanent or temporary task forces etc., when it cannot be done through an umbrella organization or coalition of organizations of persons with disabilities;

(e) Adopt legislation and policies that recognize the right to participation and involvement of organizations of persons with disabilities and regulations that establish clear procedures for consultations at all levels of authority and decision-making. This legislative and policy framework should provide for the mandatory realization of public hearings prior to the adoption of decisions, and include provisions requiring clear time frames, accessibility of consultations and an obligation to provide reasonable accommodation and support. This can be done through clear references in laws and other forms of regulations to the participation and selection of representatives from organizations of persons with disabilities;

(f) Establish permanent consultation mechanisms with organizations of persons with disabilities, including round tables, participatory dialogues, public hearings, surveys and online consultations, respecting their diversity and autonomy, as indicated in paragraphs 11, 12 and 50. This can also take the form of a national advisory board, such as a representative national disability council representing organizations of persons with disabilities;

(g) Guarantee and support the participation of persons with disabilities through organizations of persons with disabilities, reflecting a wide diversity of backgrounds, including birth and health status, age, race, sex, language, national, ethnic, indigenous or social origin, sexual orientation and gender identity, intersex variation, religious and political affiliation, migrant status, impairment groups or other status;

(h) Engage with organizations of persons with disabilities that represent women and girls with disabilities and secure their direct participation in all processes of public decision-making in a safe environment, particularly relating to the development of policies regarding the rights of women and gender equality, and gender-based violence against women, including sexual violence and abuse;

(i) Consult with and actively involve persons with disabilities, including children and women with disabilities, through their representative organizations, in the planning, execution, monitoring and measuring of public decision-making processes at all levels, especially in matters affecting them, including in situations of risk and humanitarian emergencies, giving them reasonable and realistic timelines in providing their views and adequate funding and support;

(j) Encourage and support the creation, capacity-building, funding and effective participation of organizations of persons with disabilities or groups of persons with disabilities, including parents and families of persons with disabilities in their supportive role, at all levels of decision-making. This includes at the local, national, regional (including within a regional integration organization) or international levels, in the conception, design, reform and implementation of policies and programmes;

- (k) Ensure monitoring of States parties' compliance with articles 4 (3) and 33 (3), and facilitate organizations of persons with disabilities' leadership in such monitoring;
- (l) Develop and implement, with the involvement of organizations of persons with disabilities, effective enforcement mechanisms, with meaningful sanctions and remedies, for non-compliance with State parties' obligations under articles 4 (3) and 33 (3);
- (m) Ensure the provision of reasonable accommodation and the accessibility of all facilities, materials, meetings, calls for submissions, procedures and information and communication related to public decision-making, consultation and monitoring to all persons with disabilities, including persons isolated in institutions or psychiatric hospitals and persons with autism;
- (n) Provide disability and age-appropriate assistance for the participation of persons with disabilities, through their representative organizations, in public decision-making, consultation and monitoring processes. Develop strategies to ensure the participation of children with disabilities in consultation processes for the implementation of the Convention that are inclusive, child-friendly, transparent and respectful of their rights to freedom of expression and thought;
- (o) Conduct consultations and procedures in an open and transparent manner and understandable formats, inclusive of all organizations of persons with disabilities;
- (p) Ensure that organizations of persons with disabilities can receive and/or seek funding and other forms of resources from national and international sources, including private individuals and companies, civil society organizations, States parties and international organizations, including access to tax exemptions, and the national lottery;
- (q) Make existing consultation procedures in non-disability-specific areas of law accessible and inclusive of persons with disabilities, through their representative organizations;
- (r) Actively involve and closely consult with persons with disabilities, through their representative organizations, on public budgeting processes, the monitoring of the Sustainable Development Goals at the national level, international decision-making and international cooperation with other States parties, and adopt development policies that mainstream the rights and opinions of persons with disabilities when implementing and monitoring the 2030 Agenda at the national level;
- (s) Guarantee the participation, representation and easy access of persons with disabilities to focal points at all levels of Government and the coordination mechanisms, and their cooperation and representation within the independent monitoring frameworks;
- (t) Promote and ensure the participation and involvement of persons with disabilities, through their representative organizations, in international human rights mechanisms at the regional and global levels;
- (u) Define in close consultation with organizations of persons with disabilities verifiable indicators for good participation, concrete timelines and responsibilities for implementation and monitoring. Such participation can be measured, for example, by explaining the scope of their participation in connection with proposals for amending laws or reporting on the number of representatives from such organizations involved in decision-making processes.