Participation of Persons with Disabilities in the implementation and monitoring of the Convention

**Submission to the UN Committee on the Convention on the Rights of Persons with Disabilities: Draft General Comment No. 7 on Articles 4.3 and 33.3.**

There are sentences in plain language in this document.

They explain what is important to us.

You can find them before each number.

# Introduction

Inclusion Europe fights for the rights of people with intellectual disabilities and their families.

1. Inclusion Europe is the association of people with intellectual disabilities and their families in Europe. We have **71 members in 38 countries**, and we represent more than 7 million people in Europe. Our members include organisations of people with intellectual disabilities and their families at national, regional and local level. **We fight for the recognition of equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of life.** As a European association, we work in many different areas which our members have identified as important to them.

This General Comment is about people with disabilities helping to make laws about their rights.

1. Inclusion Europe very much welcomes the work of the UN CRPD Committee on publishing a General Comment on Articles 4.3 and 33.3 of the United Nations Convention on the Rights of Persons with Disabilities (hereinafter UN CRPD, or Convention). **Participation of persons with disabilities in the implementation and monitoring of the Convention is a fundamental component in ensuring that the rights of persons with disabilities are respected in all Member States and that they are included in the society.**

# Exclusion of Persons with Disabilities

People with intellectual disabilities are often left out of the

community because of laws that stop them making decisions.

1. **People with intellectual disabilities are especially affected by barriers preventing them from participating in the community such as** deprivation of legal capacity, institutionalisation. The lack of access to mainstream education or lack of education impede the future participation of children with disabilities as equal citizens in the community for events related to key issues, electoral processes. The lack of accessible information in easy to read and to understand results in a situation where people are not informed about their rights, including the right to participate.

People with complex support needs can be left out in decision-making.

1. A special attention should be paid to people with disabilities who may face more difficulties to participate because of higher or a more complex need of support. They are often under-represented in disability-specific discussions and remain invisible in mainstream ones.

It is often not easy for people with intellectual disabilities to take part in writing laws. The documents are often not easy-to-read.

1. In European countries, **people with intellectual disabilities are particularly prevented from participating in the implementation and monitoring of the Convention.**  Too often they are not invited to participate in the creation of law and policies directly or indirectly affecting their lives. When they are invited, documentation, materials, presentations are frequently inaccessible.

The General Comment must explain how to get rid of laws that stop people with disabilities from taking part in making law.

1. **The General Comment must address barriers that prevent persons with intellectual disabilities from participating in the implementation and monitoring of the Convention.** Persons with intellectual disabilities may be prevented from participating in the implementation and monitoring of the Convention due to legal or physical barriers such as denial of legal capacity, guardianship or institutionalisation. Persons with disabilities may not receive an invitation to participate in the implementation or monitoring of the Convention because they are isolated, secluded or do not receive the information due to interference by third parties. Where persons with disabilities receive an invitation, it may not be in an accessible form or they may be prevented from participating by attending or responding to the invitation as a result of substituted decision-making mechanisms and isolation, including institutionalisation.

# Accessibility and Inclusive Environment

The Draft General Comment says taking part in law about the UNCRPD should be easy for all persons with disabilities.

1. The Draft General Comment requires that **persons with disabilities be consulted and involved in the implementation and monitoring of the Convention, and in all other laws that may affect their lives**. The Draft General Comment requires that organisations of persons with disabilities be “*consulted timely*, *with guarantees of accessibility and, including all relevant information, and reasonable accommodation when required, such as the provision of sign language interpreters and Easy Read text and language, Braille and tactile communication”* regarding the implementation of the Convention.
2. The Draft General Comment stipulates that the Convention and its implementation strategies should be made accessible to civil society participants “*including persons with all kinds of impairments, to access information, understand and evaluate the issues involved and provide meaningful inputs.”* **Inclusion Europe supports this emphasis on accessibility of materials and processes to ensure meaningful participation of persons with disabilities**. This Draft General Comment has highlighted one of the greatest barriers to participation and provided insightful guidelines towards an inclusive and accessible environment for all persons. We welcome these requirements and hope that improvements in accessibility will allow for genuine participation of persons with disabilities in all law and policy that affect their lives, including the implementation of the Convention and General Comments.

Participation of Persons with Disabilities

The General Comment should explain what taking part is about.

1. **The general comment should remind States and regional bodies of their obligation to ensure genuine participation of persons with disabilities, including persons with intellectual disabilities, in the implementation and monitoring of the Convention.** The lack of understanding by Member States and regional bodies of what participation is in practice creates barriers to meaningful participation, and results in information giving or consultation being considered genuine participation.

People with disabilities’ voices should be heard and listened to.

1. It is essential to distinguish meaningful participation from consultation or offering of information that may be mislabelled as participation**. In many cases, people with disabilities can be involved physically in meetings or virtually in public consultation, without really participating in it. Therefore, this is more tokenism than participation and it should be fought together with the absence of participation.**

People with disability are not always allowed to vote or to stand for election.

1. The general lack of participation is enshrined by the denial of the right to vote and to stand for elections. Without political participation in society, people with disabilities cannot have people to represent them. Moreover, without elected representatives, people will not have many opportunities to be represented and included in debates.

All people with disabilities should be allowed to vote and stand for election.

1. **The General Comment must acknowledge that a fundamental aspect of ensuring that persons with disabilities may participate in the implementation and monitoring of the Convention is recognising the right of persons with disabilities to vote and to be elected to office.** Member States that do not permit persons with disabilities to vote and stand for elections as required by the Convention, prevent meaningful participation and representation of persons with disabilities in debates and/or decision-making. Legal restrictions on the right of persons with disabilities to vote or to be elected to office prevents them from electing representatives that will advocate for their rights and interests.

There must be “nothing without us” and people with disabilities

should be included in talks about all types of laws.

1. The Disability movement must progressively move from “Nothing about us without us” to “Nothing without us” and make sure that people with disabilities can take part in all discussions where they are not directly affected as persons with disabilities but as citizens. This is an important aspect of the Draft General Comment and recognises the need all for persons with disabilities to be included in “*any decision-making processes, whether disability-specific or mainstream, such as general laws, disability specific laws and the public budget, which might have an impact on their lives.”[[1]](#footnote-1)*

Here is what we are asking the Committee to change in the General Comment:

General Comments

Reasons why people with disabilities are stopped from taking part in writing laws about the UNCRPD:

11(a): Some people do not think that people with disabilities are able to participate

11(b): People with disabilities are sometimes not really taking part and being listened to when they participate.

11(c): Laws that stop people with disabilities from making

their own decisions and voting leave people out.

11(d): People with complex support needs are often left out

when writing the law.

11(e): People with disabilities may be unable to take part

because of not enough of support.

11(i): Organisations of persons with disabilities should receive

more money.

11(j): There is not enough money and support for organisations

of people with disabilities to provide training.

11(k) People with disabilities are not always allowed to vote or be heard.

11(m): People with disabilities who live in institutions can be stopped from taking part in the community and making decisions about their lives.

1. ***Paragraph 11***

*11(a): Stereotypes and beliefs that impede the recognition of people with disabilities as experts and key stakeholders to engage with during policy-making processes*

*11~~(a)~~ (b): The lack of understanding of the concept of meaningful participation and knowledge of the process of meaningful participation itself and the absence of best practices for proper implementation;*

*11~~(b)~~(c): Laws that prevent persons with disabilities on the basis of certain types of impairment, from being closely consulted and actively engaged in decision-making processes and the monitoring of the Convention, including substituted decision-making laws and laws preventing persons with disabilities from voting and being elected to office;*

*11~~(c)~~ (d): The lack of consultation and active involvement of persons with disabilities, including children and women with disabilities and persons with complex support needs in the planning, execution, and monitoring of public decision-making processes;*

*11~~(d)~~ (e): The lack of support and participation of persons with disabilities from disadvantaged groups, in particular those who experience discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age, level of support required, or other status; (better phrasing needed)*

*11~~(h)~~ (i): The lack of insufficient ~~[non-conditional]~~ international and national public funding to organisations of persons with disabilities to guarantee autonomy and self-determination of the organisations;*

*11~~(i)~~ (j): The lack of well-funded and supported international and national DPOs/OPDs and the absence of comprehensive organisations collaborating with DPOs/OPDs to build capacity for developing their advocacy strategies and to provide high quality empowerment training;*

*11~~(j)~~ (k): The lack of or low political will and or initiative by State authorities to closely consult and actively involve DPOs or OPDs in the monitoring of the Convention, as a result of the inability of some persons with disabilities to elect representatives or to stand for election themselves;*

*11~~(l)~~(m): The insufficient accessibility, accommodation, disability and age-appropriate support to persons with disabilities to have access to all facilities, procedures and information related too public decision-making, consultation and monitoring processes, especially for persons who are living in isolated areas such as institutions and psychiatric hospitals.*

14(a)(iv): Self advocacy organisations are organisations of people with disabilities.

14~~(e~~)(d): Organisation of family members of persons with disabilities support people with disabilities to take part and fight for their

own rights and should take part in writing laws about the Convention.

14(~~g~~)(f): Some organisations for people with disabilities have

more than one aim, for example they may also represent families.

1. ***Paragraph 14***

14(a)(iv):Self-advocacy organisations, networks and platforms are groups of persons with intellectual disabilities who advocate for their rights and the rights of other persons with intellectual disabilities. Self-advocate organisations, platforms and networks are an important part of OPDs/DPOs. In many countries self-advocacy organisations are discriminated against and are refused legal status because of laws which deny the legal capacity of their members. They are of fundamental importance to political participation particularly for persons who are denied the right to vote, prevented from exercising legal capacity and/or are institutionalised. Their establishment, with appropriate, sometimes extensive, support to express their opinions, is indispensable to guarantee their participation in decision-making, monitoring and implementation processes. Such support includes any necessary form of reasonable accommodation.

***~~(d) Organizations of self-advocates~~*** *~~are composed of and represent persons with intellectual disabilities, autistic persons or persons with psychosocial disabilities. Their establishment, with appropriate, sometimes extensive, support to express their opinions, is indispensable to guarantee their participation in decision-making, monitoring and implementation processes. Such support includes any necessary form of reasonable accommodation. While organizations of parents and relatives of persons requiring support have often played a role in providing such support, it is important to ensure that persons with disabilities are and remain in full control~~.*

*14~~(e)~~(d): Organisations of* *~~parents of children with disabilities~~ family members of persons with disabilities are key to promoting ~~and securing the interests, autonomy and active participation of their children with disabilities~~ and supporting autonomy and active participation of their relative, and advocating for their own support needs and should be included in the consultation, decision-making and monitoring processes.*

14(~~g~~)(f): The structures of some representative organisations may be more complex and may fulfil the description of two or more of the representative organisation. These multifaceted networks or platforms may be a hybrid of two or more of the representative organisations and may serve several of the purposes.

21: People with disabilities should be able to take part and information should be easy to understand.

1. ***Paragraph 21***

*To “closely consult with and actively involve” persons with disabilities through their representative organisations means that their consultation and involvement in the development and implementation of legislation and policies to implement the Convention, and in other decision-making processes, is a full-fledged strong obligation under international human rights law. This includes the right of organisations of persons with disabilities to be consulted timely, meaningfully, with guarantees of accessibility, including to all relevant information, and reasonable accommodation when required, such as the provision of sign language interpreters and Easy Read text and language, Braille and tactile communication. Their respective views must be given due consideration and weight and they must be duly informed of the outcome of the process, including an explicit explanation in an understandable format, in the findings, considerations or reasoning of decisions, on how their views were considered and why.*

23: All people with disabilities should be able to vote and be supported, for example support to make decisions.

1. ***Paragraph 23***

*…This includes being encouraged and receiving appropriate support including support-decision making such as peer support, to participate in society, freedom from stigma and feeling safe and respected when expressing oneself in public. It is an obligation of immediate application, to be applied not only to decision-making, monitoring and implementation processes but also to be guaranteed the right to due process of law, the right to participate in political life and the right to be heard including the right to vote and stand for elections. If participation is to be effective and meaningful, it needs to be understood as a process, not as an individual one-time event.*

32: Organisations should be provided with support persons.

1. ***Paragraph 32***

*Particularly organisations of persons with sensory and intellectual impairments including organisations of self-advocates should be provided with meeting assistants and support persons, information in accessible formats (such as Easy Read), sign language interpretation, guide interpreters for deafblind persons, and/or captioning during public debates. States parties should also support representatives of DPOs/OPDs for expenditures related to transport and other expenses related to their participation in the decision-making processes.*

37: No one should be able to stop people with disabilities from being in an organisation of people with disabilities.

1. ***Paragraph 37***

*Article 37: States parties are also required to take measures to prevent persons, professionals and organisations ~~family members and third parties~~ from directly or indirectly interfering with DPOs/OPDs enjoyment of the right to be closely involved in the development and legislation policies to implement the Convention, and in other related decision-making processes. The duty to protect requires States parties to put in place and implement laws and policies to prevent persons with disabilities from being deterred from accessing their right to be consulted and involved by others. It includes awareness raising of family members, service providers, public employees and others on the rights of persons with disabilities to participate.*

44: Laws that stop persons with disabilities from making decision should not stop these organisations from getting money.

1. ***Paragraph 44***

*[The access to the least restrictive [non-conditional] funding and resources is an integral and vital pre-condition [part of the right to freedom of association and] for the effective participation of persons with disabilities, and essential for DPOs/OPDs to ensure the capacity-building of persons with disabilities for DPOs/OPDs to grow internally]. States parties* *should ensure that any organization is able to seek and secure funds and resources from domestic and international donors, including private individuals, private companies, all public and private foundations, CSOs, state and international organizations.[[2]](#footnote-2) Funds should not only be intended for service providers, but rather be aimed at existing and potential DPOs/OPDs focusing primarily on advocacy. Inability of organisations to gain legal standing due to laws which deny the legal capacity of their members should not be a justification for denying funding to organisations of persons with disabilities, especially self-advocacy organisations. Funding should be made available to all organisations of persons with disabilities and application processes for funding should be in an accessible format.*

46: Organisation of persons with complex support needs should get money to take part in fighting for their rights.

Self-advocate organisations should get money to fight for their rights.

1. ***Paragraph 46***

*Article 33.3 read in conjunction with article 4.3 requires States parties to provide DPOs/OPDs, including organizations of women with disabilities and of children with disabilities, with appropriate [non-conditional] sufficient funding and resources to enable full and effective participation in the monitoring framework, as well as in the process of drafting, development and implementation of laws and policies concerning all persons with disabilities, including persons exposed to discrimination, such as persons with psychosocial and/or intellectual disabilities,* *persons with complex support needs, children, women, older persons, indigenous persons, migrant, refugee and asylum-seekers with disabilities. States parties could guarantee such appropriate and sufficient funding, through the establishment of a responsible legally recognised formal mechanism.* This funding must also be made accessible to self-advocacy organisations or networks that are currently prevented from receiving funding due to laws that deny the legal capacity of their members.

47: People with complex support needs should get money to fight for their rights.

1. ***Paragraph 47***

*An increase of the non-conditional public resources available for DPOs/OPDs, including those representing persons with complex support needs, children and women with disabilities, should be implemented to enable them to fulfil their role under the Convention…*

60: Self-advocate organisations must be able to get money.

1. ***Paragraph 60***

*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 and be directly and effectively consulted and involved in the development and implementation of legislation and policies to implement the Convention. However, the current lack of compliance with article 12 must under no circumstance preclude the inclusive implementation of articles 4.3 and 33.3. Laws and policies must be changed to address this barrier to participation based on denial of legal capacity, for example self-advocacy organisation must be able to receive funding even if they are unable to obtain legal standing as an organisation based on denial of legal capacity of their members. Recalling and living up to the Committee’s general comment No. 1 (2014), legal capacity is the key to accessing full and effective participation in society, and participation in decision-making processes should be guaranteed to all persons with disabilities, including persons with intellectual and/or psychosocial disabilities as well as children with disabilities, through their DPOs/OPDs, and if necessary through supported decision-making regimes that respect the person’s autonomy, will and preferences.*

61: There should be no laws that stop people with disabilities’ right to be free for example living in an institution.

People with complex support needs should take part in making new laws.

1. ***Paragraph 61***

*The Committee has noted with concern that in many State Parties, persons with disabilities are deprived of their right to liberty and security (art. 14) and has recommended that States parties immediately repeal laws permitting deprivation of liberty based on impairment, forced treatment and the use of restraints and seclusion, such as institutionalisation and forced psychiatric care. All new legislation and policies adopted in this regard must prohibit such practices and provide for reasonable accommodation in, among others, prisons, to persons with disabilities. In developing and implementing new legislation and policies, DPOs/OPDs must be consulted and involved, especially those representing children, women and persons with intellectual and/or psychosocial disabilities and persons with complex support needs.*

64: Education should include all people with disabilities.

1. ***Paragraph 64***

*To ensure the right to education (art. 24), States parties must consult with and actively involve persons with disabilities, including children with disabilities, through DPOs/OPDs, in all aspects of planning, implementation, monitoring and evaluation of inclusive education policies and legislation. Inclusive education is essential to 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 implementation and monitoring of the Convention. Persons with disabilities and, when appropriate, their families, should be recognized as partners and not merely recipients of education and be ensured their right to be heard and to have their opinion be given due consideration within the education system.*

66: People with disabilities should be able to work.

They are afraid to lose their benefits.

People with complex support needs should take part in making laws.

1. ***Paragraph 66***

*The right to an adequate standard of living and social protection (art. 28) is directly interrelated with article 4.3 of the Convention, especially with regard to persons with disabilities and their families living in poverty, who are unemployed or who do not have a fixed income, or who cannot work because of the implied loss of benefits (cf: Social benefit trap), those in rural and remote areas, those belonging to indigenous communities, women and older persons. 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 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 including persons with complex support needs.*

67: People with disabilities must be able to vote and help make laws.

1. ***Paragraph 67****:* The right of persons with disabilities to participate in political and public life (art.29) is of extreme importance to ensure equality of opportunity for persons with disabilities to be fully and effectively participating and included within society. The right to vote and be elected is an essential component of the right to participate, as elected representatives decide the political agenda and are key to ensure the implementation and monitoring of the UN CRPD. This is closely interrelated with their right, through DPOs/OPDs, to be consulted and involved in the decision-making and monitoring process and assert their individual autonomy, including the freedom to make one’s own choices, and their right to be recognized as persons before the law. States parties are required to establish an enabling environment in which persons with disabilities can effectively and fully participate without discrimination and on an equal basis with others, including through the provision of accessible information.

68: People with disabilities everywhere should be included when collecting information.

1. ***Paragraph 68***

*States parties must collect appropriate information, including statistical, budgetary and research data (art. 31) to formulate and implement proper policies to give effect to the Convention. Persons with all kinds of disabilities everywhere should be consulted and involved, through their DPOs/OPDs, in the process of data and information collection and the interpretation thereof.*

75(a): we should get rid of Laws that stop people with disabilities from taking part in the making of laws, including laws that stop people with disabilities making decisions.

75(l): Materials, meetings and invites to take part should be easy to use for all people with disabilities, including people who live in institutions.

75(o): Meeting and processes should be easy to use and include all orgainsations of people with disabilities.

1. ***Paragraph 75***

*75: The Committee notes that States parties may face challenges when implementing the right of DPOs/OPDs, including those representing persons with complex support needs, women or children, to be consulted and involved in the development, implementation and monitoring of legislation and policies to implement the Convention. In the light of the normative content and obligations outlined above, States parties should among others take the following steps to ensure the full implementation of articles 4.3 and 33.3 of the Convention:*

*75(a): Repeal all* *laws that prevent any person with disabilities, regardless of type of impairment, to be closely consulted with and actively involved, through their DPOs/OPDs, including denial of legal capacity of persons with disabilities and the right not to be confined, including through forced institutionalisation and isolation within the family, on the basis of any kind of disability*

*75(l)* Ensure the accessibility of all facilities, materials, meetings, calls for submissions, procedures and information related to public decision-making, consultation and monitoring to all persons with disabilities including persons isolated, in institutions or psychiatric hospitals;

*75(o): Guarantee that consultations and procedures are conducted in an open and transparent manner and understandable format, which is inclusive of ~~towards~~ all DPOs and OPDs.*

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1. *Draft General Comment on Article 4.3 ad 33.3 of the Convention on the Rights of Persons with Disabilities in the Implementation and Monitoring of the Convention,* para 20. [↑](#footnote-ref-1)
2. See A/HRC/20/27, para. 68. [↑](#footnote-ref-2)