

**March 2024**

NDA Submission to the Joint Committee on Disability Matters on “The role of disabled persons organisations and self-advocacy in providing equal opportunities under the UNCRPD”

# Introduction

The National Disability Authority (NDA) is the independent statutory body with a duty to provide information and advice to the Government on policy and practice relevant to the lives of persons with disabilities, and to promote Universal Design. The NDA welcomes the opportunity to input on the Joint Committee’s public consultation on “The role of disabled persons organisations and self-advocacy in providing equal opportunities under UNCRPD”.

Strategic Priority 4 of the NDA’s current **Strategic Plan (2022-2024)** commits the organisation ‘To foster strong and open processes for engaging and consulting with persons with disabilities and the wider disability community’.[[1]](#footnote-1) To this end, the NDA has sought to enhance internal processes for consultation and engagement with persons with disabilities and Disabled Persons Organisations (DPOs) across the NDA’s work programme, and provide guidance and information to public sector bodies to progress a culture of meaningful engagement with disabled persons and DPOs.

The NDA regularly consults DPOs in the development of research and policy advice. Recent examples include the **NDA's advice paper on disability language and terminology**[[2]](#footnote-2)and the **NDA’s** **Collaborative research with disabled people**: **Guidance for researchers**[[3]](#footnote-3). In addition, the NDA has undertaken a body of policy and research work on DPO participation and consultation (more detail below).

Furthermore, the NDA hosts annual listening exercises with DPOs and disabled people, providing them with a forum to raise and discuss their lived experience, with reports delivered to government. Themes for recent listening exercises have included ‘Building Back Better: The Post-Covid-19 World For Persons With Disabilities’, ‘Improving participation and inclusion through creating liveable communities’ and ‘Raising Awareness (Article 8 UNCRPD)’.[[4]](#footnote-4)

The NDA is aware that the primary objective of this consultation is to elicit the experiences of DPOs and self-advocates regarding the realities of human rights protections, and their views on Ireland’s progress in making the UNCRPD a reality for people with disabilities. Therefore, we have limited our submission to the following three points:

1. an outline of UNCRPD requirements relating to the role of DPOs and those with lived experience in UNCRPD monitoring and implementation
2. an update regarding the development of a new National Disability Strategy, including consultation with DPOs
3. an overview of some of the NDA’s most recent work on DPOs

# UN Convention on the Rights of Persons with Disabilities

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in March 2018. The Convention outlines obligations on Government to ensure the meaningful participation of disabled people, in particular Disabled Persons’ Organisations (DPOs), in the development, implementation and monitoring of policies and legislation and in other decision-making processes.

Article 4(3) of the UNCRPD states that:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 33 addresses the participation of people with disabilities in national implementation and monitoring processes stating that:

Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

The UN Committee on the Rights of Persons with Disabilities issued General Comment No. 7 on the participation of persons with disabilities in 2018 to provide States Parties with guidance on how to implement Article 4(3) and Article 33.[[5]](#footnote-5) General Comment No. 7 elaborates on what it means to closely consult with and actively involve DPOs as follows:

* it states that each person’s legal capacity to take part in decision making processes must be recognised and that supported decision-making should be used where necessary
* it requires that public authorities systematically and openly approach, consult with and involve DPOs in a meaningful and timely manner, providing all relevant information in accessible formats and providing reasonable accommodation when needed
* it states that public authorities should give due consideration and priority to the opinions and views of DPOs when addressing issues directly related to persons with disabilities
* it states that DPOs must be informed of the outcomes of such processes, in an accessible format, which includes an explanation of the decisions taken and how their views were considered

The NDA notes the views of the Joint Committee that people with disabilities and DPOs are not currently being consulted as required by Article 4(3)[[6]](#footnote-6) and shares the Joint Committee’s opinion that consultation on any proposed legislation should meet the requirements of Article 4(3) of the Convention.

The NDA also welcomes the recent publication by the DPO Network on the **Role of Disabled Persons' Organisations (DPOs) in Ireland**. We recognise the importance of DPOs, as the representatives and voices of disabled people, setting out their understanding of the role of DPOs in advancing the effective and meaningful participation and inclusion of disabled people in Ireland in line with the Convention. We note that one of the recommendations in the report is for the NDA to establish and maintain a national register of DPOs. While this proposal has merits, it merits careful consideration, in particular whether the Authority would be the most appropriate body for this function.

# New National Disability Strategy

The Department of Children, Equality, Disability, Integration and Youth is currently coordinating work across Government to develop Ireland’s next National Disability Strategy, which will be the successor to the National Disability Inclusion Strategy 2017-2022. The NDA notes the Joint Committee’s recommendation that a UNCRPD Implementation Plan be published[[7]](#footnote-7) and is aware that the new strategy will seek to progress Ireland’s implementation of the UNCRPD.

The NDA has been assisting the Department of Children, Equality, Disability, Integration and Youth with the strategy development process by undertaking a comprehensive public consultation initiative to inform its development. The consultation has sought to elicit the views of a wide variety of stakeholders, in particular DPOs, on measures to include in the strategy that would improve the lives of disabled people. The public consultation has been broad and wide-ranging, including:

* ongoing engagement by the Department of Children, Equality, Disability, Integration and Youth with DPOs
* themed focus groups on transport, employment & training, education, health & social care services, cost of disability, employment, housing and independent living
* targeted focus groups, including with seldom heard disabled people, such as people with intellectual disabilities or autism
* focus groups with disabled people with marginalised identities
* focus group discussions with children and young people with disabilities
* written and video submissions
* national survey targeting disabled people and carers
* town hall discussions

The NDA is pleased to inform the Joint Committee that DPOs have actively participated in the consultation process. The NDA is currently analysing all the information and data gathered during the consultation exercise and is highlighting the contribution of DPOs within this. We would be happy to meet with the members of the Joint Committee to brief them on the main findings, once completed. The NDA also intends to publish a consultation report and would be happy to share this with the Joint Committee.

The NDA further notes that the Joint Committee has recommended strengthening mechanisms for the participation and consultation of people with disabilities and their DPOs in the implementation, evaluation and monitoring of the UNCRPD Implementation Plan.[[8]](#footnote-8)

While responsibility for the exact form of the monitoring and implementation structure for the new strategy lies with the Department of Children, Equality, Disability, Integration and Youth, the NDA anticipates that DPOs will be assigned a formal monitoring role. During recent consultations on the new National Disability Strategy, DPO representatives stressed the importance of enhancing engagement with government departments, of DPOs being centrally involved in any monitoring and implementation processes, and of providing adequate resources and support to DPOs to ensure meaningful participation in decision-making.

# NDA work on Disabled People Organisations

Since Ireland’s ratification of the UNCRPD, the NDA has undertaken a range of policy and research work on DPO engagement and participation. Three important pieces of work are highlighted below, with the latter two publications developed following requests by government departments to the NDA for guidance on how to fulfil their commitments towards DPOs.[[9]](#footnote-9) The NDA would be happy to meet with the Joint Committee to discuss any of these publications in greater detail.

## Evaluation of the Disability Participation and Consultation Network

In 2020, the former Department of Justice and Equality established the Disability Participation and Consultation Network (DPCN) to facilitate participation by persons with disabilities in the policy development process. This arose from the inclusion of a new action (3C) in the previous National Disability Inclusion Strategy 2017-2022, following a mid-term review. The DPCN is comprised of an Organising Member, four grant-funded members, and a larger unfunded network of individuals and organisations thought to number approximately 170 members.

In March 2022, the Joint Committee on Disability Matters published a report setting out its view that the DPCN in its current format does not satisfy the requirements of UNCRPD with regard to consultation. The Joint Committee further stated that additional direct consultation with DPOs is required until such time as the DPCN is changed to come in line with these requirements.[[10]](#footnote-10)

In November 2022, the Department of Children, Equality, Disability, Integration and Youth requested that the NDA carry out an independent evaluation of the DPCN model to determine the extent to which it achieves the aims and expectations of such a mechanism in light of UNCRPD obligations, advice from the UN Committee through general comments (in particular General Comment No. 7), as well as having due regard for international practices.

Similar to the Joint Committee’s assessment, the NDA’s evaluation concluded that the design of the DPCN, which consisted of Disabled Persons Organisations (DPOs) other non-DPO organisations and individuals, is not aligned with the requirements of the UNCRPD.[[11]](#footnote-11) The report recommended that:

* a mechanism consisting of DPOs only is established through a process of co-creation with DPOs
* DPOs are supported to develop their capacity to input into policy design and monitoring processes
* Departments and state agencies need to improve their understanding of their obligations under the UNCRPD to consult with people disabilities and the role of different stakeholder groups in consultation processes
* consideration will need to be given to how the voices of seldom heard people with disabilities (children and young people, people with intellectual disabilities people with dementia for example) can be included in policy discussions

## Participation Matters guidelines

In September 2022, the NDA published guidelines on implementing the obligation to meaningfully engage with disabled people in public decision-making, entitled **Participation Matters**.[[12]](#footnote-12) Specifically, it provides detailed guidance to government departments, public bodies and local authorities on how to closely consult with and actively involve DPOs in participation and decision-making processes on issues relating to persons with disabilities.

The guidance specifically addresses the following questions:

* how to contact a DPO?
* how to know which DPOs to engage with?
* what to do if there is no relevant DPO or none available to participate?
* how to consider the views of DPOs?

DPOs were actively involved in the development of the guidelines, providing regular input and feedback during the consultation process. The NDA also published a consultation report for the Participation Matters guidelines, which outlines some of the barriers to participation encountered by disabled people and DPOs, including lack of training and support for DPOs.[[13]](#footnote-13) We note and welcome the reference to the Participation Matters guidelines in the Joint Committee’s most recent report.[[14]](#footnote-14)

## NDA review of Disabled Persons DPOs and their participation in implementing and monitoring the UNCRPD

In November 2021, the NDA published a review of DPOs and their participation in implementing and monitoring the UNCRPD.[[15]](#footnote-15) The review found that Ireland has a less developed DPO infrastructure than some comparative countries and needs to build this infrastructure, potentially through a long-term sustainable funding model for DPOs.

The international literature review identified several factors that promote the effective participation of persons with disabilities and DPOs in the implementation and monitoring of the UNCRPD, including:

* provision of education/capacity-building for DPOs in human rights, public policy and law, and evaluating the effectiveness of training. DPOs need to acquire knowledge about CRPD implications, understand how to use regional and international monitoring processes and acquire the skills to participate in CRPD monitoring and implementation
* awareness building and education for government departments and public bodies on accessible meeting techniques and transparent and accessible information and communication
* financial support for DPOs to participate in public processes on disability issues
* independent funding for DPO involvement in CRPD monitoring, which may include collecting disability data for parallel reporting
* DPOs establishing good working relationships and networks with politicians and other stakeholders
* finding and supporting efforts to give a voice to persons with disabilities including those who are not members of umbrella DPOs
* DPOs collaborating and cooperating among themselves including umbrella DPOs and building alliances with other human rights NGOs
* in addition to disability specific initiatives, DPOs can monitor and proactively request participation in relevant mainstream initiatives and developments
* DPOs providing decision-makers with evidence-based information to influence decisions and outcomes

The NDA recommended that the following actions should be considered:

* appoint UNCRPD champions as focal points in each government department and agency. These champions could coordinate UNCRPD awareness-raising initiatives, help outline what the Department is already doing to disability proof policies and plans and what they plan to do; and promote a study of how DPOs and/or persons with disabilities might input into the work of the department.
* consider how to improve formal mechanisms for engaging persons with disabilities in all stages of the UNCRPD monitoring process. This might include the UNCRPD focal point (the Department of Children, Equality, Disability, Integration and Youth) detailing how they intend to engage with DPOs and persons with disabilities.

# Conclusion

The NDA welcomes the Joint Committee’s ongoing attention to the role of Disabled Persons Organisations and self-advocacy in providing equal opportunities under the UNCRPD. We would be happy to engage with members of the Joint Committee on any of the points raised in this submission.

1. National Disability Authority (2021) Strategic Plan 2022-2024. [↑](#footnote-ref-1)
2. National Disability Authority (2022)Advice Paper on Disability Language and Terminology. [↑](#footnote-ref-2)
3. National Disability Authority (2023) Collaborative research with disabled people: Guidance for researchers. [↑](#footnote-ref-3)
4. Summary reports of the annual listening exercises are available on the NDA website at the following link: <https://nda.ie/about/engaging-with-disabled-people/annual-listening-session> [↑](#footnote-ref-4)
5. UN Committee on the Rights of Persons with Disabilities (2018) General Comment No. 7. [↑](#footnote-ref-5)
6. JOC Disability Matters (2024) Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities. [↑](#footnote-ref-6)
7. JOC Disability Matters Report (2024) Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities. [↑](#footnote-ref-7)
8. JOC Disability Matters (2024) Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities. [↑](#footnote-ref-8)
9. Other work has included NDA (2020) Working Paper on Engagement with DPOs and NDA (2022) A note for Government officials and staff of public bodies: Engaging and consulting with disabled people in the development and implementation of legislation and policy. [↑](#footnote-ref-9)
10. JOC Disability Matters (March 2022) Ensuring independent living and the UNCRPD. [↑](#footnote-ref-10)
11. National Disability Authority (2023) Independent Evaluation of the Disability Participation and Consultation Network. [↑](#footnote-ref-11)
12. National Disability Authority (2022) Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making. [↑](#footnote-ref-12)
13. National Disability Authority (2022) Consultation Report for “Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making”. [↑](#footnote-ref-13)
14. JOC Disability Matters (2024) Towards harmonisation of national legislation with the United Nations Convention on the Rights of Persons with Disabilities. [↑](#footnote-ref-14)
15. National Disability Authority (2021) A review of Disabled Persons Organisations (DPOs) and their participation in implementing and monitoring the UNCRPD. [↑](#footnote-ref-15)