

# Independent Evaluation of the Disability Participation and Consultation Network

December 2023



Údarás Náisiúnta Míchumais  
National Disability Authority

## Table of contents

<b>Executive Summary .....</b>	<b>4</b>
<b>Introduction.....</b>	<b>13</b>
Statement on language.....	13
Background to the evaluation .....	13
Evaluation process.....	14
Next steps.....	15
Structure of this report.....	16
<b>Background to the Disability Participation and Consultation Network .....</b>	<b>16</b>
NDIS action 3C.....	16
Launch of call for expressions of interest to join the DPCN .....	19
Second expression of interest process for DPO members .....	21
Structure of the DPCN.....	21
<b>Consultation and engagement .....</b>	<b>21</b>
Design of the DPCN and subsequent changes .....	22
Examples of consultation and engagement by the DPCN .....	29
Strengths of the DPCN in relation to consultation according to stakeholders	30
Weaknesses of the DPCN in terms of consultation and engagement according to stakeholders .....	31
<b>Capacity building within the DPCN .....</b>	<b>35</b>
Scope of capacity building within the DPCN.....	35
Scope of capacity-building within General Comment 7 .....	36
Examples of capacity-building initiatives led by the DPCN .....	37
Strengths of DPCN in relation to capacity building according to stakeholders	37
Weaknesses of DPCN in relation to capacity building according to stakeholders.....	38
<b>Funding.....</b>	<b>40</b>
Funding arrangements for the DPCN .....	40
Positive aspects of DPCN funding according to stakeholders.....	42
Challenges according to stakeholders.....	42

<b>Additional considerations .....</b>	<b>46</b>
Intersectionality within UNCRPD and General Comment 7 .....	46
Child and youth participation .....	50
<b>International DPO consultation and engagement mechanisms .....</b>	<b>52</b>
New Zealand .....	53
England.....	54
Denmark.....	57
Iceland .....	58
Serbia.....	61
Sweden.....	61
<b>NDA Findings .....</b>	<b>63</b>
UNCRPD article 4.3 .....	63
UNCRPD article 4.4.....	69
Achieving the best approach for consultation and engagement with disabled people .....	71
Define indicators for measurement of article 4.3 implementation with DPOs	80
Funding.....	81
Feedback on the draft final evaluation report.....	83
<b>Recommendations .....</b>	<b>83</b>
<b>Conclusion .....</b>	<b>88</b>
<b>Appendix.....</b>	<b>89</b>
Recent concluding observations by the UNCRPD Committee in relation to article 4.3.....	89

## Executive Summary

In 2020 the Department of Justice and Equality set up a Disability Participation and Consultation Network (DPCN) to facilitate participation by persons with disabilities in the policy development process. This arose from a new action (3C) included in the National Disability Inclusion Strategy 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 November 2022, the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) requested that the National Disability Authority (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.

In the preparation of this report, the NDA undertook an analysis of UNCRPD article 4.3 and 4.4, General Comment No. 7, relevant UNCRPD Committee concluding observations and international practices. The NDA carried out a consultation process to inform the review, which included interviews with DPCN Steering Group members, public officials and officials from two international Ministries. The NDA also sought input from the wider DPCN membership, although only one response was received. Consultation with stakeholders examined experiences and recommendations in relation to consultation and engagement, capacity building, funding, intersectionality and child and youth engagement.

The review has found that DPCN Steering Group members consider that the DPCN, as currently constituted, does not meet UNCRPD obligations in relation to consultation and engagement with Disabled Persons' Organisations (DPOs)<sup>1</sup>, while in the view of the State it could be considered compliant with these obligations. The NDA considers that the DPCN as currently constituted does not capture the spirit of the Convention when taking into account the advice of the UNCRPD Committee through its General Comment 7, which, while not legally binding, was developed by the Committee in order to “clarify State Parties’

---

<sup>1</sup> It should be noted that some organisations, including some members of the DPCN, prefer the term Disabled Persons Representative Organisation (DPRO) to Disabled Persons Organisation (DPO).

obligations”<sup>2</sup> under articles 4(3) and 33(3). Furthermore, the NDA advises that the current DPCN structure is not working effectively, in large part because of the lack of buy-in to the design of the mechanism from its Steering Group and that it is crucial to address this if a future mechanism is to be successful. For example, this lack of a shared understanding has led to operational issues as a result of the design of the DPCN which has hindered its ability to achieve its stated objectives, despite the best efforts of the organisations involved. For example, as the DPCN is not considered compliant with UNCRPD by its members, it was agreed by its Steering Group that it is not in a position to return a joint submission based on inputs by its members in response to government consultations. Therefore, the DPCN has operated instead as an information-sharing network in which members are informed of government consultations taking place and supported with information in order to make their own individual submission. Furthermore, the inclusion of approximately 170 members in the DPCN proved difficult to manage, with Steering Group members reporting challenges in establishing effective ways of working and in facilitating the inputs of a large membership with different levels of knowledge in relation to UNCRPD, as well as managing different expectations of members in relation to the role of the DPCN.

While some public officials reported good experiences in relation to the organisation of information sessions by the DPCN to assist with their consultations, it was also highlighted that there had been an expectation by some officials that the DPCN could return one joint submission from its membership which was not the case in practice. Officials also highlighted a lack of clarity regarding where the DPCN fits into the disability stakeholder landscape as a whole, particularly in relation to the obligation to consult with DPOs. One public body highlighted, for example, that despite its positive experience engaging with the DPCN, it is not planning to engage with this group for an upcoming consultation because it is not certain that engagement with the DPCN fulfils its obligations to consult with DPOs under UNCRPD. As a result, this public body is planning a consultation with DPOs only. In addition, DPCN Steering group members and public officials reported low engagement of the wider DPCN membership in consultation and capacity-building activities, which further declined over the lifetime of the DPCN. In one case, for example, only five participants attended an information session and in another case a session was cancelled as no participants showed up.

In relation to capacity-building, many DPCN Steering Group members welcomed the opportunity provided by the range of organisations within the Network with

---

<sup>2</sup> UNCRPD Committee (2018) General Comment no. 7.

different expertise to share. Some capacity-building took place through webinars organised by Steering Group members for the wider network. Topics included training on how to write a submission, how to talk to your TD, webinars on different articles of UNCRPD, a webinar which aimed to increase understanding of DPOs, self-advocacy workshops, and information sessions to inform members about government consultations. The review also found that some capacity-building took place informally through member organisations learning from their engagement with each other in DPCN meetings and events. However, the review found that the capacity-building initiatives undertaken do not meet the scope which is recommended by the UNCRPD Committee through its General Comment No. 7. The advice of the Committee is that capacity-building should be provided for DPOs and should encompass issues such as establishing structures of governance and accountability and supporting the access of DPOs to funding, which did not take place through the DPCN.

In relation to funding, the review found that the DPCN model does not align with the advice of the UNCRPD Committee in relation to funding for DPOs, including through access to core funding. The review also highlights some operational issues in relation to how funding for the DPCN worked, such as the accessibility of some of the documentation; the need for more guidance from the Department on the use and reporting of DPCN funding; and the need for coordination of funded members' project work were highlighted by interviewees. However, the review found that the funding element of the original DPCN design is by far the most significant funding issue. The funding arrangements of DPOs and non-DPOs created tensions within the DPCN as the funding which was made available to DPOs as part of the DPCN was not seen as meeting the advice of the UNCRPD Committee set out in General Comment 7. The issue of multi-annual core funding for DPOs was highlighted by a number of Steering Group members as being required for DPOs to develop their capacity to engage in consultative processes and to enable longer-term planning. A number of Steering Group members highlighted the dilemma that a number of DPOs face in which some DPOs lack the resources to establish the governance structures to attract funding or to participate in any future core funding scheme.

The review also considers the extent to which intersectionality is embedded within the DPCN model. It is evident that intersectionality was a consideration in the original design of the DPCN model. In practice, many DPCN Steering Group members pursue various strategies and activities to diversify their membership and address intersectional issues within their individual organisations. However, several Steering Groups members stated that the DPCN as an entity itself has not reached a point whereby it has been able to focus on strengthening intersectionality. Reasons cited include a lack of clarity on the purpose of DPCN within its own membership and therefore the value added for intersectional

groups whose time and resources are also limited; the need for a clear engagement plan with intersectional groups; the funding and resources required to deliver such a plan; and difficulty with reaching diverse groups experiencing intersecting inequalities.

The review also considered whether child and youth participation could be delivered within a network such as the DPCN. Several Steering Group members stated that, at least in its current form, the DPCN structure would not be conducive to child and youth engagement for reasons including lack of capacity to take on child and youth engagement within the current structure; the need for further resources; additional practical considerations for engaging children and youth, including consent, garda vetting and specific methodologies for including children and youth. In addition to these practical considerations, it is noted that at present there does not appear to be a children and young persons' DPO which could join a future DPCN type structure. However, some of the Steering Group members spoke of structures that their own organisation has for engaging with children and young people.

In our recommendations we advise that a new mechanism consisting only of DPOs is established through a process of co-creation with DPOs. The process of co-creation is particularly important in the context of previous attempts by the State to create disability consultation mechanisms which, in the view of some stakeholders, were ultimately unsuccessful because they were designed from the top-down rather than in collaboration with relevant stakeholders. As the DPCN has begun in recent months to more effectively facilitate networking and capacity building we have advised that DCEDIY could consider whether there is value in supporting the DPCN to evolve to play an ongoing role in those areas. However, there are other ways to fulfil this function and the DPCN would be only one of a number of options.

Our recommendations also include strategies to make such a mechanism work in practice and advises on the role and inclusion of non-DPO organisations who we believe also have a contribution to make to policy development. We also advise that an individual's right to participate in consultation processes is best upheld through strengthening DPOs, and through promoting a universal design approach to the design of public consultation and engagement initiatives in order to ensure that disabled people, including those who choose not to join a DPO, can participate on an equal basis with non-disabled people. However, we advise that the approach to engagement with individuals should reflect that individuals represent their own view only and not that of a wider membership. We advise in relation to how capacity-building could be delivered to support the development and strengthening of DPOs. We also present recommendations in relation to funding to support the development of DPOs, reduce the barriers to accessing

funding and enable their effective participation. We also highlight considerations for local level consultation and engagement processes and considerations for supporting the participation of disabled children and young people.

**The NDA's recommendations are summarised as follows:**

### **Consultation and engagement**

**Recommendation I:** Establish a co-created national-level body of Disabled Persons' Organisations (ideally the DPCN would be funded up until its replacement is established to ensure continuity). Provide funding for meetings of this mechanism including Secretariat supports. (See page 71 for more details).

**I (a):** Define, together with national DPOs, the scope of DPOs to be included in the national mechanism. For example, by developing a co-created checklist which creates a shared understanding of eligibility criteria for the national mechanism. For example, a process similar to that taken by New Zealand to develop its DPO Coalition checklist could be followed.

**I (b):** Consider how to create spaces for collaboration between the DPO mechanism and wider civil society (were the DPCN to continue it could potentially play a role in this space). For example, consider funding meeting costs for periodic 'town hall' meetings or workshops between organisations working on disability issues, with the agenda set by DPOs. (See page 79 for more details.)

**I (c):** Examine how to strengthen consultation and engagement with the most seldom heard disabled people.<sup>3</sup> For example, through including on the DPO mechanism certain organisations of family members/advocates of persons with intellectual disabilities, dementia and children which meet the criteria outlined in General Comment 7, and by developing guidance on engaging seldom-heard disabled people in consultation processes.<sup>4</sup>

**I (d):** Consider the scope of work that the new national-level body of DPOs could reasonably be expected to take on. Any new umbrella body of will take time to develop as its members learn to work together. Many of the DPOs will

---

<sup>3</sup> Some examples include people with intellectual disability, people with profound intellectual disability, people with mental health difficulties, deafblind people, people with a communication impairment, disabled children, people living in institutions, and others.

<sup>4</sup> For example, this could include guidance similar to DCEDIY's 'Seldom-heard toolkit' for engagement with children and youth and the forthcoming NDA and DCEDIY guidance on engaging disabled children and youth, particularly those who use assistive and augmented communication, but with a general focus on seldom-heard disabled people.



also require time to develop their own organisational capacity. Therefore, caution may be advisable with regard to expectations around the scope of work that such a new national-level body of DPO could reasonably take on in terms of monitoring UNCRPD implementation and wider consultation on policy initiatives in its initial phase.

**I (e):** Consider whether the Disability Participation and Consultation Network should end or whether it could evolve to play an ongoing role in the areas of networking and capacity building among stakeholders (DPOs and non-DPOs) with an interest in the Convention.

**Recommendation 2:** Raise awareness among Departments, agencies, public bodies, local authorities of their article 4.3 and 4.4 obligations, clarifying the State's position on the role of different stakeholder groups in consultation processes. For example, the NDA sets out its advice in its 'Participation Matters' guidance, and the Department as UNCRPD focal point could consider adopting this position. We advise the following:

- **Role of DPOs:** DPOs, as representative organisations of disabled people, must be closely consulted with and actively involved in decision making processes concerning issues related to people with disabilities. Public authorities are advised to systematically and openly approach, consult with and involve DPOs in a meaningful and timely manner. If the State adopts the recommendation to create a national-level DPO mechanism, it should include in its advice to public officials information about how to engage with this mechanism.<sup>5</sup>

We advise that organisations of family members of disabled people with intellectual disabilities, dementia or children with disabilities are also identified under General Comment 7 as organisations with a key role in consultation processes.

- **Role of non-DPO organisations:** There are many civil society organisations such as non-governmental organisations and disability service providers which advocate on behalf of people with disabilities or highlight issues related to disability rights. These organisations may also be involved in consultation, as they hold important and valid points of view and relevant expertise. The NDA does not advise that consultation take place with DPOs to the exclusion of all others, but that consulting with these

---

<sup>5</sup> The NDA has outlined more detail on the suggested role of this mechanism later in this report.

other stakeholders does not replace the requirement to consult with DPOs. The NDA advises that the State clarify its position regarding the role of non-DPO organisations in consultation processes and communicates this across government. We suggest the NDA guidance outlined in our 'Participation Matters' guidelines in this regard.

**Role of individuals:** Individuals have a right to participate in decisions affecting them. We advise that the engagement of individuals take place in the following ways:

- We advise that supporting the growth and development of DPOs is ultimately supportive of creating a stronger environment for individuals to collectively advocate for their rights.
- Individuals have the right not to join a DPO or other association. We advise that public consultation and participation processes at all levels of government should be accessible and underpinned by the principles of Universal Design as standard. This supports the participation of all and allows engagement in public decision making by those individuals with a disability who exercise their right to not join an association.
- There may also be contexts in which an individual will have specific local knowledge or lived experience which adds particular value to a consultation or fills a gap which is necessary to achieve the objectives of a particular consultation, and in this case it may be relevant to seek to engage these individuals. Engaging with disabled individuals outside of a DPO structure does not replace the requirement to consult with DPOs.

The above approach reflects the right of individuals to participate in decisions affecting them, while recognising that individuals give their own personal opinions, while organisations bring together the voices of a wider community and offer a position that is accountable to their members.

### **Capacity building and funding**

Capacity-building and funding are inextricably linked to meaningful consultation and engagement. The NDA recommends the following:

**Recommendation 3:** Consider a project funding stream for the development of capacity building programmes for DPOs, with the various types of capacity building needed identified by DPOs in line with their organisational requirements.

Organisations or individuals from any sector<sup>6</sup> with expertise in a relevant area could be eligible to apply to deliver capacity-building programmes to DPOs. (See page 79 for more details). Were the DPCN to continue it could have a role to play in relation to capacity building.

**Recommendation 4:** Support the growth and development of DPOs through various strategies to support their access to the necessary funding to develop their governance systems where necessary, grow their membership, improve their capacity to advocate for disability rights, and engage effectively in consultation, including:

**4 (a):** Consider developing a once-off programme of supports to assist those DPOs who need to develop the requisite governance structures to attract State funding. The programme design detail should be discussed with DPOs but could for example include some financial support and access to expertise in governance and organisational development.

**4 (b):** Consider how State funding such as the Disability Participation and Awareness Fund could be made more accessible to DPOs. For example, reducing barriers in funding criteria, giving due regard to the State's responsibility to ensure good governance of public money, and by ensuring the application and reporting processes are accessible.

**4 (c):** Consider developing a model of multi-annual core funding to which DPOs that meet required governance requirements and can demonstrate a capacity to deliver on agreed strategic objectives could apply. For example, consider looking at models from other sectors such as the Community and Voluntary sector fund administered by Pobal, and other relevant examples (See page 82 for more details). Any scheme would have to respect the independence of the DPO space by, for example, not requiring a DPO to report into a non-DPO disability organisation.

**4 (d):** While some DPOs work towards establishing their governance structures, consider interim measures which would support access to funding for these organisations. For example, allowing organisations to apply collaboratively with another established organisation for funding in which one organisation acts as a conduit organisation which distributes the funding to another DPO, as has been the case with the grant to the DPO Network from DECDIY to support the DPO Network's participation in the DPCN.

---

<sup>6</sup> Including DPOs with relevant expertise.

## **Other issues for consideration**

**Recommendation 5:** Consider undertaking the following scoping exercises which could be included as actions under the next UNCRPD strategy:

**5 (a):** Explore how to map and maintain a list of all national and local DPOs for the purposes of supporting officials to identify relevant organisations for consultation and engagement.

**5 (b):** Consider how to define and measure progress in relation to article 4.3 as part of the new UNCRPD strategy. For example, consider developing indicators with DPOs to measure implementation of article 4.3, informed by General Comment 7 and OHCHR guidance. (See page 80 for more details).

**5 (c):** Explore whether the introduction of national legislation and policies that recognise the right to participation and involvement of DPOs would be appropriate in an Irish context, given that some other EU countries have introduced such measures (See page 80 for details). This could take place in the context of any future reviews of disability legislation.

**5 (d):** Consider how to promote DPO consultation and engagement at the local level including potential linkages between local and national structures of engagement.

**5 (e):** Explore how the development of child and youth DPO(s) could be supported by the State. In the interim, explore alternative mechanisms to ensure that disabled children and young persons' views are included in consultative fora, for example, by supporting the inclusion of disabled children in mechanisms of engagement for the UN Convention on the Rights of the Child.

## 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.

### Statement on language

Throughout this report, the NDA refers to “organisations of persons with disabilities” and “representative organisations” in keeping with the language of the UNCRPD and General Comment No. 7. These terms are synonymous with “Disabled Persons’ Organisations” or DPOs.

In this report, the terms “people/persons with disabilities” and “disabled people” are used interchangeably. The term “disabled people” is recognised by many within the disability rights movement in Ireland to align with the social model and human rights approach of disability, as it is considered to acknowledge the fact that people with an impairment are disabled by barriers in the environment and society. However, we also recognise that others prefer the term “people/persons with disabilities” because of the inherent understanding in the term that they are first and foremost human beings entitled to human rights. This also reflects the language used in the UNCRPD. We recognise that many people with an intellectual disability, people with a mental health difficulty or psycho-social disability prefer person-first language. We also recognise that some people don’t identify with either term.

The term ‘Deaf’ with an uppercase ‘d’ is used in this document when referring to those who identify culturally and linguistically as part of the Deaf community. A lower case ‘d’ is used to refer to those who are deaf or hard of hearing and who do not identify culturally and linguistically as a member of the Deaf community. The term ‘d/Deaf’ is used to refer to both groups.

Please see the NDA advice paper on disability language and terminology for further information.<sup>7</sup>

### Background to the evaluation

The Department of Children, Equality, Disability, Integration and Youth (DCEDIY) requested in November 2022 that the National Disability Authority

---

<sup>7</sup> NDA (2022) Advice paper on disability language and terminology:  
<https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology>

(NDA) carry out an independent evaluation of the Disability Participation and Consultation Network.

The aim of the evaluation is to assess the operation of the DPCN model and determine the extent to which it achieves the aims and expectations of such a mechanism in light of UNCRPD obligations and advice from the UN Committee through general comments (in particular General Comment No. 7) and concluding observations to State reports to date. The evaluation is expected to outline relevant recommendations for the enhancement of this consultation model, having due regard for a model that aligns with, or generates, international best practice.

This evaluation does not examine the specific performance of each funded organisation measured against relevant grant agreements, but evaluates the conceptualisation and progress achieved by the DPCN as a whole, with a view towards making recommendations that build on the foundation of experience achieved to date.

### **Evaluation process**

The NDA developed a scoping document for the evaluation and a consultation plan which was shared with DCEDIY. This was presented to the DPCN Steering Group in December 2022 for discussion and agreement.

DCEDIY shared key documents with the NDA project team including application information, grant agreements, and reporting documents from the DPCN members.

Steering Group members of the DPCN were invited for an interview with the NDA project team to ascertain their perspectives on the strengths and weaknesses of the DPCN model and their recommendations for future. Representatives from the following Steering Group member organisations took part in an interview: Inclusion Ireland, Mental Health Reform, Disability Federation Ireland, As I Am, Voice of Vision Impairment, Independent Living Movement Ireland, Irish Deaf Society, Disabled Women Ireland, the National Platform of Self Advocates, and the Chair of the DPO Network. An interview also took place with the current independent facilitator, Kieran Murphy.

A mail-out was circulated to the wider DPCN membership of approximately 170 individuals and organisations seeking the views of this cohort to inform the evaluation. Inputs were sought through a call for submissions and a call for expressions of interest to join a focus group. Only one response was received.

The NDA invited representatives from five departments/agencies which had been recorded as having engaged with the DPCN to take part in an interview. Two

departmental representatives responded stating that a consultant had carried out the consultation on their behalf. Three departments/agencies took part in an interview including officials from the Department of Children, Equality, Disability, Integration and Youth, the Housing Agency, and the Department of Health. The NDA also drew on findings from focus groups with public officials carried out in 2022 as part of our consultation on the development of our Participation Matters guidelines.<sup>8</sup>

The NDA, through DCEDIY, circulated a request for information to Ireland's Permanent Representatives and attaché networks in Brussels, Geneva and New York. The request sought information on comparative international practice in relation to standing consultation mechanisms or other approaches that have been developed to date under the UNCRPD to consult with and support the participation of disabled people in policy and law-making processes, mechanisms of capacity building, and mechanisms of State funding for organisations of persons with disabilities. Unfortunately, no responses were received.

The NDA referred to its own research into international practices in relation to engagement with disabled people and their organisations. In addition, an analysis was carried out into relevant comments of the UNCRPD Committee in relation to article 4.3.

The NDA held a meeting with officials from Whaikaha, the Ministry of Disabled People, within the Government of New Zealand to discuss its stakeholder engagement and funding mechanisms under UNCRPD. In addition, a meeting was held with officials from the Disability Unit of the UK Cabinet Office to find out more about its stakeholder engagement mechanisms with disabled people.

Finally, the NDA offered both DCEDIY and DPCN Steering Group members the opportunity to provide feedback on any errors of fact and observations on the recommendations in the draft final report. The NDA amended the report where appropriate to reflect the feedback received.

### **Next steps**

The NDA submits this report and its independent recommendations to DCEDIY for consideration. This report has been shared with DCEDIY and with the DPCN Steering Group for their reflections before publication.

---

<sup>8</sup> NDA (2022) [Participation Matters Consultation Report](#).

## **Structure of this report**

The report begins by setting out the background to the formation of the Disability Participation and Consultation Network in the context of National Disability Inclusion Strategy 2017 – 2021 (NDIS) action 3C. It outlines details of the expressions of interest process for members and how the DPCN membership is currently structured. Next it examines how the structure of the model evolved from its original terms of reference in order to contextualise the subsequent activities carried out by the DPCN.

The report then examines the strengths and weaknesses of the DPCN model in relation to consultation and engagement, capacity building and funding as highlighted by stakeholders in the consultation. A summary of examples of international practices is then included. International examples are not necessarily presented as practices for Ireland to follow but explore some similar issues and ideas from other contexts. Next, the NDA outlines its findings and recommendations in relation to the overarching evaluation questions using the feedback from stakeholders in the context of relevant CRPD articles, General Comment 7 guidance, CRPD Committee concluding observations and other relevant sources in order to formulate our recommendations for a future model. The appendix contains an overview of some recent concluding observations by the UNCRPD Committee in relation to article 4.3.

## **Background to the Disability Participation and Consultation Network**

### **NDIS action 3C**

Ireland ratified UNCRPD in 2018. The ratification of UNCRPD informed the addition of new actions to the National Disability Inclusion Strategy (NDIS) 2017 – 2021 after the mid-term review of the strategy in 2020.<sup>9</sup> One such action, action 3C, to be led at that time by the Department of Justice and Equality,<sup>10</sup> stated

---

<sup>9</sup> [Midterm-Review-of-the-National-Disability-Inclusion-Strategy-2017-2021 \[1\].pdf \(ipo.gov.ie\)](#)

<sup>10</sup> The Department of Justice and Equality was Ireland's designated Focal Point and Coordination Mechanism under the UNCRPD. However, following the establishment of the Department of Children, Disability, Equality and Integration, this role moved to the new Department as part of the transfer of functions that took place in October 2020.



We will implement a consultation and participation model, in line with the UN CRPD, to facilitate participation by persons with disabilities in the policy development process

A proposed consultation and engagement approach was set out in the appendix of the mid-term review report. It stated that UNCRPD requires State Parties to

**‘closely consult and actively involve persons with disabilities, including children with disabilities’** in the development and implementation of legislation and policies concerning persons with disabilities

The quoted text from UNCRPD within the mid-term review document (bold added) leaves out the end of the sentence within the Convention, which states “through their representative organisations”. The reason for not including the entire sentence is unclear, but it appears to have had important implications for the design and functioning of what would later become the DPCN.

The full text of UNCRPD Article 4.3 states

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.

The UNCRPD Committee expands on article 4.3 (and article 33.3) in its General Comment No. 7 (2018) which the Committee states aims to “clarify State Parties’ obligations under articles 4 (3) and 33 (3) and their implementation” based on its jurisprudence.<sup>11</sup> General Comment 7, while not legally binding, sets out the advice of the UNCRPD Committee in relation to the implementation of article 4.3. and State Parties are encouraged to apply it. In requesting this evaluation from the NDA, the Department asked that we review the DPCN in the context of the advice set out by the Committee in its General Comment 7 and in its concluding observations and to highlight measures the State could continue or introduce in order to work towards this standard.

---

<sup>11</sup> UNCRPD Committee (2018) [General Comment No. 7.](#)

While we note the wide range of State Parties that are signatories to the UNCRPD, and the varying extents of implementation, in General Comment 7, the Committee states that it has observed a gap in the spirit of article 4.3 and the degree to which it has been implemented by State Parties, due to the absence of meaningful consultation with an involvement of persons with disabilities through their representative organisations in the development and implementation of policies and programmes. It goes on to define 'representative organisations' as organisations led and governed by disabled people, as distinct from other civil society organisations which advocate or provide services on behalf of disabled people, and which are not led by disabled people themselves.<sup>12</sup> These organisations are more commonly known in Ireland as Disabled Persons' Organisations (DPOs).

The mid-term review document also outlines the intention that an expressions of interest process would seek an organisation which would

undertake coordination between the organisations and groups involved in supporting specific categories of representative and would organise the network of disabled people's organisations.

References to Disabled Persons' Organisations within the document suggests an awareness of this type of stakeholder group by officials, but also reflects an evolving understanding of changes in terminology at that point in time, whereby the description of 'representative body' becomes firmly linked to the concept of a Disabled Persons Organisation. For example, the document separates these two terms at this time, stating

People with disabilities need a mechanism to raise issues with public bodies and to have their perspectives taken into account in public consultations and policy processes. Such mechanisms can include Disabled Persons Organisations (DPOs), representative bodies, umbrella organisations, and the perspectives of individuals.

It is not incorrect to suggest that various stakeholder groups as well as individuals need mechanisms to raise issues and have their perspectives taken into account. However, the document does not highlight the difference between a DPO and other stakeholder organisations or individuals, their unique role as representative organisations, and the

---

<sup>12</sup> Full definition available at General Comment No. 7. II (a)

prioritisation of DPOs among stakeholder groups as set out in General Comment 7.

It is important to acknowledge also that this document was written shortly after ratification of UNCRPD. The landscape of DPOs in Ireland was and still is evolving. The mid-term review document states

It is proposed that a consultation and participation model will be developed that over time will support the emergence and ongoing operation of Disabled Persons Organisations in line with the Convention.

This suggests a recognition of the evolving landscape of DPOs and the need to support their emergence and development over time, which could be supported through the proposed consultation model. It should also be noted, however, that there were DPOs in operation in Ireland at this time, General Comment 7 has been available since 2018 and the UN Committee states that the right to participate is a civil and political right and an obligation of immediate application, and not one of progressive realisation.<sup>13</sup>

### **Launch of call for expressions of interest to join the DPCN**

The Minister of State with responsibility for Disability announced a call for expressions of interest to join the new Disability Participation and Consultation Network (DPCN) in August 2020.<sup>14</sup> The press release stated that the DPCN will “provide a channel for involving persons with disabilities more meaningfully in the development of policy and legislation in line with the requirements of the UNCRPD.” The call for expressions of interest was closely aligned with what was set out in the NDIS action 3C proposition and the application information for members explicitly referenced action 3C. However, the applicant information does quote the entire article 4.3, including the reference to ‘representative organisations’ as well as article 33.3.<sup>15</sup>

The proposed DPCN model would be made up of three tiers with an Organising Member, four grant-funded member organisations and a wider unfunded

---

<sup>13</sup> Progressive realisation applies to economic, social and cultural rights only.

<sup>14</sup> Department of Justice and Equality (2020) [Launch of Expressions of Interest to establish a Disability Participation and Consultation Network - The Department of Justice \(ipo.gov.ie\)](https://www.ipd.gov.ie/launch-of-expressions-of-interest-to-establish-a-disability-participation-and-consultation-network)

<sup>15</sup> UNCRPD article 33.3 “Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.”

membership of organisations and individuals. Applications were sought for an Organising Member which it stated should be “an organisation representing persons with disabilities, or with experience on disability” with a role to “provide administrative and organisational support, including training, to the network.” The application information also stated that the Organising Member would be in receipt of €70,000 for a period of one year “for the purpose of establishing the Participation and Consultation Network and the engagement of the Network for the purpose of the UNCRPD Initial State Report consultation process.”

The Minister also announced that up to four grants would be available to “organisations or groups representing persons with disabilities to develop their capacity and to their support members, to provide training and to run consultations on behalf of the network.” Grants of up to €20,000 were available to successful applicants stating that “The grant amount being provided by the Department of Justice and Equality is for the purpose of establishing the Participation and Consultation Network and the engagement of the Network for the purpose of the UNCRPD Initial State Report consultation process.”

The application information for grant-funded members stated that “The grant-funded members will be tasked with carrying out the consultation and participation work of the Network and providing the results of that work to the Organising Member. In addition, members will be expected to engage with the Organising member of the Network in relation to administration, capacity building training, events and other activities that will progress the work of the Network.”

The Minister announced that there would be a separate application process for “organisations, groups or suitable qualified individuals with disabilities who wish to join the network.” Participants in this wider network would not be in receipt of funding but would be eligible to avail of the activities of the Network.

Following the call for expressions of interest, Inclusion Ireland was appointed as the Organising member. The four grant-funded members appointed were Disability Federation Ireland, Mental Health Reform, As I Am, and the DPO Coalition which was made up of seven organisations who were collectively awarded one grant.<sup>16</sup>

The wider Network of unfunded organisational and individual members of the DPCN was made up of approximately 170 members, although different exact

---

<sup>16</sup> The DPO Coalition was a group of seven DPOs including As I Am, Disabled Women Ireland, Independent Living Movement Ireland, Irish Deaf Society, The National Platform of Self Advocates, Physical Impairment Ireland, Voice of Vision Impairment.

membership numbers were cited by different stakeholders in the consultation, ranging from 120 to 170.

### **Second expression of interest process for DPO members**

Following the submission by the DPCN of the consultation report on Ireland's first State Party report to the UNCRPD Committee, the DPO Coalition disbanded leaving a vacancy on the DPCN. In January 2022, the Minister announced a call for expressions of interest for a DPO grant-funded member to join the DPCN,<sup>17</sup> stating

Funding is available for a Disabled Persons' Organisation (DPO) to join three existing grant-funded members and an Organising Member to advance the aims and goals of the Network in 2022.

The DPO Network, a newly formed network of five DPOs<sup>18</sup> which had all previously been part of the DPO Coalition, was collectively awarded the grant.

### **Structure of the DPCN**

The Organising Member and the four grant-funded members formed a Steering Group. The Steering Group was initially made up of Inclusion Ireland, Disability Federation Ireland, Mental Health Reform, As I Am, and the seven organisations of the DPO Coalition (which together formed one grant-funded member). Following the disbanding of the DPO Coalition and the appointment of the DPO Network to the DPCN in 2022, the Steering Group retained the same organisational membership, but the two DPOs which are not part of the DPO Network are not in receipt of any funding as part of their involvement in DPCN. Therefore, the Steering Group is currently made up of both funded and unfunded DPCN members.

## **Consultation and engagement**

Understanding the background of the DPCN, how it was conceived and designed and how its structures were established is essential in order to understand the

---

<sup>17</sup> DCEDIY (2022) <https://www.gov.ie/en/press-release/9dcf5-minister-rabbitte-launches-call-for-expressions-of-interest-for-dpo-grant-funded-member-to-join-the-disability-participation-and-consultation-network/>

<sup>18</sup> The DPO Network includes As I Am, Disabled Women Ireland, Independent Living Movement Ireland, Irish Deaf Society, the National Platform of Self Advocates.

nature of the consultation and engagement activities undertaken by the DPCN and some of the challenges which arose.

## **Design of the DPCN and subsequent changes**

The interviews with Steering Group members, including DPOs and non-DPOs, highlighted that the design of the DPCN created challenges in its operation from the beginning which have persisted throughout.

### **Membership structure**

#### **Article 4.3 compliance**

Steering Group members, both DPO and non-DPO, stated in interviews with the NDA that they understood that the DPCN was intended as a structure of engagement with the disability community in order to meet article 4.3 requirements, as the call for expressions of interest explicitly stated this and quoted article 4.3. However, there is a divergence in view between the State and members of the DPCN Steering Group in relation to whether or not the DPCN as currently constituted can be considered compliant with article 4.3. The State understands that the DPCN could be considered compliant with article 4.3 as DPOs are included in it. However, in the view of DPCN Steering Group members, because the DPCN is not DPO-led and does not prioritise and distinguish DPOs from other stakeholders in the way this is outlined within General Comment 7, they do not consider it to be a representative body for the purposes of meeting article 4.3. obligations. While this issue was initially raised by DPO members, non-DPO members also supported this, and no member of the Steering Group disagreed on this point. Some DPO Steering Group members stated a view that non-DPO organisations, such as service providers, should not be members of the DPCN if it is to be compliant with article 4.3. Other DPO Steering Group members stated they would accept non-DPO organisations as members of the DPCN but stated there should be a mechanism within the DPCN to prioritise DPOs as outlined in General Comment 7. Some DPO Steering Group members felt that although well-intentioned, the formation of the DPCN was based on a misunderstanding of article 4.3 and expressed disappointment that the DPCN was designed without DPO input which in their view would have avoided this. Some Steering Group members stated that in their view the process of establishing the mechanism was rushed in order to meet timelines for developing the State Party report to the UNCRPD Committee.

This central tension of whether or not the DPCN can meet article 4.3 requirements has consistently dominated DPCN meetings, according to Steering Group members. Many Steering Group members alluded to conflicts within the group and during meetings centred around this point, creating a 'fractious' environment and even leading to some members disengaging from the DPCN, including one DPO member which has not engaged in DPCN meetings or

activities in more than one year. This issue also created barriers towards progressing joint work on consultation and engagement. For example, DPCN members decided that it cannot produce joint submissions and papers based on inputs from its membership as it cannot be considered a representative body as per article 4.3 and General Comment 7. It is important to note that all interviewees spoke highly of the Organising Member and DPCN Coordinators and stated that the issues arose primarily from the design of the structure.

One DPO Steering Group member stated

Everybody realises that it's difficult, but it's difficult because it's very badly designed, as if there was no such thing as the CRPD and article 4.3. The very thing that it was designed to ostensibly to fulfil.

It is important to highlight that attempts were made by DPCN Steering Group members to establish a way forward through this issue. Many members highlighted in interviews the huge amount of work which took place over the first 12 months after the establishment of the DPCN to remedy this. For example, an attempt was made by the Steering Group to create a list of DPOs within the DPCN in order to develop a mechanism of prioritisation so that the model of the DPCN could be adapted to meet article 4.3 requirements, in their view. However, it proved difficult to determine which organisations within the wider membership of 170 are DPOs or not and therefore this effort was ultimately unsuccessful. Many Steering Group members, including both DPO and non-DPO members, highlighted the need for a register of DPOs which will be discussed in more detail later in this report.

The Steering Group instead went through a process of redeveloping its terms of reference at the end of its first year, with the support of an independent facilitator in order to agree upon what kind of work the DPCN could progress. In terms of consultation, it was agreed that the DPCN would share information about government consultations with its membership and facilitate information sessions with and on behalf of departments with their members. However, it was decided that members would be expected to make their own submissions to the consultation and that a group position would not be formulated by the DPCN as it cannot be considered a representative body that meets article 4.3 requirements, in their view. Members expressed that this shift came about after a huge amount of work and difficult conversations during which time not much else was progressed. More information on the consultation and engagement activities carried out by the DPCN is included in the next section of this report.

Another initiative undertaken by the Steering Group to improve ways of working included the addition of a new independent facilitator from February 2022 who facilitates two meetings a month for the Steering Group and one 'agenda setting' meeting which takes place one week before the Steering Group meeting. The facilitator, in his interview with the NDA, reflected that tensions within the group arising from different views regarding the legitimacy of DPCN member organisations and the question of who is considered a representative organisation has been the dominant issue. The facilitator held one to one meetings with each Steering Group member to talk about their expectations of the group, their experiences, and the challenges faced. He then facilitated the development of a group contract. The facilitator highlighted the importance of taking the time to establish processes and ways of working when developing a network such as the DPCN. Many Steering Group members, including DPOs and non-DPOs, highlighted that having an independent facilitator has had a positive impact on Steering Group meetings and on the relationships between the organisations. A DPO Steering Group member highlighted that this "shows that you just don't throw people randomly together, it's not going to work" and that there is a need to invest time in establishing relationships and ways of working.

### **Large membership**

The second main issue raised by Steering Group members with regard to membership was the number of unfunded wider network members whose applications to join the DPCN were accepted. The number of members in this wider network is estimated at around 170 members made up of individuals and organisations.

The Department in its interview indicated that the intention was that the DPCN would encompass a broad range of members in order to be more inclusive. Reference has been made by Department officials to UNCRPD article 4.4 in this regard. While article 4.4 is not explicitly referenced in the original call for expressions of interest, Department officials have included reference to it in the evaluation information document for the NDA which states

Obligations in Article 4(3) of the UNCRPD require the State to consult with people with disabilities through their representative organisations in the development of law and policy. Membership of the DPCN has been open widely to individuals and organisations including but not limited to representative organisations.

In this way, the DPCN model was intended to facilitate engagement with representative organisations and individuals, organisations for people with disabilities, and civil society more widely. While the evaluation of the DPCN model and function must be cognisant of



Article 4(3), it must also take into account Article 4(4) in considering more generally how people with disabilities, however they choose to be represented, including in structures similar to the DPCN and in alternate form to the DPCN, can be consulted.

The Department also cited article 4.4. in its interview with the NDA suggesting that the DPCN model embraces article 4.4 by going beyond the parameters of article 4.3. That is to say, that it does not only include DPOs but also other organisations and individuals. However, this is a point of divergence with the views and the experience of the DPCN Steering Group which needs to be further examined.

Many Steering Group member organisations stated that their expectation had been that the wider DPCN membership was intended to be a network of 20 members appointed through a selection process. However, Steering Group members indicated that everyone who applied to join the unfunded tier of the DPCN was accepted without a selection process, and the membership grew to somewhere in the region of 170 members. Several Steering Group organisations indicated that this growth in membership was not expected and that it caused problems with the operation of the group.

It is important to highlight that the DPCN Organising Member made an effort to make this work. An NGO Steering Group member reported that the DPCN Coordinator attempted to hold meetings online with the entire membership in its first year, splitting them into groups of about 50 per meeting, in order to establish what everyone expected and wanted from the Network. Ultimately this was unsuccessful. This Steering Group member commented

You can imagine with 120<sup>19</sup> people all with different levels of experience and activism and advocacy, different disabilities. Getting any kind of consensus turned out to be impossible.

As well as the number of members, some Steering Group members expressed a view that a mechanism such as the DPCN is not the right forum for individuals. Two DPO Steering Group members stated that in their view, article 4.3 is about collective organising, and therefore a structure such as the DPCN, if intended to meet article 4.3 requirements, is not the right approach for including individuals in their view. They stated that individuals can take part in public consultation but cannot be at the table on the same basis as an organisation (whether DPO or

---

<sup>19</sup> A variation of membership numbers was quoted by different Steering Group members, but it is thought to be in the region of 170.

non-DPO) which represents a collective voice. A DPO Steering Group member further explained that it is not about limiting the participation of disabled people, but that

Nobody even with the best facilitation skills within a random assembly of 100 people will get a consistent message.

Another DPO Steering Group member stated that allowing in members without a selection process, including individual members all with their own personal stories and little understanding of CRPD, resulted in many challenges.

Another DPO member similarly stated that having so many members does not allow for strategic or constructive discussions. This member highlighted the National Disability Inclusion Strategy 2017 – 2021 which they describe as “unfocused” with a long list of actions, stating “You cannot engage with 650,000 individuals and make a long list of things.” In their view, taking the approach of engaging primarily with collectives rather than individuals could be communicated better by the State, led by the DCEDIY as UNCRPD focal point, stating

You go back and say it is not about excluding individuals, but we have made this commitment at an international level and if we are serious about it then we are serious about creating those spaces and investing in them.

The wider unfunded tier of the DPCN is now functioning essentially as a mailing list for sharing events and information. Engagement from this wider network is very low as evidenced by the numbers of participants attending DPCN events, which will be highlighted in a later section of this report. It is also evident in the preparation of this evaluation as an attempt by the NDA to seek feedback on the DPCN from this cohort resulted in just one returned submission.

### **Shared vision and clarity regarding obligation towards DPOs**

While there were different views and ideas on what the membership of the DPCN should comprise in future, or whether the DPCN should continue at all, the overwhelming message coming from all interviews is the need for clarity of vision and purpose of the DPCN, or a future model, and clarity regarding how the State intends to meet its obligations towards DPOs so that this issue can be resolved. This was expressed by both DPO and non-DPO Steering Group organisations.

One NGO Steering Group member stated, for example

The department need to clearly articulate the vision for DPO development in Ireland and put a three-year plan in place to address some key issues. You know, this isn't only coming out through the DPCN, obviously it's in most forums, this same issue is coming up.

Public officials have also expressed that they are unclear about which stakeholder groups to involve in consultation on disability matters and where the DPCN fits within this landscape. The NDA carried out focus groups with public officials as part of a 2022 consultation for the development of our 'Participation Matters guidelines' in which public officials highlighted that they are not clear on the role of the DPCN in consultation processes. Officials stated they would welcome clarity in relation to the role of DPOs, NGOs, service providers, and the DPCN. In particular, officials highlighted that it is not clear who you need to contact in the first instance and how best to contact them, include them and involve them. A public official who engaged the DPCN in a consultation process also highlighted as a challenge understanding the various disability stakeholder groups and where the DPCN fits in.

### **DPO Register**

Many NGO and DPO Steering Group members stated that in their view, there is a need for a DPO register in Ireland. Some Steering Group members cited General Comment 7 which states

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.

The Special Rapporteur on the Rights of Persons with Disabilities in 2016 stated

States must implement registration systems that are simple, flexible, expeditious, fully accessible, nononerous and/or even free of charge, to facilitate the registration of organizations of persons with disabilities.<sup>20</sup>

---

<sup>20</sup> UN General Assembly (2016) Human Rights Council, 31<sup>st</sup> session, [Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development. Report of the Special Rapporteur on the rights of persons with disabilities](#). January 12<sup>th</sup>, 2016. Para 40.

Beyond implementing the guidance set out in General Comment 7, Steering Group members highlighted other reasons why a register of DPOs would be beneficial. One such reason given by an NGO Steering Group member, is that it would help improve the reach of consultations towards local level DPOs. This member highlighted that at present, it finds DPOs on Twitter to invite to its events.

A DPO Steering Group member highlighted the importance of a DPO register for accountability purposes in relation to the use of State funding, stating

If we don't [register DPOs] there is going to be problems down the line. Accountability, reporting, honesty in relation to use misuse of funds. Every other week you pick up the paper and see some problems with agencies and charities regulator or some other regulator because of mismanagement and there is very high risk of that happening in this space.

Another DPO member stated a register would help with some of the confusion around which organisations can be considered DPOs. For instance, a question that is often raised is whether or not a DPO can provide services. One DPO Steering Group member which provides services to its members stated that there is confusion even within its own organisation about whether or not it can be considered a DPO for that reason.

### **Structure of project planning within the DPCN**

The Steering Group members also highlighted challenges in the way in which work-planning is structured within the DPCN. The Organising member and four grant-funded members each develop their own workplans which are then submitted to and signed off by the Department in order for each grantee to receive their funding. The grant-funded members report directly to the Department on their activities and spending (not to the Organising Member). There is no requirement to join up workplans before submitting them to the Department, and this together with the individual nature of the reporting has, according to some members, led to a lack of cohesion between the Steering Group members' activities as part of the Network.

One NGO Steering Group member also highlighted that an added complexity is that the Steering Group is made up of organisations which are funded and unfunded, and the unfunded members do not develop a work plan and therefore do not shape the work of the DPCN. The two unfunded DPO Steering Group members have indicated that they have had little awareness of the activities on the workplans of the other Steering Group members. This appears to have further contributed to tensions within the Steering Group.

There was an attempt made by the Organising Member to join up members' workplans, but it proved unsuccessful. According to Department officials, in response to this effort, DPCN Steering Group members indicated a preference to continue to submit individual project plans. Instead, the Steering Group members agreed to share workplans with each other to improve transparency and it was agreed that if another organisation wanted to support on a certain activity they could do so. An NGO Steering Group member highlighted that since members have shared workplans, they realised they had not been sufficiently costing out their staff time for certain activities and were able to make adjustments to ensure their grant meets the amount of staff time needed to deliver projects.

The Department has acknowledged that individual plans were requested for a collective project, and because funded members applied for single grants based on separate project plans, this meant that the funded organisations had different expectations of the DPCN and different plans for the funding which created challenges.

Two NGO Steering Group member organisations also highlighted that the process of developing and submitting a workplan was rushed in their view. For example, one organisation stated that they had only one and a half weeks to prepare their project plan. It was acknowledged that this was to do with officials being redeployed to support with the Ukrainian crisis response and that when they came back into post they needed the project plans very quickly, but that this was a challenging timeframe for DPCN organisations.

## **Examples of consultation and engagement by the DPCN**

### **Consultation on the State Party report to the UNCRPD Committee**

The first task of the DPCN was to coordinate a consultation on the State Party report to the UNCRPD Committee. Steering Group members reported that this was a huge undertaking with quite a short deadline. The delivery of this consultation took place in the context of an unexpected rise in the number of members admitted to the DPCN to around 170 members. As a result, there was not much 'bedding in' time for the group to establish relationships and ways of working and to develop a shared understanding of the function of the DPCN.

Some DPO Steering Group members shared their perspective on this consultation. One DPO Steering Group member highlighted that they had been asked to facilitate one of the focus group sessions for this consultation as a DPCN member. In their view it amounted to carrying out administrative tasks for free under the guise of inclusion of DPOs, by being tasked with organising and facilitating the session, while as a result of their facilitation role, they could not input their own views into the consultation session. Another DPO member

stated that the consultation went well overall, but in their view the output from the meetings was weak. In their view it did not capture or explore some of what was said in the meeting and was not informed by a strong policy context.

From the perspective of DCEDIY officials, the process was well run and well received and the contribution of the DPCN made an impact on the State Report. The Department noted that they recognise it was a big ask at an early stage and that the first 6 to 9 months of DPCN went into preparing this report, which bypassed the initial period of finding ways of working together. The Department acknowledged that this wasn't a consideration the Department took into account.

### **Information sessions**

As outlined in the section above, the DPCN Steering Group members redeveloped its terms of reference in response to the view of members that the DPCN cannot be considered a representative body under article 4.3 and therefore cannot return a joint position on behalf of its membership in response to a consultation. Therefore, the DPCN instead hosts information sessions about relevant consultations relating to disabled people among its membership and provides support to officials in the organisation of these sessions. Information sessions planned by the DPCN for its members in 2022, for example, included:

1. Third National Strategy on Domestic, Sexual and Gender-based Violence- 10 March 2022
2. Housing Strategy Implementation Plan - 14 March 2022
3. Autism Innovation Strategy - 19 May 2022 (did not go ahead)
4. Reasonable Accommodation Fund - 3 May 2022
5. Draft Regulations for Providers of Home Support Services - 14 July 2022
6. Roadmap for Social Inclusion Mid-Term Review - 29 September 2022

### **Strengths of the DPCN in relation to consultation according to stakeholders**

One NGO Steering Group member highlighted that from a department's perspective, the strength of the DPCN is in being able to outsource consultation to this group when they do not have the expertise themselves. This was also reflected by officials who took part in interviews with the NDA for this evaluation. An official from one public body stated that operationally the focus groups with DPCN members worked really well. The DPCN Coordinator sourced facilitators and notetakers from the Steering Group. In advance of the session, the Coordinator supported the officials to refine their consultation questions and ensure adequate accessible supporting documentation for

participants. An official from a different department also highlighted that support in the preparation of consultation materials was very useful and that the session was very well facilitated.

A representative from one public body highlighted that another benefit from their perspective was that no payment was required from their organisation to enlist the services of the DPCN. They highlighted that for other parts of their consultation process, they had consulted with local authorities and the HSE and had paid an organisation to support them to do so. In fact, three Departments which the NDA reached out to in order to request an interview about their experience engaging with the DPCN, responded to say they had hired a consultant to carry out their consultation work.

One NGO Steering Group member stated that a strength of the DPCN is the variety of different members and stakeholders involved, stating that the mailing list reaches many different areas and groups in Ireland.

## **Weaknesses of the DPCN in terms of consultation and engagement according to stakeholders**

### **Not a representative body under article 4.3**

As highlighted in the first section of this report, an issue which dominated within the DPCN was the view within the Steering Group that the DPCN cannot be considered a representative body as per article 4.3. As a result, the DPCN decided that it cannot produce a joint submission based on inputs from its members, but instead facilitate information sessions for its members regarding consultations by government.

A public official who engaged with the DPCN stated that they had expected upon hearing about the DPCN that it would have been able to put forward a joint response to the consultation process based on inputs from its members. However, they stated it was made clear at the outset that that was not their role, and that their role is that of a facilitator to ensure that people could articulate and voice what was their concerns.

Another official from a public body which took part in an interview with the NDA stated that on paper the DPCN sounds great because it brings together a range of disability stakeholders in one network. However, in practice, this has not been how it operates. This public body highlighted their increasing awareness, especially in the last year, of their obligation under the UNCRPD to consult with DPOs. Officials from this public body stated that they were not sure whether DPOs were being sufficiently represented by the DPCN. They stated that even though they had a great experience organising focus groups with the DPCN, they

are conscious that they have an obligation to consult with DPOs, and currently as they plan another upcoming consultation, they are not considering the DPCN as a stakeholder network but instead considering a separate consultation with DPOs in order to ensure they meet their obligations.

The Joint Oireachtas Committee on Disability Matters, in March 2022, also took this view, stating that the DPCN in its current format is not a representative organisation and “must be strengthened to ensure the spirit of Article 4(3) can be truly met”. The Committee advised that additional direct consultation with DPOs is required in the interim.<sup>21</sup>

### **One single body for consultation**

Many Steering Group members, including DPOs and non-DPOs, stated that the department, in their view, had envisioned the DPCN as a ‘one stop shop’ for consultation with the disability community. As outlined above, the issue of compliance with article 4.3 meant that the DPCN does not consider that it can fulfil this role. However, in addition to this, there were other views expressed in relation to this concept and its appropriateness as well as the practicalities of implementation.

Several Steering Group members expressed a view that consultation with disabled people cannot take place through one body. One DPO member stated in their view this approach would amount to a box ticking exercise for government departments. An NGO member stated that disabled people have different requirements, perspectives, intersecting identities which cannot be captured in a ‘one stop shop’ approach.

### **Low engagement of membership**

Several Steering Group members highlighted low engagement of the wider membership in DPCN events. One NGO Steering Group member stated

Most of the 120 non-funded members honestly lost interest when they saw very little happening for them and have since drifted away.

Many members highlighted that, in their view, the DPCN has too many members making it very unwieldy in terms of ways of working. In spite of attempts by the DPCN Coordinator to engage the wider membership in meetings and events, engagement has been consistently low and has declined over the lifetime of the DPCN.

---

<sup>21</sup> JOC Disability Matters report (March 2022) Ensuring independent living and the UNCRPD.



Low engagement was also highlighted by public officials. One public body which has engaged with the DPCN twice observed that engagement declined from the first to the second year. This interviewee stated there were no more than 20 participants in attendance and as low as 15 in another session. They also highlighted that they did not feel confident they had captured a broad representation of disabled people. For example, they highlighted that an attempt to engage the Deaf community by organising a Deaf-only session with a Deaf facilitator from the DPCN was unsuccessful as no Deaf participants showed up. They stated they had questions over the buy-in of different disability organisations into the DPCN as a result of the low engagement. This public official suggested that perhaps better feedback from public officials about how the input of the DPCN was used in the development of the policy on which they were consulted could be a way to increase buy-in amongst the DPCN's membership.

An official from another Department stated that a perceived benefit of the DPCN was its access to networks of disabled people that the Department did not have. However, less than five participants attended the morning and afternoon focus group discussions organised for their consultation information session. Similarly, there was no participation from Deaf participants although ISL was provided.

Steering Group members also reported that a planned session on the Autism Innovation Strategy with DCEDIY was cancelled. According to Steering Group members, only three people registered to attend and then no attendees showed up on the day.

An NGO Steering Group member highlighted that most information is shared online through social media which only reaches those with internet access which may reduce reach particularly into some cohorts who are more likely to get information from newspapers and radio.

### **Low awareness of DPCN amongst public officials**

One of the tasks within the terms of reference of the Organising Member is to raise awareness of the DPCN amongst public officials. DPO and non-DPO Steering Group members highlighted that there is limited awareness of the DPCN among public officials in Departments, agencies and local authorities.

An NGO Steering Group member stated that DCEDIY needs to play a stronger role in promoting the DPCN to other Departments and agencies. Department officials acknowledged that there was no cross-Department notice issued about the DPCN by DCEDIY.

The DPCN Steering Group members took steps towards increasing the visibility of the network by starting to develop plans for a DPCN website which they report was a large focus of their work towards the end of 2022. Part of the plan includes a function to allow people to sign up to the DPCN newsletter through the website. The Steering Group members have sent some information for the website to the Coordinator, but some have stated they do not have capacity to contribute to the website. Plans to develop the website have also stalled until the DPCN has more clarity about its purpose, according to an NGO Steering Group member. This member stated it would like to see the DPCN develop an engagement plan, but that they are hesitant to do so without clarity around the purpose, function and future plans for the DPCN.

### **Accessibility of processes and meetings**

Some Steering Group members highlighted accessibility issues as a challenge for their engagement. For example, an NGO Steering Group member highlighted there can be insufficient lead-in time before an information session and therefore not enough time to get accommodations for accessibility needs in place, agree a date that suits everyone, and send out the information ahead of time. Another challenge highlighted was the low availability of Irish Sign Language interpreters which means it can be difficult to book ISL. A DPO Steering Group member stated there is very little accessibility planning in the consultations and in their view, there is not always a receptiveness to feedback on this. Another DPO Steering Group member stated that their representatives found it difficult to participate in some of the meetings and consultations because they were often on during the working day. As they are volunteers, getting a day off work at short notice is difficult.

### **No opportunity for agenda-setting**

Two DPO Steering Group members highlighted that there is not scope for the DPCN organisations to set the agenda in terms of the consultations, but that it is based on officials informing the DPCN that there is a consultation taking place on a piece of legislation or policy and asking them to contribute. They also stated there is no agenda setting in terms of the design or scope of the consultation processes undertaken by Departments. Another DPO Steering Group member highlighted the importance of being able to set the agenda so that they can put their limited resources towards issues which are a priority for their members.

## Capacity building within the DPCN

### Scope of capacity building within the DPCN

In addition to carrying out consultation and engagement on government policy and other processes, another key purpose of the DPCN, for which funding was allocated was to create

A forum in which the capacity of disability organisations, civil society actors, and in particular DPOs, could be developed, peer supported, and facilitated to engage in consultative processes across the State.<sup>22</sup>

The application information for the Organising Member stated that one of its key tasks would be

Developing training and capacity building to be provided to members of the Network, in order to ensure they, and those they may engage in consultations, are empowered and facilitated to contribute effectively.

The assessment criteria for those applying for the role of Organising Member includes the following

Please describe specific examples of where your organisation has delivered relevant capacity training and building measures to aid persons with a disability to remove barriers to inclusion.

In addition, the application information for grant-funded members stated that these members

Will be expected to engage with the Organising member of the Network in relation to administration, capacity building training, events and other activities that will progress the work of the Network.

Finally, the wider network of unfunded DPCN members would be

---

<sup>22</sup> DCEDIY (2022) Evaluation proposal document

Eligible to avail of the capacity building and training activities of the Network.

While there is no specific definition of capacity-building provided in the information materials, it is understood from the above that it is meant to be focused on supporting members to effectively engage in the consultations to be run by the DPCN.

### **Scope of capacity-building within General Comment 7**

There are some key differences between the scope of capacity-building within the DPCN and the scope of the advice to State Parties with regard to capacity-building as set out under General Comment 7.

General Comment 7 states that

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.<sup>23</sup>

The General Comment also refers to the creation of an “enabling environment for the establishment and functioning of organizations of persons with disabilities” including through “the provision of support, including technical assistance, for empowerment and capacity-building.”

The General Comment advises that State Parties provide capacity-building to persons with disabilities and organisations of persons with disabilities (DPOs). The intention that the DPCN would support capacity-building of DPOs and of the wider Network is in line with this. The main difference is that the focus is not only on building capacity to engage in consultation (which is one important piece) but also goes broader than this to

---

<sup>23</sup> UNCRPD General Comment No. 7 para. 60.

encompass governance, accountability, pluralism, access to funding and the creation of an enabling environment for DPOs.

### **Examples of capacity-building initiatives led by the DPCN**

Through the DPCN, capacity-building initiatives mostly took the form of webinars. The Steering Group members, both funded and unfunded, are able to make proposal for webinars or events to be hosted by the DPCN. These are then shared on LinkedIn and Twitter, and further shared on Steering Group members' social media, by email to the wider membership and in the DPCN newsletter. Examples of capacity building activities which took place that were highlighted by Steering Group members included the following:

Training on how to write a submission, how to talk to your TD, webinars on different articles of UNCRPD, a webinar which aimed to increase understanding of DPOs, self-advocacy workshops, DPCN Social Seminar, Information sessions to inform members about consultations, a paper titled 'Effective Consultation Processes and Persons with Disabilities Paper'.

In addition to planned webinars, some capacity-building appears to have happened informally. For example, a DPO Steering Group member said that they learned from one NGO member about the Assisted Decision Making (Capacity) Act which they had not known much about before. This DPO member also highlighted that one NGO organisation in the DPCN had, in their view, more of a charity model approach to disability when it first joined, but that this DPO observed that their attitude changed through their membership on the DPCN and through the discussions they realised how important it is to engage more with UNCRPD. Another DPO Steering Group member stated that in their view different organisations have different knowledge and that members have benefited from organisations sharing their expertise.

### **Strengths of DPCN in relation to capacity building according to stakeholders**

One NGO Steering Group member stated its view that the DPCN is carrying out capacity-building better than consultation and engagement. This member suggested organisations might be more comfortable in the capacity-building space as it is "less political" than the consultation piece.

Several Steering Group members (both DPO and non-DPO members) highlighted that the mixture of organisations with different expertise in the DPCN is a strength in relation to capacity-building. A DPO Steering Group member spoke of the benefits of the DPCN to their organisation with regard to capacity building, stating they have participated in a number of different training sessions with the DCPN with others DPOs around legislation. This DPO stated

that the DPCN funding that covered the training made it possible for them to participate and that they would not have been able to without access to that funding. Two DPO Steering Group members stated that in their view, a DPCN-like model, which includes DPO and non-DPO member organisations, could potentially have a role to play in supporting capacity building and training in a future iteration of the model.

### **Weaknesses of DPCN in relation to capacity building according to stakeholders**

In contrast to the above, DPO and non-DPO Steering Group members also highlighted some weaknesses in relation to capacity-building within the DPCN.

#### **Limited scope of capacity-building initiatives within the DPCN**

One DPO member drew a distinction between information sessions and capacity building, stating that to their knowledge, no capacity-building work took place, in terms of what is advised by General Comment 7. Other Steering Group members stated that capacity-building around governance and organisational development of DPOs did not take place and is part of the advice of General Comment 7.

Many Steering Group members, both DPO and non-DPO organisations, stated that they would like to see more capacity building focused on supporting the development of DPOs, in line with General Comment 7, particularly in terms of governance structures, access to funding, governance principles, how to work with the charity regulator and so on. It was also acknowledged that some DPOs are already well established and have these in place, while others might need more support and time.

A DPO Steering Group member suggested capacity building could support DPOs to develop their membership stating

I think the focus should be on enabling and empowering participation of DPOs to be reflective of as many people as possible in a genuinely representative way.

A DPO Steering Group member stated

DPOs are very young but we have great potential. There are some that are working very well together both nationally, regionally and locally. We are not talking about huge amounts of money. If you took that full pot of money and said we are going to fund 4 or 5 or a national grouping of DPOs and literally have someone who has the role to go out and build capacity of DPOs to be involved in

consultation, to get engagement with people, and that would be their role.

Another DPO Steering Group member observed that DPOs were quieter in DPCN meetings compared to larger organisations and service providers, stating

The service providers are big organisations, have no issue, they know how to talk.

In their view, as DPOs don't have as much time or funding and many members are volunteers, they do not always feel empowered to speak up as much. They highlighted the need, in their view, to empower DPOs with capacity-building in order to level the playing field.

### **Clarity around who should lead on capacity-building**

The Organising Member is tasked with leading on capacity-building for the DPCN according to the application information. Steering Group members reported that the tensions surrounding DPO and non-DPO members also surfaced in relation to capacity building. An NGO Steering Group member stated that questions had been raised in relation to whether DPOs should lead on capacity building. For example, one DPO Steering Group member noted that a webinar called 'DPOs – the basics' which was led by a DPO, was not helped by some of the notes of the meeting not accurately capturing points made in relation to General Comment 7. In the view of an NGO Steering Group member there is a reluctance to invest more time and resources into capacity building until there is clarity around the purpose of the DPCN and these tensions are resolved.

A DPO Steering Group member also stated its view that DPOs, rather than the State, should be leading on capacity building on human rights as the DPOs have a better understanding of the issues.

### **Low engagement of wider network**

Similar to reports regarding attendance in the information sessions on consultations, Steering Group members also reported low attendance at capacity-building webinars. An NGO Steering Group member said attendance has been varied overall but that the webinar on 'DPOs – the basics' had about 35 attendees which was described as "very successful". In contrast, other Steering Group members described the same event as unsuccessful because an attendance of 35 was low from their perspective. One DPO Steering Group member observed that for some of their webinars, participation was mostly comprised of family members of disabled people, rather than disabled people themselves. This member also stated that it was not always easy to find out what kind of issues that the wider network wanted to see covered.

## Funding

### **Funding arrangements for the DPCN**

As outlined in the “Background to the Disability Participation and Consultation Network” section above the DPCN is comprised of three tiers of membership: the Organising Member, grant-funded member organisations and a wider unfunded membership. These tiers relate to the funding arrangements set out in the original expression of interest for the DPCN. The DPCN Steering Group initially reflected these tiers with the Organising Member and the four grant-funded members forming the DPCN Steering Group. However, following the disbanding of the DPO Coalition and the appointment of the DPO Network to the DPCN in 2022, the two DPOs which are not part of the DPO Network (and are therefore not in receipt of any funding as part of their involvement in DPCN) remained on the Steering Group. As a result, the Steering is now made up of both funded and un-funded members.

The initial expression of interest call stated that Disabled Persons Organisations could apply to be grant-funded members and that “suitable organisations (including Disabled Persons Organisations)” could apply to be the Organising Member. The Department’s initial expression of interest for grant-funded membership of the DPCN sought DPOs from a number of disability areas (Intellectual Disability, Physical Disability, Neurodiversity / Autism, etc.) and also specified that the Department was interested in DPOs with experience in working with people with disabilities who face intersectional barriers, such as disabled women and disabled children and young people. However, as discussed earlier in the report the expression of interest material didn’t provide a definition of or criteria for what constituted a DPO for the purposes the funding for the grant scheme.

The Organising Member was initially funded €70,000 to progress the establishment of the DPCN and to support the Network to engage in the UNCRPD Initial State Report consultation process. The majority of the Organising Member’s budget was allocated to the remuneration of a staff member to support the work of the Network.

Grants of up to €20,000 were available in the initial call for expressions of interest to DPCN grant-funded members for the purposes of “carrying out the consultation and participation work of the Network and providing the results of that work to the Organising Member”. In addition, members were expected to “engage with the Organising member of the Network in relation to administration, capacity building training, events and other activities that will



progress the work of the Network”<sup>24</sup>. Grant funded members therefore were to be funded both for the expenses associated with participating in the Network and for some project work related to building their capacity for consultation and participation activities in the context of their membership of the Network. Table I below summarises the funding made available to DPCN members in the years 2020 to 2023.

**Table I - DPCN Funding 2020 to 2023**

Year	Inclusion Ireland	Mental Health Reform	DPO Network (5 organisations collectively awarded grant)	DPO Coalition (7 organisations collectively awarded grant)	Disability Federation of Ireland	As I Am
20/21	70,000	20,000	-	20,000	20,000	10,500
21/22	90,000	20,000	20,000	-	20,000	20,000
22/23	90,000	20,000	20,000	-	20,000	20,00

Each funded member of the DPCN (including the organising member) was required to submit a Project Plan and sign a grant agreement with the Department for each year of funding. Funded members are required to report progress on their Project Plan. The reporting requirements appear to have varied somewhat over the period that the DPCN has operated but, for example, in 2022 funded members were required to report quarterly.

### **Funding advice under General Comment 7**

Various sections above have analysed the obligations contained in the UNCRPD and the advice of General Comment 7 in relation to the inclusion of persons with disabilities and organisations of persons with disabilities (DPOs) in implementing and monitoring the Convention and in other policy making processes. In relation to funding specifically, General Comment 7 advises for DPOs to be funded. Paragraph 39 states that, “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

---

<sup>24</sup> Department of Justice and Equality (2020) [Launch of Expressions of Interest to establish a Disability Participation and Consultation Network - The Department of Justice \(ipo.gov.ie\)](#)

the processes of the independent monitoring frameworks”. Paragraph 60 calls for State parties to, “strengthen the capacity of organisations 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”. Paragraph 61 calls on State parties to adopt criteria to allocate funds for consultation, for example, by

- providing funds directly to organizations of persons with disabilities;
- prioritising resources to organizations of persons with disabilities that focus primarily on advocacy for disability rights;
- 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;
- 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;
- distinguishing between funding for the running of organizations of persons with disabilities and the projects carried out by such organisations;
- 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 organisations.

### **Positive aspects of DPCN funding according to stakeholders**

One Steering Group member stated that DPCN funding had been positive for the DPO Network to allow it to develop more as a network and allow them to cover the costs associated with holding meetings, such as ISL interpretation costs.

### **Challenges according to stakeholders**

#### **Barriers to funding for DPOs**

Many Steering Group members, including DPO and non-DPO members, highlighted barriers faced by DPOs in accessing funding generally, including:

- Some DPOs, as emerging organisations, don’t meet the legal requirements to be in receipt of State funding.
- Some grants have requirements to be able to demonstrate how you will run the organisation for the coming years, which can be difficult for a DPO to demonstrate.

- Some grants have a requirement to already have a project up and running in order to receive funding for it.
- Cost of ISL interpretation is rising which increases meeting costs and reduces available funding.
- An NGO Steering Group member stated, “It’s a catch 22 situation because we need DPO’s to have more structure around their funding, bank accounts, reporting but they can’t do that till they get the funding.”

### **Inconsistency between the model of DPCN funding and UNCRPD Committee advice**

DPO Steering Group members highlighted that the funding structure of DPCN does not, in their view, align with the advice of the UNCRPD Committee. These Steering Group members highlighted that

- The largest grant was awarded to an NGO as Organising Member. Grants awarded to the second-tier grant-funded members went predominately to non-DPOs.
- Some DPOs reported they could not receive funding directly as they are not a legal entity.
- DPCN funding does not provide core funding, but project-based funding.
- DPCN funding does not enable DPOs to be actively involved in consultation

An NGO Steering Group member stated that the Organising Member role was likely given to an established organisation because they have established governance structures and are a legal entity, acknowledging this is a barrier faced by many DPOs.

### **Process of submitting workplans**

As noted above, the Organising Member and grant-funded members develop workplans which are signed off by the Department in order to receive their funding. The funded members report directly to the Department on their spending (not to the Organising Member). Some Steering Group members noted that there is no requirement to join up workplans before submitting them to the Department, and this together with the individual nature of the reporting has led to a lack of cohesion between the Steering Group members’ activities as part of the Network. For example, the DPCN Coordinator reported seeing DPCN events on social media that they hadn't known about. In addition, the unfunded Steering Group members which do not submit a workplan, have indicated that they were not aware of the planned activities of the other Steering Group members. An NGO Steering Group member highlighted that their grant is not meeting the amount of time that was going into delivering the projects and activities and that when Steering Group members shared plans, they realised they

could put more in on the staffing costs for the time of the staffing that was going into it.

A couple of NGO Steering Group member organisations highlighted that the process of developing and submitting a workplan was rushed. For example, one organisation said they had one and a half weeks to prepare their project plan. It was acknowledged that this was to do with officials being redeployed to support with the Ukrainian crisis response and that when they came back into post, they needed the project plans very quickly.

### **Administrative barriers**

Steering Group members highlighted several administrative barriers in relation to DPCN funding, including wanting more guidance on reporting requirements and improved accessibility of the processes. While the NDA recognises the importance for the State of ensuring good governance and oversight of any public funds allocated in this manner.

### **Clarity and capacity-building around grants and funding**

One grant of €20,000 was allocated to the DPO Network as a group of five organisations. The five member organisations of the DPO Network were awarded the grant collectively and the funding was distributed through one DPO from the DPO Network which is a legal entity acting as a conduit organisation.

However, in the interviews, it emerged that there is a view among some DPOs that they are not in receipt of funding from the State through the DPCN.

A DPO Steering Group member stated they do not receive funding and are expected to volunteer their time for DPCN activities. However, this DPO is part of the DPO Network and named as a party in the grant agreement between the department and the DPO Network. The DPO member stated that the DPO Network, as an umbrella organisation, has a work schedule to fulfil for the funding from DPCN and that their organisation takes part. They state that they receive expenses but that relates only to this work which is determined through the DPCN and the DPO Network. This organisation states that “the DCPN is still really, to be blunt, more of a drain on our time.” However, this organisation also state that they collectively developed and submitted the workplan from DPO Network to the department.

In addition, another DPO Steering Group member highlighted that participation in the DPCN takes up a lot of the member organisation’s time and that some members are volunteers. This DPO also highlighted it is difficult to know what is a reasonable number of activities to put into their project plan and difficult to estimate personnel hours. They stated that they surrendered a thousand euro to the department that was not spent one year. Another DPO Steering Group

member stated they had to ask for an extension to use their 2022 funding as there wasn't enough capacity within the organisation to spend it.

This perhaps points to the need for capacity building and/or guidance from the Department around costing out activities within workplans to account for the time of each organisation, as well as clarity on all sides regarding the purpose of any funding granted.

One DPO which is funded as a grant-funded member in its own right, is also part of the DPO Network which receives funding as a network of five DPOs. However, this DPO stated it does not take any of the funding from the DPO Network pot towards its activities and only uses its own individual grant. However, this organisation is also named as a party in the grant agreement between the DPO Network and the department. Similarly, another DPO which is part of the DPO Network indicated in our interview that it has left the DPCN. However, it is a named party in the grant agreement between the department and the DPO Network and has not formally resigned.

This could mean members of the DPO Network see the DPO Network as a separate entity and state that their organisation does not have an individual grant from the Department. Or it could mean that the organisations do not understand that the grant to the DPO Network was awarded collectively to all five organisations and that their organisations are named in the grant agreement. This should be taken into account in future if awarding grants collectively and steps taken to ensure that each organisation understands fully what has been awarded.

### **Accessibility costs**

Another DPO Steering Group member highlighted that approximately €5,000 to €7,000 of their €20,000 grant goes towards reasonable accommodation costs such as ISL interpretation. Another DPO Steering Group member stated they estimate it costs about €500 per meeting for ISL and therefore, as the DPO Network meets about once per month, it is estimated that it costs about €6,000 just to hold meetings throughout the year among its members. Covering essential costs such as ISL to allow for inclusion of all DPO Network members means less grant money is available for activities to be carried out by this grantee whereas other grantee organisations which do not require ISL for their meetings can allocate more of their funding towards activities.

### **Allocation of funding**

Stakeholders made a number of comments regarding the allocation of funding between DPO and non-DPO members of the Steering group. A DPO Steering Group member said the funding has been positive for the DPO Network to allow it to develop more as a network but questions whether the larger NGO/service provider organisations need this funding, stating that the DPOs need it more.

Another DPO member highlighted concerns about NGOs/service providers setting up self-advocacy networks in order to claim to be a DPO and that these would take funding that should go towards DPOs. Another DPO representative stated that the allocation of funding towards DPOs within the DPCN, a shared grant among 5 DPOs, is “an insult.” A DPO Steering Group member stated five DPOs share €20,000 as part of the DPO Network but that they would like to see the majority of funding going to DPOs. DPO Steering Group members stated the funding model of DPCN does not reflect UNCRPD Committee advice.

There are also some apparent tensions between unfunded DPO Steering Group members and funded DPO Steering Group members. One Steering Group member expressed the view that their organisation’s contribution to the DPCN is less valued because they are not a funded member.

### **Short-term nature of funding**

Some DPO Steering Group members highlighted the need for multi-annual funding. One DPO member stated “If you develop in a new or emerging group on a 12-month period, you might just get them to the cusp to be able to move into the next phase. Then it falls off the cliff because there is no follow-on funding.” Another stated that you can’t make any plans and it’s needed for “for developing and capacity for enabling participation of DPO’s in Irish Society particularly in engagement and consultation with the state.”

## **Additional considerations**

This section examines to what extent intersectionality<sup>25</sup> is embedded within the DPCN model in concept and in operation.

### **Intersectionality within UNCRPD and General Comment 7**

Article 6 of the Convention requires measures to ensure the full development, advancement and empowerment of women and girls with disabilities.<sup>26</sup> Article 7 states that States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. Article 5 on equality and non-discrimination is also relevant to intersectionality in the implementation of the Convention.

---

<sup>25</sup> Intersectionality will be considered in the context of paragraph 50 of General Comment 7 (2018).

<sup>26</sup> GC 7, para 72.

General Comment 7 is explicit in advising an intersectional approach, stating

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.<sup>27</sup>

General Comment 7 further states

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.<sup>28</sup>

The CRPD Committee has commented on intersectionality in its concluding observations. For example, in its recent concluding observations on the combined second and third periodic reports of New Zealand<sup>29</sup> the Committee stated its concern about

The lack of a comprehensive intersectional approach to ensure that issues for women and girls with disabilities, including for Māori, Pasifika persons, and migrant women and girls with disabilities, are mainstreamed in both gender and disability legislative and policy areas; The lack of a representative organization of women and girls with disabilities to advance and promote their human rights.

In its recommendation to New Zealand, the Committee recommended that

the State party develop strategies and measures, including financial resources to support persons with disabilities to form sustainable

---

<sup>27</sup> General Comment 7, para 50.

<sup>28</sup> GC 7, para 54.

<sup>29</sup> UNCRPD Committee (2022)

representative organizations, including to support the development of organizations of Māori persons with disabilities, Pasifika persons with disabilities, lesbian, gay, bisexual, transgender and intersex persons with disabilities, children with disabilities, and women and girls with disabilities

### **Examples of intersectionality within the DPCN**

In concept, it is evident that intersectionality was considered in the initial development of the DPCN. The application information for grant-funded members stated

The Department would also seek to include within the membership of the Network DPOs with experience in working with children with disabilities, women with disabilities and other groups of persons with disabilities who may face intersectional barriers.

Among the funded members of the DPCN, just one DPO explicitly represents one of the above-named categories (women and non-binary persons with disabilities). The profile of unfunded DPCN membership is not known by the NDA. Other organisations within the DPCN in their individual capacity (not acting as DPCN members) have made efforts to reach out to intersectional groups and to diversify their membership. For example, a DPO Steering Group member highlighted that its organisation runs a Youth Collective and a Women's Collective. It has also attempted to make connections at the intersection between disability and ethnicity by becoming a member of the Irish Network against Racism. Members of this DPO also visited direct provision centres to present their projects and how to get involved. However, they stated that it is a challenge and, in their experience, anti-racist organisation or asylum seeker organisations are less than likely to understand what spaces there are for disabled people.

One NGO Steering Group member highlighted that there are a number of Traveller groups and ethnic minorities who are members of their organisations' network.

Another NGO Steering Group member describes how, in their experience, relationships with intersectional groups tend to form around a common theme, such as exclusion. For example, this organisation was advocating around the issue of the cost of disability for many years and highlighting intersectional issues such as the burden that primarily falls on women as carers. Over the last number of years this organisation has seen these points raised in submissions by other community and voluntary organisations such as St. Vincent De Paul, the Children's Rights Alliance, and the National Women's Council also.



A DPO Steering Group member stated that it has made quite a number of efforts to reach out to the Irish Traveller community. For example, it has held specific webinars, developed a pride badge for Autistic Traveller Pride. However, they highlight it is a challenge and they still get very little engagement from that community, and therefore caution that it is not accurate to assume that the multiplier effect will achieve these relationships being developed.

Another DPO Steering Group member stated that sometimes links are forged between communities on an ad hoc basis. For example, Ukrainian Deaf people meet the Red Cross when they arrive in Ireland, and if they meet a person from the Red Cross who knows about the Irish Deaf Society, they will be referred there. However, there is no structured engagement at present.

### **Challenges in relation to intersectionality within the DPCN**

The Steering Group members agreed that intersectionality is important in the context of consultation and engagement. This is evidenced by the efforts many Steering Group organisations have taken to engage with intersectional groups in their own organisations' work. Several Steering Groups members stated, however, that the DPCN as an entity itself has not reached a point whereby it has been able to focus on achieving this.

An NGO Steering Group member stated that in order to establish relationships with intersectional groups there must be clarity on the purpose of DPCN and the value added for these groups whose time and resources are also very tight and a clear engagement plan. A DPO Steering Group member similarly shared the view that the DPCN has not been able to do this yet as it “doesn't know what it's about” and that it needs to get its own structures in place first.

A DPO Steering Group member and an NGO Steering Group member highlighted that money and staff resources are required to achieve this. Another DPO Steering Group member stated that if intersectionality is an explicit goal, it will need a lot of thought and time into how it is done effectively.

Another DPO Steering Group member stated that an added difficulty with reaching diverse groups could be attributed to people who experience intersecting inequalities having less confidence to advocate and fewer support networks.

### **Recommendations from stakeholders in relation to intersectionality**

One DPO Steering Group member suggested having a working group subcommittee of the DPCN, for example, that brings together Steering Group members and representatives of those other minority groups. Another DPO Steering Group member highlighted a view that the State could do more to encourage the development of intersectional DPOs. It recommended an

additional prioritisation for groups such as ethnic minorities be embedded in a DPO consultation mechanism. Several DPO and NGO Steering Group members recommended that resources are needed in order to achieve cross-community linkages and collaboration. In addition, stakeholders stated that there must be clarity regarding what is being offered to these groups by the DPCN or future iteration of same.

### **Child and youth participation**

This section examines whether a model such as the DPCN would be appropriate for the purpose of meeting UNCRPD obligations, and the advice of the Committee, with regard to consultation and engagement with disabled children and young people.

Article 7 (3) “Children with Disabilities” states

States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Paragraph 24 of General Comment 7 also advises that article 4.3 applies to children, stating that

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.

As noted above the Department’s initial expression of interest for grant-funded membership of the DPCN sought DPOs from a number of disability areas but also specified that the Department was interested in DPOs with experience in working with people with disabilities who face intersectional barriers such as disabled children and young people.

All Steering Group members agreed that engagement with disabled children and youth as required by UNCRPD is important. However, Steering Group members stated that, at least in its current form, the DPCN structure would not be conducive to child and youth engagement for the following reasons:

- An NGO and DPO Steering Group member stated that the DPCN does not have the capacity to take on child and youth engagement.
- A DPO Steering Group member noted that including children and young people would need to be resourced to be carried out effectively and that it is challenging to do it well and in a representative way, but very important.
- Three NGO and one DPO Steering Group members highlighted there are additional considerations when engaging children and youth. For example, practically you would need parental consent for children to attend the information sessions, considerations about who is speaking for who and ensuring the voice of the child, garda vetting.
- A DPO Steering Group member stated that the DPCN in the current format is an adult space with very dominant voices and that a more child-centred space and approach would be needed. An NGO Steering Group member suggested that children and young people may not feel empowered to speak up when there are adults present.

In addition to these practical considerations, it is noted that at present there doesn't appear to be a children and young persons' DPO which could join a future DPCN type structure. However, some of the Steering Group members spoke of structures that their own organisation has for engaging with children and young people.

Therefore, while the expression of interest highlighted consideration of inclusion of children and young persons in the DPCN, and Steering Group members agree that the inclusion of children and young people in consultative mechanisms is important a number of challenging practical questions around how best to meet the obligations of the UNCRPD and the advice of the Committee through General Comment 7.

There are a number of factors which perhaps should be considered in relation to these questions. For example, Ireland has well developed structures for including children and young people in the policy making process. Work by the DCEDIY and the NDA is currently underway in relation to developing guidance to make these structures more accessible to children and young people with disabilities. Perhaps there is scope use these structures include disabled children and young people in policy consultations and UNCRPD implementation issues.

General Comment 7 Paragraph 12(d) states that

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;

This raises the question as to what role a family organisation (which operates in accordance with Paragraph 12 [d]) could play in supporting the voice of children and young people to be heard in consultative processes, including in a future DPCN, in the absence of a children and young person's DPO.

A number of civil society organisations exist that are involved in monitoring Ireland implementation of the UN Convention on the Rights of the Child and have developed considerable capacity on engaging the children on rights issues. Such organisations are not DPOs (and could not therefore join a DPO only future DPCN) but could perhaps have a role in facilitating children to be involved in UNCRPD consultations and or have a role in support the development of a disabled children and young person's DPO.

## **International DPO consultation and engagement mechanisms**

The international practices outlined below are presented as examples and not necessarily as suggested practice for Ireland. Every national context is different and requires a national approach. However, some international examples highlight similar challenges and potential approaches to addressing these challenges. The below examples are not comprehensive reviews of every mechanism within each country but intended to give a snapshot of some of the issues and approaches in other countries in relation to State Party engagement with DPOs.

## **New Zealand**

The Office for Disability Issues (ODI) was the New Zealand government focal point on disability from 2002 until the establishment of the new Ministry of Disability, Whaikaha, in July 2022. Whaikaha officials describe the Ministry as the steward of New Zealand's Disability Strategy and Action Plan as well as the government's UNCRPD response.

The New Zealand DPO Coalition formed in 2010. According to Whaikaha, it came about because of Ministries across government needing an efficient way to engage with the disability community. There was a recognition amongst officials that this mechanism of engagement should comply with UNCRPD, and therefore a literal view of the Convention and General Comment 7 was taken in its formation. National level DPOs in New Zealand co-created with the Ministry a checklist to establish criteria for joining the DPO Coalition, based on the guidance of General Comment 7. There is also a term of engagement, outlining a list of the responsibilities of government and the responsibilities of the DPO Coalition in relation to consultation and engagement with government policy.<sup>30</sup> The officials acknowledge the need for capacity-building is on both sides and that officials and DPOs learn from each other by working together.

The Ministry states that it takes a partnership approach with the DPO Coalition. For example, it co-developed the Disability Action Plan with the DPO Coalition and collaboratively carries out reporting every six months. The Ministry requests information from government agencies tasked with progressing actions. Ministry officials and DPO Coalition members then come together to review the reports to discuss whether a reported action is on track or not and agree a traffic-light rating of green, orange or red. The agreed rating is then published on the government's website.

The Coalition tends to meet two days a month with 14 representatives of 7 DPOs attending (two per DPO). Representatives tend to be the Executive of the DPO and the President, who is elected by their members. Whaikaha provides funding of approximately \$285,000 per year to the DPO Coalition to enable them to work together as a coalition. The funding covers their time for meetings so that they are all paid to attend, the associated costs of accommodations, and preparation time for meetings. The Ministry also pays for Secretariat costs. The Ministry outlines to the DPOs what they can invoice for and then each organisation invoices the Ministry separately for their costs. These are paid in advance. The Ministry also funds the Coalition for approximately \$280,000 per

---

<sup>30</sup> DPO Coalition checklist and ways of working: <https://www.odi.govt.nz/guidance-and-resources/disabled-peoples-organisations/>

year to develop a monitoring report. The DPO Coalition chooses which article(s) of the Convention they want to focus on. In recent years, they have contracted this work out to an external contractor.

The Ministry of Health also provides some fees to DPOs for services. DPOs also get money from their membership fees.

When other government agencies need advice from the DPO Coalition, they might attend one of the Coalition meetings for input in the first instance. If they need ongoing input from representatives of the Coalition on a piece of work, the Ministry of Disability advises they must pay them for their time as they would pay a consultant.

In relation to article 33.3, the DPO Coalition also forms one branch of the Independent Monitoring Mechanism (IMM) together with the Office of the Ombudsman and the Human Rights Commission. There is a Ministerial Leadership Group on Disability Issues which meets every six months with the IMM. When preparing its response to the CRPD Committee concluding observations, Whaikaha prepared a paper for Cabinet and invited the IMM, which includes the DPO Coalition, to include a comment in it from their perspective. The Cabinet then has an opportunity to also consider the perspective of the IMM.

Whaikaha acknowledges that the disability stakeholder landscape is wider than only DPOs, but recognises the importance placed on DPOs in the Convention and invests in the relationship with them. The Ministry does however seek to engage other stakeholders where relevant, for example with family and parent member groups and service provider organisations. For certain projects such as the development of the Disability Strategy, there is a recognition of the need for a diverse advisory group. The advisory group would include the DPO Coalition, but also, for example, people from rural areas, Māori people, women, and other under-represented groups if representation from these groups is low. When engaging a diversity of stakeholder groups, officials acknowledge it is important to be very clear who is being involved and why and to give feedback on how the inputs of stakeholders has been used. This is essential to build trust.

## **England**

The Cabinet Office has responsibility for coordination of disability policy in the UK, through its Disability Unit. There was some UK government funding for DPOs from 2005 until 2015. However, after then many DPOs were dependent on local funding bodies, which have no statutory requirement to engage with or fund DPOs or other such groups in England. While the Social Services and Well-

being Act 2014 (Wales) requires local authorities to promote the involvement of persons for whom they provide care and support or preventative services, there is no such requirement under the Care Act for English Councils.

At the end of 2018, the Office for Disability Issues announced that it would set up a Regional Stakeholder Network (RSN) to enable persons with disabilities to influence government. The intention was that the RSN would support the government to meet its UNCRPD commitments to engage with disabled people. However, some hold the belief that such stakeholder groups are not a substitute for central funding and do not meet the policy objective of developing DPOs.<sup>31</sup>

The RSN currently operates across nine regions in England. Each region is led by a Chair who is appointed by the Disability Unit on a voluntary basis and tasked with developing a network of disabled people and advocates and to independently govern this network group within their region. According to the Disability Unit, many of the chairs are disabled people, while others work in Disabled Persons' Organisations or organisations that support disabled people.<sup>32</sup> They are expected to convene four regional network meetings per year, attend various meetings in order to represent the views of their regional network, including monthly meetings with the other regional Chairs and the Disability Unit stakeholder engagement lead, attend meetings every six months with the Minister and every quarter with the Disability Unit team. The administration and accessibility costs of organising meetings are paid for by the Disability Unit. The Disability Unit produces an annual "You said, we did" report to summarise the feedback provided by RSN members via the Chairs, and its impact on government policy making. Some examples of engagement by the RSN include providing input into a review by the Department for Work and Pensions regarding supporting autistic people into employment. In addition, the network is inputting into the White Paper on health and disability within the Department of Health and Social Care as well as initiatives with the Department for Transport.

In addition to the RSN, the government also has well established relationships with the disability NGO and service provision sector.

The government attempted in more recent years to better establish its engagement with DPOs and to develop a coordination structure. The Disability

---

<sup>31</sup> Carter, R (2019) Accelerating closure of user-led bodies, amid care cuts, creates 'perfect storm' for disabled people, Community Care <https://www.communitycare.co.uk/2019/04/29/accelerating-closure-user-led-bodies-amid-care-cuts-creates-perfect-storm-disabled-people/>

<sup>32</sup> Disability Unit (2020) <https://www.gov.uk/government/news/regional-stakeholder-network-to-give-disabled-people-a-stronger-voice>

Unit established the DPO Forum in July 2020 to strengthen its engagement with disabled people.<sup>33</sup> Membership of the Forum included national DPOs, regional organisations and chairs of the Regional Stakeholder Networks. The decision to allow non-DPO members to be part of the DPO Forum was criticised by DPO members, as well as the ways of working, which they stated did not take a co-production approach.<sup>34</sup> The Minister for Disabled People brought an end to the Forum after only three meetings. Members of the DPO Forum re-established the group as DPO Forum England in 2021, independently of government. The DPO Forum England released a statement expressing “outrage” that the government had published the National Disability Strategy in 2021, citing lack of meaningful engagement with disabled people and their organisations in its development.<sup>35</sup> In January 2022, the High Court ruled the National Disability Strategy unlawful, based on a case brought by four disabled people in relation to the consultation process.<sup>36</sup>

In this context, the Disability Unit has been working to repair the relationship with DPOs since 2022. The steps taken include changing representatives on both sides – for example, the DPOs have nominated new representatives to take on the government relations brief and the Disability Unit has hired new staff to lead on engagement with DPOs. The Disability Unit team has invited the DPO Forum England to attend closed consultations and to review embargoed documents on a par with its other stakeholder networks including the RSN and engagement with charities and service providers. Recurring meetings between the DPO Forum England and the Minister for Disabled People and officials have been set up. This has allowed meetings to take on a more strategic focus as DPOs understand they will have further meetings in future and do not see it as their one chance to raise all issues. Investing time and resources in rebuilding this relationship has yielded positive results according to officials.

---

<sup>33</sup> Disability Unit Press release, July 2020. Available at: <https://www.gov.uk/government/news/disabled-peoples-organisations-dpos-forum-launches-this-month>

<sup>34</sup> Disability News Service (2021) <https://www.disabilitynewsservice.com/dpos-take-control-after-tomlinson-shuts-down-his-own-forum/>

<sup>35</sup> Disability Rights UK (2021) <https://www.disabilityrightsuk.org/news/2021/july/disabled-peoples-organisations-forum-reject-new-%E2%80%98tick-box%E2%80%99-national-disability>

<sup>36</sup> House of Commons Library (2023) <https://commonslibrary.parliament.uk/research-briefings/cbp-9599/#:~:text=The%20National%20Disability%20Strategy%20was,relation%20to%20the%20consultation%20process.>



Finally, to note there is no official DPO register in England and the DPO Forum England is not funded by the State.

## Denmark

The Disabled People's Organisations Denmark, DPOD, is the national umbrella organisation of persons with disabilities in Denmark. Established in 1934, DPOD is the umbrella DPO of 35 national democratic persons with disabilities organisations. DPOD is a member of the European Disability Forum (EDF).

The NHRI, which is the Danish Institute for Human Rights, collaborates with DPOD. In compliance with the Paris Principles, DPOD has representation on the NRHI board as part of the independent monitoring framework - five of the eighteen members are from DPOD. DPOD engages in the legislative process to implement the CRPD through informal and formal contacts and through meetings with civil servants, ministers and members of Parliament. They meet, for example, once or twice a year with the Ministry of Social Affairs, which is the focal point, to discuss disability issues. They write bilateral letters and use the mass media.<sup>37</sup> DPOD works with the Ministry of Foreign Affairs of Denmark to support disability movements in developing countries capable of advancing CRPD implementation. The 2018 Danish Finance Act states that projects implemented **directly** by DPOD should support activities in the global South.<sup>38</sup> This is in line with CRPD Article 32 on international cooperation, which states that States Parties to the CRPD have a duty to evaluate their development aid programmes from the perspective of the CRPD.

DPOD highlighted that in the ideal case, the State recognises and considers their opinions as well as providing them with education, financial support, information and transparent and accessible communication. Education should focus on democracy and techniques to improve representativeness of DPOs. DPOD defines necessary knowledge, sufficient resources, adequate complaint procedures and advisory services as prerequisites for the active and effective involvement of civil society.

DPOD received approximately €120,000 from the government to cover costs of coordinating and drafting the alternative report of civil society for the initial

---

<sup>37</sup> BIRTHA, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBIRTHA\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBIRTHA_final_submission.pdf)

<sup>38</sup> Restricted procedure: Review of the Disabled People's Organisations Denmark (DPOD)  
<https://um.dk/en/about-us/procurement/contracts/short/contract-opportunities/newsdisplay>

review of Denmark for the CRPD Committee.<sup>39</sup> This allocation of funding allowed DPOD to carry out the workload of drafting a comprehensive and systematic report on the Conventions implementation.<sup>40</sup> Until 2017, the Danish Ministry of Foreign Affairs supported DPOD through a Framework Agreement (€975,000 in 2017) and a Disability Fund managed by DPOD (€4.3 million in 2017) from which DPODs Danish member organisations obtain funding for development interventions in the developing world. Starting from January 2018 the Danish Ministry provided DPOD support under one consolidated grant (€5.7 million), which DPOD operated as fund administrator and implementer of its own projects and programmes.

CRPD feedback in 2014 on Denmark's initial report noted the operation of the State party's Inter-ministerial Committee but expressed concern that government seeks inputs from DPOs in Denmark only occasionally. In its 2014 feedback on Denmark's initial CRPD report, the CRPD Committee commended it on its exemplary role in international development assistance and on the integration of a disability policy perspective therein.

## **Iceland**

The Organization of Disabled in Iceland (ÖBÍ), is the national DPO with the number of member DPOs totaling 33. ÖBÍ's role is to represent persons with disabilities and to safeguard their interests, for example regarding legislation and the implementation of law and regulations. The organisation furthermore provides a mechanism of consultation for disabled persons and their relatives. ÖBÍ is an active participant in cooperation with associations and organizations of persons with disabilities abroad. ÖBÍ is a member of the European Disability Forum (EDF).

This case study illustrates the impact of DPOs in the drafting of core disability legislation to align Icelandic law with the CRPD.<sup>41</sup> The initial stages of the drafting process started in 2014. DPOs were not meaningfully involved and there was a lack of political interest in issues affecting persons with disabilities. However, a general election resulted in a new Government who decided to review the draft

---

<sup>39</sup> p. 135, Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

<sup>40</sup> ibid

<sup>41</sup> Löve, L., Traustadóttir, R., Rice, J (2019) Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing 'a Seat at the Table'  
<https://www.mdpi.com/2075-471X/8/2/111/pdf>

legislation a second time. This last stage of the legislative process began in January 2018. A newly appointed committee asked for additional comments and suggestions from DPOs and from the Centre for Disability Studies at the University of Iceland. Identifying a window of opportunity, representatives and leaders of DPOs and the research community formed a joint working group. They formulated a strategy to strengthen their ability to influence the development of legislation and policy. The strategy included presenting a united front by focusing on issues where DPO positions aligned. Previously DPOs had focused on issues specific to the interests and needs of their membership, which had resulted in diverse and conflicting critical comments on draft legislation, etc. The new strategy was more successful. The united front of the working group, their in-depth knowledge of the CRPD, and their ability to state a right and an obligation by the State, as called for by the CRPD, was important. Being part of a group created synergy, mutual support and shared enthusiasm for the work. It made it possible to divide the workload, which was useful as meetings happened at short notice and DPO representatives participated predominantly on a voluntary basis. Other factors perceived to have contributed to the success of the working group included strategies such as leaving a paper and electronic trail of suggestions, comments and memoranda to preclude claims of a lack of clarity concerning the DPOs' intent.<sup>42</sup>

Among changes to the draft that the members of the group attributed to their participation in the consultation process were changes to articles that instituted personal assistance as a legally mandated service form. The initial draft legislation allowed authorities to limit access to the right to personal assistance. The new working group pushed for personal assistance for everyone. The adopted law contains the right to personal assistance for disabled people, regardless of impairment or age. Members of the joint working group perceived that referring to the CRPD was effective in calling for changes to the draft legislation. Another change to draft legislation, achieved through DPO participation, was an addition to article 36 of the law, which states that membership of a consultative body to the Minister, must have a majority of disabled people. Leaders of DPOs consider that their emphasis on Article 4.3 of the CRPD also resulted in the Ministry consulting with them frequently. Members of the group emphasized their successful effort to change the name “Laws regarding services for disabled people with significant support needs” to “Laws regarding services for disabled people

---

<sup>42</sup> ibid

with long term support needs.” Members of the joint working group took the lead in the translation of definitions, based on their understanding of the CRPD.<sup>43</sup>

However, research also shows that DPOs have had to dedicate a lot of time and energy to preventing roll backs of acquired rights.<sup>44</sup> An example cited was a directive issued by the Ministry of Welfare that expanded the number of apartments permissible within apartment complexes for disabled people. The DPO leader stated that his organization had opposed this action and had pointed out that increasing the number of units contradicted the CRPD. Another example was where proposals by representatives of DPOs on a proposed amendment to laws pertaining to facilitating equal access to actualize voting rights were disregarded. The proposed draft legislation did not include the suggested changes by DPOs while Icelandic disability law requires that due consideration be given in its execution to international obligations, particularly the CRPD, as stipulated by a 2010 amendment to the law. The limited ability of DPOs in Iceland to effect legislation and policy that relate to their lives in any stable way has led some DPOs to develop approaches that aim to empower persons with disabilities to become the leaders of the process of achieving full rights. The more recently formed activist DPOs have redefined issues that pertain to their needs and lives, based on their perceptions. They then present them in the public arena, and this is allowing them to emerge more clearly as leaders and experts in their own affairs. However, the slowness of progress and the limited ability of DPOs in Iceland to effect legislation and policy that relate to their lives has led activist groups to develop approaches that aim to empower disabled people and assert them as the leaders of the process of achieving full rights. The more recently formed activist groups have redefined issues that pertain to their needs and lives, based on their perceptions and present them as such in the public arena. This allows them to emerge as leaders and experts in their own affairs.

Despite frustrations, other DPOs in Iceland continue to cultivate relationships with politicians, including parliamentarians, government ministers and elected officials at the local level. DPOs felt that they collaborated effectively with the authorities in a process that had led to the ratification of the CRPD – a process where they were also heavily involved behind the scenes. With their emphasis on collaboration, leaders of these DPOs reject the more confrontational approach employed by some activist DPOs. Nevertheless, many expressed support and

---

<sup>43</sup> Löve, L., Traustadóttir, R., Rice, J (2019) Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People’s Organizations in Securing ‘a Seat at the Table’ <https://www.mdpi.com/2075-471X/8/2/111/pdf>

<sup>44</sup> Löve L., Traustadóttir, R., Rice, J (2018) Achieving Disability Equality: Empowering Disabled People to Take the Lead, *Social Inclusion*, 6 (1), 1–8

even admiration for the work of these groups, particularly their effectiveness in generating public and media attention.<sup>45</sup>

## **Serbia**

In Serbia in order to register as a DPO or other non-governmental organization it is possible with three individuals who have legal capacity, including children aged 14-18 years, to register. There are no specific additional conditions for setting up a DPO in Serbia.

In Serbia there is one umbrella DPO, 15 national DPOs, 33 regional ones and 500 local DPOs. On an annual basis, Serbian DPOs receive approximately 3 million euros (350 million Serbian dinars) from the national lottery to undertake projects tendered by the Department for Persons with Disabilities in the Ministry for Social Protection. One project was the writing of an alternative report on the implementation of CRPD and included funding the travel costs to Geneva for two representatives of the National network of DPOs and their personal assistants in order for them to interact with the CRPD Committee. In 2018, the Serbian Office for Human and Minority Rights funded (approximately €4,000) the publication of an analysis of the implementation of the UN Committee's recommendations to Serbia. Two DPOs, the Centre for Independent Living – CIL Serbia, and the National Organisation of Persons with Disabilities Serbia (NOOIS) participated in the review process, including preparing and submitting the Alternative report to the UN Committee in June 2015 and its presentation to the Committee in September 2015.<sup>46</sup>

## **Sweden**

Sweden has a Disability Delegation, which is a forum for consultation and dialogue to ensure that DPOs and persons with disabilities participate in the CRPD monitoring mechanism. Government representatives meet the forum four times a year and discuss monitoring the CRPD and the policies under development. The Chair of the Disability Delegation is the minister who has responsibility for coordinating disability policy. The government obtains opinions from DPOs on specific issues through a variety of discussion forums. In 2018, it had a discussion forum regarding the CRPD Committee's recommendations. In this forum, the government provided information on its work on the

---

<sup>45</sup> Löve L., Traustadóttir, R., Rice, J (2018) Achieving Disability Equality: Empowering Disabled People to Take the Lead, *Social Inclusion*, 6 (1), 1–8

<sup>46</sup> Personal communication from Damjan Tatic, lawyer, who has drafted Serbian laws on the rights of persons with disabilities, including the Law on the Prevention of Discrimination against Persons with Disabilities and who participated in drafting the CRPD Convention on the Rights of Persons with Disabilities. Damjan also served on the UN CRPD Committee.

recommendations and on its bill on the national goal and direction of disability policy to obtain the views of the DPOs. The government sought the help of the Disability Delegation in preparing its responses to the UN Committee and held two special meetings in 2019 with representatives from civil society organisations including DPOs. DPOs or persons with disabilities are also included as experts in governmental inquiries.<sup>47</sup>

With regards developing indicators and helping the municipalities to implement the CRPD, the Swedish Agency for Participation with a remit to work towards participation for all, actively involves DPOs and is working with the municipalities including what indicators to use, etc. It monitors public sector actors' work to implement disability policy at national, regional and local levels. Between 2014 and 2016, it monitored the efforts of municipalities and regional public transport authorities to ensure accessibility and participation, using various indicators (labour market, education, culture, sport, physical accessibility and transport). This monitoring was difficult so in 2015, the Agency worked with other agencies to develop its monitoring. It developed a survey in consultation with disability organisations, the Swedish Association of Local Authorities and Regions and a selection of municipalities, county councils and government agencies. Since 2017, it has carried out a survey of municipalities, county councils and government agencies and is developing a digital tool to replace the survey mailings. The results of its monitoring shows that longer term, systematic work at management level is a success factor for disability policy to have an impact in practice.<sup>48</sup> Since 2018, the Swedish Agency for Participation has an agreement with the disability movement, which includes a disability council that meets three times a year and deals with strategic and disability issues at management level. The Agency also involves the disability movement and civil society in other ways. The Agency has developed a consultation model for strategic and effective cooperation with the disability movement and civil society. The disability movement has representation on the Agency's knowledge council and the Agency plans to draw up support materials on active involvement for the municipalities.<sup>49</sup>

---

<sup>47</sup> The Ministry of Health and Social Affairs (October 2019) Responses to questions from the UN Committee on the Rights of Persons with Disabilities  
<https://www.regeringen.se/4aa39a/globalassets/regeringen/dokument/socialdepartementet/funktionshinder/crpd---submission-of-the-combined-second-and-third-reports-of-sweden.pdf>

<sup>48</sup> The Ministry of Health and Social Affairs (October 2019) Responses to questions from the UN Committee on the Rights of Persons with Disabilities  
<https://www.regeringen.se/4aa39a/globalassets/regeringen/dokument/socialdepartementet/funktionshinder/crpd---submission-of-the-combined-second-and-third-reports-of-sweden.pdf>

<sup>49</sup> *ibid*

## **NDA Findings**

The following findings are based on our analysis of stakeholder feedback, CRPD, General Comment 7, UNCRPD Committee concluding observations, and international practices. In undertaking this analysis, the NDA has considered both compliance with CRPD obligations, the extent to which the advice of General Comment 7 is currently being reflected or where measures could be introduced to strengthen alignment with this advice, and more broadly, what kind of model will deliver the most effective outcomes in terms of consultation and engagement for disabled people in Ireland, and for public officials seeking to develop policy and legislation aligned with disability rights.

### **UNCRPD article 4.3**

The NDA consultation found that the DPCN Steering Group stakeholders did not consider the design of the DPCN compliant with article 4.3 for the purpose of fulfilling the State's obligation to closely consult with and actively involve persons with disabilities through their representative organisations. In the view of DPCN Steering Group members, because the DPCN is not DPO-led and does not prioritise and distinguish DPOs from other stakeholders in the way this is outlined within General Comment 7, they do not consider it to be a representative body for the purposes of meeting article 4.3. obligations. However, in the view of the Department it could be considered compliant with the legally binding article 4.3, as DPOs are included in the DPCN.

The NDA suggests that the current mechanism may not wholly capture the spirit of the Convention when taking into account the advice of the UNCRPD Committee through its General Comment 7, which, while not legally binding, was developed by the Committee in order to “clarify State Parties’ obligations”<sup>50</sup> under articles 4(3) and 33(3). Furthermore, the NDA advises that the current DPCN structure is not working effectively, in large part because of the lack of buy-in to the design of the mechanism from its Steering Group and that it is crucial to address this if a future mechanism is to be successful. Some stakeholders also drew comparisons with the DPCN to previous attempts by the State to create a consultation mechanism on disability issues, citing the National Council for People with Disabilities and People with Disabilities Ireland as examples. In the view of some stakeholders, previous mechanisms failed because the structures

---

<sup>50</sup> UNCRPD Committee (2018) General Comment no. 7.

were created from the top-down, rather than facilitating the development of the structures with disabled people.

Article 4.3 indicates that the State's obligation regarding meaningful consultation with persons with disabilities is "through their representative organizations." To further clarify this, the UNCRPD Committee, through its advice outlined in General Comment 7, provides a definition of "representative organizations".<sup>51</sup> General Comment 7 states

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,

---

<sup>51</sup> General Comment 7, 11(a) "Definition of representative organisations".



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.

The Committee, in its advice, explicitly makes a distinction between organisations of persons with disabilities and other civil society organisations, stating

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.

The NDA is aware that at least one DPO is unsure whether the fact that it provides services to its members means it cannot be defined as a representative organisation. The Special Rapporteur on the Rights of Persons with Disabilities stated that organisations of persons with disabilities “may use different strategies to promote their goals, including advocacy, awareness-raising, service delivery and peer support.”<sup>52</sup> The NDA understands therefore that an organisation led by persons with disabilities whose primary purpose is promoting the rights of persons with disabilities, which also provides some element of service to support, engage or otherwise benefit their members, may be considered a DPO. However, the NDA advises (as per the recommendations of this report) that the appropriate way to define the scope and role of DPOs in an Irish context is for DCEDIY and the DPOs to co-create a shared understanding of the criteria for an organisation to be a DPO.

---

<sup>52</sup> UN General Assembly (2016) Human Rights Council, 31<sup>st</sup> session, [Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development. Report of the Special Rapporteur on the rights of persons with disabilities](#). January 12<sup>th</sup>, 2016.

The Committee also identifies certain kinds of organisations of family members which it considers to fall under the definition of representative organisations.<sup>53</sup> General Comment 7 paragraph 12(d) states

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

The NDA observes that there may be a gap in terms of engagement with these specific organisations in the development of policy and legislation and that their inclusion could support engagement with groups which are often excluded from consultations. However, we emphasise that the Committee expressly states the role of relatives and caregivers in these organisations is to ‘assist and empower’ persons with disabilities to express their own views.

We consider that it is very important that the State aligns its position with the definition of representative organisations set out in the advice of the Committee and that DCEDIY as UNCRPD focal point consistently communicates this position across departments and to public bodies. Article 4.3 is a general obligation which cuts across the whole of UNCRPD and any ambiguity in its application will create challenges across all areas of implementation of policy and legislation in relation to the Convention. The Special Rapporteur on the Rights of Persons with Disabilities stated

The failure of States to acknowledge the distinction between organizations “of” and “for” persons with disabilities lies at the

---

<sup>53</sup> General Comment 7, 12(d)

heart of historical tensions between the two types of organization, such as those around legitimacy, choice and control, and the allocation of resources. In their pursuit of genuine participation by persons with disabilities in decision-making processes, States need to ensure that the will and preferences of persons with disabilities themselves are given priority.<sup>54</sup>

#### According to General Comment 7

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.<sup>55</sup>

The Committee through General Comment 7 advises that mechanisms of consultation should be established “in close and effective consultation and with the active involvement of organizations of persons with disabilities.” The NDA considers therefore that the co-creation of a funded national-level mechanism of consultation with DPOs is required. A mechanism comprised solely of national DPOs would support the growth and development of these organisations, begin to address the historical inequity in funding and influence of this stakeholder group, provide space for DPOs to engage in strategic planning and agenda-setting, and provide support to officials in meeting their CRPD obligations in the development of policy and legislation at the national level. A co-creation approach is particularly important in the context of previous attempts by the State to create a disability consultation mechanism which, in the view of some stakeholders, were designed from the top-down and experienced operational issues as a result. Co-creation is a process whereby something is designed collaboratively from beginning to end. In this case, the NDA advises that relevant State officials and representatives from DPOs collaborate to co-create the structure, processes and ways of working of

---

<sup>54</sup> UN General Assembly (2016) Human Rights Council, 31<sup>st</sup> session, [Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development. Report of the Special Rapporteur on the rights of persons with disabilities](#). January 12<sup>th</sup>, 2016.

<sup>55</sup> GC 7, para 47.

the new consultation mechanism so that a system is developed which has buy-in on both sides and which works for all parties. This process could be facilitated by an independent facilitator.

### **Defining the scope of DPOs**

The Committee also states<sup>56</sup> that it is important for State Parties and the relevant stakeholders to define the scope of organisations of persons with disabilities and recognise the different types that often exist. The NDA considers it very important to provide clarity regarding which organisations at a local and national level can be considered representative organisations in order to support officials to meet their consultation obligations. The NDA advises in the first instance, the State co-creates with DPOs a checklist in order to determine a shared understanding of eligibility criteria for the proposed national DPO consultation mechanism. For example, a process similar to that taken by New Zealand to develop its DPO Coalition checklist could be followed. In the longer term, the NDA advises that the State consider how to map and maintain a list of all national and local DPOs for the purposes of supporting officials to identify relevant organisations for consultation and engagement.

### **Defining the role of other stakeholder groups**

The NDA recognises the need for engagement with other stakeholders, including individuals and civil society disability organisations which are not DPOs in relevant consultation and engagement processes. The NDA acknowledges that there are many civil society organisations such as non-governmental organisations and disability service providers which advocate on behalf of people with disabilities or highlight issues related to disability rights which hold important and valid points of view and relevant expertise. The NDA does not advise that consultation take place with DPOs to the exclusion of all others, but that consulting with these other stakeholders does not replace the requirement to consult with DPOs. The NDA advises that the State clarify its position regarding the role of non-DPO organisations in consultation processes and suggest our 'Participation Matters' guidance in this regard.

The role of individuals is often discussed in relation to UNCRPD article 4.4 and therefore this is examined further below.

---

<sup>56</sup> GC 7, 10.A.

## **UNCRPD article 4.4**

While article 4.4 is not explicitly referenced in the original call for expressions of interest to join the DPCN, Department officials have included reference to it in the evaluation information document for the NDA which states

Obligations in Article 4(3) of the UNCRPD require the State to consult with people with disabilities through their representative organisations in the development of law and policy. Membership of the DPCN has been open widely to individuals and organisations including but not limited to representative organisations.

In this way, the DPCN model was intended to facilitate engagement with representative organisations and individuals, organisations for people with disabilities, and civil society more widely. While the evaluation of the DPCN model and function must be cognisant of Article 4(3), it must also take into account Article 4(4) in considering more generally how people with disabilities, however they choose to be represented, including in structures similar to the DPCN and in alternate form to the DPCN, can be consulted.

The Department also cited article 4.4. in its interview with the NDA suggesting that the DPCN model embraces article 4.4 by going beyond the parameters of article 4.3. That is to say, that it does not only include DPOs but also other organisations and individuals.

It is important therefore to further examine and clarify the meaning of article 4.4 in relation to consultation and engagement and its implications for the development of a mechanism of consultation.

UNCRPD Article 4.4 states

Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.

The NDA understands that the interpretation by the Department of article 4.4 in relation to 'provisions which are more conducive to the

realisation of the rights of persons with disabilities' is that by establishing a consultation mechanism with a large and broad membership including DPOs, other organisations and individuals it could be considered more conducive to the realisation of the rights of persons with disabilities than a mechanism with a more narrowly defined membership. The NDA advises that this does not appear to have been the case in practice. As outlined by stakeholders, the large membership has been operationally challenging and has not allowed for strategic level discussions. Additionally, the low engagement of this wider network within the DPCN indicates that this structure is not working for this cohort. In the NDA's view this interpretation of article 4.4 does not work when read in conjunction with article 4.3 and General Comment 7 which is explicit and consistent in stating that the meaningful participation of persons with disabilities, through their representative organisations, is at the heart of the Convention.<sup>57</sup>

Article 4.3, by promoting engagement through organisations of persons with disabilities, does not restrict the rights of individuals to participate in consultation processes. The Special Rapporteur on the Rights of Persons with Disabilities wrote in 2016 that organisations of persons with disabilities “play a mediating role between individuals and the State thus contributing to building inclusive societies where the rights of persons with disabilities are fully realized.”<sup>58</sup>

General Comment 7 states

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.

Prioritising the engagement with DPOs does not mean individuals cannot take part in a consultation process. It is a fundamental right of all persons to be able to participate in decisions affecting them. Article 4.4., by stating

---

<sup>57</sup> General Comment 7, para 1.

<sup>58</sup> UN General Assembly (2016) Human Rights Council, 31<sup>st</sup> session, [Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development. Report of the Special Rapporteur on the rights of persons with disabilities](#). January 12<sup>th</sup>, 2016.

that through this Convention there is no derogation from any of the human rights and fundamental freedoms recognised or existing in any State Party, recognises this.

However, in public decision-making processes on issues which are collective in nature, such as the development of public policy and legislation, the view of an individual cannot be considered with the same weight as an organisation (whether DPO or non-DPO organisation) which draws its position from a wider membership. There may be contexts in which individuals will have specific local knowledge or lived experience which adds particular value to a consultation depending on its objectives, and this is important. However, an individual can only represent their own view, and the approach to engagement with individuals should reflect this. In the view of the NDA, engagement with individuals should be complementary to engagement with organisations, but not given the same weight. Individuals can exercise their right to participate through other processes of public consultation, such as public submissions processes, surveys or relevant focus groups. Public officials should be advised that all such processes for public participation should be accessible to all to ensure this right is upheld.

There may also be contexts in which an individual will have specific local knowledge or lived experience which adds particular value to a consultation or fills a gap which is necessary to achieve the objectives of a particular consultation, and in this case, it may be relevant to seek to engage these individuals. Engaging with disabled individuals outside of a DPO structure does not replace the requirement to consult with DPOs.

### **Achieving the best approach for consultation and engagement with disabled people**

In order to satisfy article 4.3 and article 4.4, and to work towards the standard set out in the advice of the UNCRPD Committee through its General Comment 7, the NDA finds that a DPO-only mechanism of consultation, which is prioritised as a stakeholder group, would be the most satisfactory approach. In the view of the NDA, this approach would achieve the most effective representation for disabled people by supporting the longer-term development of DPOs, providing these organisations with a space for coordination and collaboration, and providing a contact point for government officials to engage with DPOs as a matter of priority. However, we advise also communicating the message to public officials that public consultation is not delivered through one single mechanism or approach and to clarify the role of non-DPO organisation and individuals in consultation also. This is further explained

below, including more detail about how we consider this would work in practice.

### **A multi-mode approach to consultation and engagement which prioritises DPOs**

The NDA agrees with the DPCN Steering Group stakeholders who stated a view that an approach in which one single body comprising all disability stakeholder groups which carries out consultation with the disability community on behalf of the State would not be desirable or effective.

This is further supported by General Comment 7 which states that

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;<sup>59</sup>

There is a risk therefore that a structure such as the DPCN, or any mechanism, if it acts as the singular entity for consultation with the disability community, could inhibit the participation of individuals, DPOs or other organisations which are not members of this mechanism. In the context of the DPCN for example, the opportunity to become a member has so far been limited to one open expression of interest process and one additional DPO-only replacement expression of interest process. Even if a process is put in place to admit new members on an ongoing basis, the NDA considers this an unnecessary additional barrier to participation for individuals and organisations not part of such a network. The NDA in its Participation Matters guidelines highlights that all public consultation processes should be universally designed and accessible to the widest range of people possible, and officials should be continuously advised of same.

Officials should be advised that engagement with other organisations and with individuals can (and in some cases should)<sup>60</sup> take place as **an additional and complementary** process to engagement with the DPO mechanism but never as a replacement. The NDA's Participation Matters and the forthcoming updated DPER guidelines on public consultation are useful resources in this regard.

---

<sup>59</sup> GC 7, para 12(a)

<sup>60</sup> For example, engagement with organisations representing people for whom there is not yet a DPO.



The NDA does not consider that the Department needs to create a membership body for these other stakeholder groups. If the Department decides to do so (for example, similar to the Regional Stakeholder Network in England) the NDA advises that engagement with the DPO mechanism must be prioritised, or the same issues faced by the DPCN will persist.

### **Embedding article 4.3 across whole-of-government**

UNCRPD is a whole-of-government commitment, and it is essential that all departments, agencies, local authorities understand the commitments therein.

The UNCRPD Committee has developed concluding observations in relation to this point. For example, in its concluding observations for New Zealand in 2022 the Committee expressed concern about

The lack of recognition, across all government portfolio areas, that disability is a whole-of-government responsibility, the lack of engagement with organizations of persons with disabilities outside the ministry of disability portfolio

The Committee recommended that New Zealand

Develop strategies to strengthen commitment across all government portfolio areas to ensure disability is recognized as a cross-cutting issue, that meaningful partnerships are developed with organizations of persons with disabilities to ensure close consultation and active involvement in legislative and policy processes to implement the Convention, including co-design, co-production and co-evaluation, and that organizations of persons with disabilities are appropriately resourced to build capacity to participate in partnerships across government portfolio areas;

The NDA finds there is a lack of clarity among many public officials in Ireland regarding how to meet their obligations under article 4.3. As UNCRPD focal point, the NDA advises DCEDIY puts together a notice for Departments and agencies outlining how to meet their obligations, including the State's position on how to do this in a way which best meets the standard set out by the Committee in General Comment 7. The NDA suggests its 'Participation Matters guidelines' which outlines the role of DPOs and other civil society groups, the NDA, and individuals could provide a basis for such advice, with the addition of instructions on how to contact a newly formed DPO consultation mechanism if this recommendation is adopted. In addition, the forthcoming updated consultation guidelines for public officials from DPER is an opportunity to

promote the meaningful participation of disabled people in decision making.

Beyond advising Departments of their UNCRPD obligations, the State could also explore in the longer term whether measures to adopt national legislation that embeds engagement with DPOs would be appropriate in an Irish context. General Comment 7 advises that State Parties take certain measures to strengthen national implementation of article 4.3 and 33.3 including the following

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;<sup>61</sup>

Measures such as these have been introduced in some other European countries. A 2014 analysis by the European Union Agency for Fundamental Rights (FRA) investigated whether EU Member States had mechanisms in place to involve DPOs in the development of disability laws and policies. This analysis showed that in nearly half (13) of EU Member States, the law provides for DPOs' engagement in developing laws and policies in different forms.

In Sweden, the constitution stipulates that the State must consult DPOs when developing disability law and policy. In Austria, Cyprus, Malta and Spain there is relevant disability-focused legislation.<sup>62</sup> In Germany, Hungary, Italy, Poland and Slovakia, general provisions require consultation of concerned parties and/or the public in law and policy-making processes and specify the duty to

---

<sup>61</sup> Ibid 94(e)

<sup>62</sup> For example, Article 9 of the Austrian Disabled Persons Act establishes a Federal Disability Board that includes seven representatives of "organised disabled persons and organised war invalids", and the Austrian government consults this body when drafting laws or policymaking. Cyprus defines the Confederation of Organisations of the Disabled, made up of nine DPOs, as the social partner of the state and the government consults with the confederation on decisions that directly or indirectly affect persons with disabilities.

consult with DPOs.<sup>63</sup> In the remaining 15 EU Member States, the law does not require consultation and involvement of DPOs in developing laws and policies. In eleven of these Member States namely, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, Ireland, Latvia, Luxembourg and the UK, it found there are mechanisms for consultation with DPOs.<sup>64</sup>

### **The proposed role of the DPO mechanism**

The proposed role of the DPO mechanism is to provide a space for coordinated, collaborative and strategic engagement of DPOs in public decision making, both in response to requests from government and also in relation to bringing forward their own priorities to the public agenda. The NDA advises that the State identify with DPOs how this would best work, however, we have some suggestions for consideration. For example, the role of this mechanism could involve

- **Coordinate a response to a request for input from government departments or agencies on draft policy or legislation.** This could include, for example, providing feedback to officials as a group in a meeting or through a joint submission; deciding amongst the membership which one or two (or more) DPO members will respond to a particular request for input based on its expertise, capacity or relevance of the subject area to its own objectives; signposting officials towards existing documents or prior relevant consultation inputs to avoid duplication of efforts and efficient use of resources.
- Subject to agreement on a sustainable funding model for DPOs, a role of this this mechanism could be to **arrange nominations for DPO members to join advisory groups or working groups in response**

---

<sup>63</sup> For example, federal ministries in Germany must consult concerned non-governmental organisations in law-making procedures or processes to develop political strategies. Similarly, Italian law establishes that non-governmental organisations (NGOs) active in the field of protection of the rights of persons with disabilities should be involved in the formulation and implementation of policies with regional consultative bodies and a national consultative assembly coordinated by the Ministry for Social Affairs  
<https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/dpo-laws>

<sup>64</sup> For example, the governments of Belgium, Bulgaria, the Czech Republic, Luxembourg and Latvia have consultative bodies of people with disabilities, which include representatives from DPOs. In the Czech Republic, DPOs are a part of the Government Board for People with Disabilities. Other governments have non-binding guidance regarding the involvement of civil society. For example, Estonia has the Good Engagement Code of Practice in Estonia establishes that government authorities have to include interest groups affected by a planned law during the drafting process. The government send affected interest groups the planned law so that they comment on it <https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/dpo-laws>

- to a request from a government department or agency.** Members may nominate representatives based on their expertise, interest, capacity, or other relevant criteria. The nominated member would be expected to update the other members on the work of the advisory/working group in the DPO mechanism meetings. More than one member may be nominated.
- **Identify areas of strategic importance for DPOs and coordinate plans to advance same.** For example, DPOs may identify a gap in policy and/or legislation in relation to disabled people based on the experiences of their members and jointly coordinate a planned approach to get this issue on the agenda; DPOs may identify a department or agency which has not requested DPO input into an upcoming policy of relevance to disabled people and coordinate their approach to same, seeking support from DCEDIY colleagues if necessary. Ideally this would be done within the context of the National Disability Strategy that is in existence.
  - **Provide advice and hold government departments and agencies accountable towards meeting their consultation obligations and achieving good practice.** Either in response to a request from a department, or by identifying a need themselves, the DPO members could play a key role in holding officials accountable in relation to their compliance with article 4.3, and in relation to the accessibility of public consultation processes in general which would support participation more widely and uphold article 4.4.
  - **Other actions as deemed appropriate by DPOs.**
  - **Other actions as deemed appropriate by Government.** We have not considered the Government's obligations in implementing article 33.3 in relation to monitoring and this is a further role that could be considered. The exact role of a DPO mechanism would have to be fully scoped within the wider context of the roles and longevity of the Disability Stakeholders Group and IHREC's Disability Advisory Group.

In order to be effective and to deliver the best representation for disabled people, the development of a DPO mechanism should be underpinned by an approach which prioritises relationship-building, trust and collaboration both amongst DPOs and with the wider stakeholder groups. This is outlined further below.

### **Embed structures supporting collaboration within the DPO mechanism**

While this proposed mechanism promotes collaboration and coordination, it must also recognise that DPOs are separate, autonomous organisations with their own priorities and objectives, and indeed each organisation includes

members with diverse accessibility requirements. In order for this collaborative mechanism to be effective, it is critical that sufficient time is dedicated to co-creating the structure and ways of working with the organisations involved, allowing for flexibility and iterative changes as the model and relationships become established over time. There must also be procedures which allow members to raise any issues within the group which are affecting their participation.

The NDA considers it important that this mechanism is non-hierarchical in its structure in order to foster trust and collaboration between the member organisations. For example, DPOs could each nominate two representatives to be the focal point for their organisation at the meetings of the joint national mechanism, similar to the New Zealand model. The NDA suggests that representatives from each DPO could rotate after a 'term of office' of which the time period should be agreed by DPO members. This could facilitate capacity-building of DPOs by offering opportunities to different members to engage in the meetings of the national mechanism. An independent facilitator could remove the need for a chair and allow the system to remain non-hierarchical.

The NDA considers that the DPCN, having been tasked with delivering a consultation on the State Party report on a relatively short deadline, did not have dedicated time to establish its relationships and ways of working which impacted negatively on relationships and subsequently on the effectiveness of the model. The NDA therefore recommends that the creation of a DPO mechanism should be followed by a period of time dedicated to establishing, with DPO members, its structures, processes and shared values with the support of an independent facilitator with expertise in facilitating diverse groups.

The NDA suggests that key elements to consider include:

- Terms of reference
- DPO membership criteria
- Accessibility requirements
- Pathway to membership for new DPOs
- How DPOs select representatives to participate in the mechanism
- How DPOs will make collaborative decisions (i.e., voting, a quorum)
- A complaints mechanism or mediation process for members if they consider that representatives are being obstructive to collaborative working, or to raise any issues affecting their participation in the group, including accessibility issues
- Frequency and duration of meetings.

The NDA highlights that the DPCN workplan process which was based on individual grants and separate project plans by each organisation was not conducive to collaborative working and contributed to mistrust, a lack of cohesion of activities, and different expectations of members regarding the purpose of the DPCN. When individual plans were shared across the Steering Group, it led to capacity building according to some stakeholders who noted that they learned from seeing others' plans. The NDA advises that after the period of establishment of its processes and structures, the members of the DPO mechanism should engage, with the support of an independent facilitator, in the process of work-planning, including deciding in collaboration with DCEDIY officials how it will consider requests for input from government departments and agencies which should be clearly defined and publicly available. See for example, New Zealand DPO Coalition guidance for officials on how to submit a request for input.<sup>65</sup> Funding underpinning the work of the DPO mechanism should support collaborative working. A separate recommendation for core funding of DPOs is outlined later in this report. However, the NDA proposes that a model of funding for the DPO mechanism could take an approach similar to New Zealand, in which the Department funds the cost of a certain number of meetings per year, including paying representatives for their time in preparation and in participation, and any accessibility costs. The NDA considers it important that the DPO mechanism be provided with a funded Secretariate consisting of the independent facilitator and an administrative support officer in order to carry out its work.

The NDA also highlights from its discussions with public officials that it is a common practice for departments to hire the services of a consultant to organise its consultation processes. The NDA advises that in considerations regarding how the DPO mechanism is funded for its work, the Department consider advising that members be paid by Departments for input into their work particularly if it is on an ongoing basis or similar in nature to services which would ordinarily be paid for if hiring a consultant. For example, this approach would be similar to the approach taken by Whaikaha New Zealand. Alternatively, there could be a central fund held by the Secretariate which departments can use to access the DPO mechanism. A third option is to automatically allocate funding to each DPO who is part of the mechanism proportionate to their engagement in the mechanism.

### **Embed structures supporting collaboration with wider civil society**

The intention behind creating a mechanism consisting only of DPOs is not to remove collaboration between DPOs and wider civil society, but to address the

---

<sup>65</sup> [Disabled People's Organisations - Office for Disability Issues \(odi.govt.nz\)](https://www.od.govt.nz/disability-issues/disabled-peoples-organisations)

inequity of influence and funding between these stakeholder groups, which hindered their collaboration within the DPCN. The NDA considers that by removing the direct competition for funding and influence between these groups within the same mechanism, it will promote better collaboration and a stronger disability rights movement overall. A number of Steering Group members, including DPO members, highlighted the value of meeting with the wide range of organisations within the DPCN, particularly from the point of view of learning from each other's expertise. Therefore, in addition to investing in relationship-building within the DPO mechanism, the NDA advises that structures are put in place which enable knowledge-sharing and collaboration between members of the DPO mechanism and wider civil society. The NDA suggests that these initiatives could take place every six months. DPOs should set the agenda for these collaborative initiatives. Other stakeholders could involve disability NGOs, service providers, individuals, members of other intersectional organisations or communities. The format of these initiatives could include

- Town hall meetings in which DPOs share their priorities and key updates with stakeholders.
- Thematic meetings on a priority issue. This could range from basic information sharing to identifying synergies in policy positions across organisations and exploring opportunities for joint advocacy or campaigns.
- Workshops for skills-sharing and peer learning.
- A call to action on a campaign.
- 'Open Day' to attract new members.

The NDA suggests that funding for the organisation of these initiatives should be a component of the funding for the DPO mechanism as a whole.

### **Capacity building**

Capacity-building is an essential component to support meaningful participation. The strength of the DPCN model was in bringing together organisations with different expertise. However, the NDA considers that the opportunity provided by this was not fully harnessed. There is an opportunity for peer learning between DPOs and NGOs which could support the growth and development of DPOs while also fostering collaboration across the disability community. The NDA considers that a project-based funding stream for the development and delivery of capacity building programmes could be established, which is open to application by organisations or individuals with relevant skills and expertise to share. DPOs should set the priority topics for inclusion in a call for proposals for capacity-building programmes. The NDA suggests based on stakeholder feedback that capacity-building programmes should focus primarily on supporting the development of DPOs as organisations, for example including training in relation to good governance, registration as a legal entity, writing effective grant

applications, reporting on grants, and so on. In addition, workshops on effective approaches to advocacy and campaigns for policy change, understanding the legislative process, and information sessions on relevant CRPD articles and their application in an Irish context could be considered.

### **Local level DPO engagement and consultation**

The NDA has advised the co-creation of a national-level DPO mechanism in the first instance. However, General Comment 7 advises that DPO engagement take place at all branches and levels of government. The NDA considers the development of a DPO checklist as a step which will enable the identification of both national and local level DPOs. The NDA advises that the State, led by DCEDIY as UNCRPD focal point, engage with local authorities regarding how to identify and engage local DPOs within its work.

The NDA considers that local engagement requires a local approach and therefore proposes that the national DPO mechanism does not try to absorb all local DPOs in its membership, particularly given the operational and strategic challenges experienced within the DPCN when attempting to organise a large membership. On matters of national policy, the NDA considers that national level DPOs are best placed to input, whereas in local level policy local DPOs are better placed to engage. However, we advise that the State explore how links between the local and national level can be established. For example, a model of regional advisory councils as implemented by Belgium could provide a regional structure which links local to national.

### **Accessible public consultation processes**

Disabled people have a right to participate in any public consultation initiative on an equal basis with others. In order to ensure the wider disability community can realise their right to participate in decisions that affect them, Departments and public bodies must be consistently reminded that all consultation and participation processes, at all levels of government, must be accessible and underpinned by the principles of Universal Design. DCEDIY as UNCRPD focal point should play a leading role in ensuring this is understood and implemented across government. It is proposed that the DPO mechanism can also play a 'watchdog' role in this regard.

### **Define indicators for measurement of article 4.3 implementation with DPOs**

General Comment 7 advises that State Parties should

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.<sup>66</sup>

The Office of the High Commissioner on Human Rights has developed a suite of illustrative indicators to support policy makers to measure implementation of the Convention.<sup>67</sup> Suggested indicators for measuring article 4.3 include the following outcome indicators which could be used as a basis for discussion

I/4 2.8. Number and proportion of organisations of persons with disabilities taking part in consultation processes for the implementation of the CRPD, disaggregated for kind of organisation of persons with disabilities, constituency represented among persons with disabilities and geographical location.

I/4 2.9. Number and proportion of consultation processes/activities which involved organizations of persons with disabilities, disaggregated by kind of organization and constituency represented among persons with disabilities.

I/4.30 Number of persons with disabilities and organizations benefitting from capacity building activities funded or provided by the State, disaggregated by sex, age, disability and geographical location.

I/4.31 Proportion of population who believe decision making is inclusive and responsive, by sex, age, disability and population group.

Measurement of article 4.3 could be considered as a key measure for inclusion within the new UNCRPD strategy.

## **Funding**

DPCN Steering Group members highlighted some operational issues in relation to how funding for the DPCN worked, such as the accessibility of some of the documentation; the need for more guidance from the Department on the use and reporting of DPCN funding; and the need for coordination of funded members' project work. However, the funding element of the original DPCN

---

<sup>66</sup> GC 7, para 94(u)

<sup>67</sup> [Articles 1 to 4: List of illustrative indicators on the purpose, definitions, principles and general obligations of the Convention on the Rights of Persons with Disabilities \(CRPD\) \(ohchr.org\)](#)

design is by far the most significant issue highlighted by stakeholders. As discussed above in relation to Article 4.3 and 4.4 the inclusion and funding of DPOs and non-DPOs in the DPCN was problematic operationally and conceptually. The funding of DPOs and non-DPOs created tensions within the DPCN and the funding which was made available to DPOs as part of the DPCN was not seen as meeting the advice set out under General Comment 7 to provide DPOs with access to funding, including core funding.

In addition to the creation of a funded national DPO consultation mechanism, the NDA advises that the State consider how to support DPOs to access core funding in order to develop as organisations, increase their membership, better advocate for disability rights and enable them to more effectively engage in consultation processes, with due regard to considerations regarding good governance in the allocation of public funding. to. The issue of access to multi-annual core funding for DPOs was highlighted by number of Steering Group members as being required for DPOs to develop their capacity to engage in policy-making consultative processes. The Scheme to Support National Organisations<sup>68</sup> (administered by Pobal and funded by the Department of Rural and Community Development) provides an example a competitive process for allocating multi-annual core funding to organisations based on requirements such as displaying good governance, membership and addressing issues such as poverty, social exclusion and promoting equality. There may be learning from such schemes as to how the State can introduce a similar competitive process for allocating multi-annual core funding to DPOs. A number of Steering Group members highlighted the dilemma that a number of DPOs face; some DPOs lack the resources to establish the governance structures to attract funding or to participate in any future core funding scheme. It may be necessary to establish a specific programme to support smaller DPOs to develop the governance structures required to apply for public funding. In the interim, other avenues could be explored such as awarding a grant to a conduit organisation which distributes the funding to another DPO, as has been the case with the DPCN grant awarded to the DPO Coalition and later the DPO Network. However, we advise that if this approach is taken, it should only be an interim measure and is not a long-term solution to the need to support DPOs to develop their organisational structures in order to allow them to receive funding directly.

---

<sup>68</sup> <https://www.pobal.ie/programmes/scheme-to-support-national-organisations-ssno-2022-2025/>

## Feedback on the draft final evaluation report

In September 2023 DCEDIY provided verbal feedback on the report where errors of fact and the recommendations were discussed. Minor amendments were made following this discussion.

The NDA invited DPCN Steering Group members to provide written comments on errors of fact in the report and invited them to provide feedback on the findings and recommendations at a meeting in November 2023.

The main feedback from the November 2023 meeting with the Steering Group members was that the DPCN had been working more collaboratively and efficiently since the period when the interviews had been conducted for this report. Specifically, the DPCN was seen as having improved significantly in the intervening period in terms of its networking and capacity building functions. This is notwithstanding the fact that there remained significant challenges with the DPCN acting as a mechanism of consultation in line with articles 4.3 and 33.3 and General Comment Number 7. Subsequent feedback from DPO members who were not at the meeting agreed that the DPCN was working more collaboratively and efficiently but emphasised that this was from a low base. They believed that several of the fundamental challenges to working together remained and they didn't see a viable future for the DPCN.

## Recommendations

### Consultation and engagement

**Recommendation I:** Establish a co-created national-level body of Disabled Persons' Organisations (ideally the DPCN would be funded up until its replacement is established to ensure continuity). Provide funding for meetings of this mechanism including Secretariat supports. (See page 71 for more details).

**I (a):** Define, together with national DPOs, the scope of DPOs to be included in the national mechanism. For example, by developing a co-created checklist which creates a shared understanding of eligibility criteria for the national mechanism. For example, a process similar to that taken by New Zealand to develop its DPO Coalition checklist could be followed.

**I (b):** Consider how to create spaces for collaboration between the DPO mechanism and wider civil society (were the DPCN to continue it could potentially play a role in this space). For example, consider funding meeting costs for periodic 'town hall' meetings or workshops between organisations working on disability issues, with the agenda set by DPOs. (See page 79 for more details.)

**I (c):** Examine how to strengthen consultation and engagement with the most seldom heard disabled people.<sup>69</sup> For example, through including on the DPO mechanism certain organisations of family members/advocates of persons with intellectual disabilities, dementia and children which meet the criteria outlined in General Comment 7, and by developing guidance on engaging seldom-heard disabled people in consultation processes.<sup>70</sup>

**I (d):** Consider the scope of work that the new national-level body of DPOs could reasonably be expected to take on. Any new umbrella body of will take time to develop as its members learn to work together. Many of the DPOs will also require time to develop their own organisational capacity. Therefore, caution may be advisable with regard to expectations around the scope of work that such a new national-level body of DPO could reasonably take on in terms of monitoring UNCRPD implementation and wider consultation on policy initiatives in its initial phase.

**I (e):** Consider whether the Disability Participation and Consultation Network should end or whether it could evolve to play an ongoing role in the areas of networking and capacity building among stakeholders (DPOs and non-DPOs) with an interest in the Convention.

**Recommendation 2:** Raise awareness among Departments, agencies, public bodies, local authorities of their article 4.3 and 4.4 obligations, clarifying the State's position on the role of different stakeholder groups in consultation processes. For example, the NDA sets out its advice in its 'Participation Matters' guidance, and the Department as UNCRPD focal point could consider adopting this position. We advise the following:

- **Role of DPOs:** DPOs, as representative organisations of disabled people, must be closely consulted with and actively involved in decision making processes concerning issues related to people with disabilities. Public authorities are advised to systematically and openly approach, consult with and involve DPOs in a meaningful and timely manner. If the State adopts the recommendation to create a national-level DPO mechanism, it should

---

<sup>69</sup> Some examples include people with intellectual disability, people with profound intellectual disability, people with mental health difficulties, deafblind people, people with a communication impairment, disabled children, people living in institutions, and others.

<sup>70</sup> For example, this could include guidance similar to DCEDIY's 'Seldom-heard toolkit' for engagement with children and youth and the forthcoming NDA and DCEDIY guidance on engaging disabled children and youth, particularly those who use assistive and augmented communication, but with a general focus on seldom-heard disabled people.

include in its advice to public officials information about how to engage with this mechanism.<sup>71</sup>

We advise that organisations of family members of disabled people with intellectual disabilities, dementia or children with disabilities are also identified under General Comment 7 as organisations with a key role in consultation processes.

- **Role of non-DPO organisations:** There are many civil society organisations such as non-governmental organisations and disability service providers which advocate on behalf of people with disabilities or highlight issues related to disability rights. These organisations may also be involved in consultation, as they hold important and valid points of view and relevant expertise. The NDA does not advise that consultation take place with DPOs to the exclusion of all others, but that consulting with these other stakeholders does not replace the requirement to consult with DPOs. The NDA advises that the State clarify its position regarding the role of non-DPO organisations in consultation processes and communicates this across government. We suggest the NDA guidance outlined in our ‘Participation Matters’ guidelines in this regard.

**Role of individuals:** Individuals have a right to participate in decisions affecting them. We advise that the engagement of individuals take place in the following ways:

- We advise that supporting the growth and development of DPOs is ultimately supportive of creating a stronger environment for individuals to collectively advocate for their rights.
- Individuals have the right not to join a DPO or other association. We advise that public consultation and participation processes at all levels of government should be accessible and underpinned by the principles of Universal Design as standard. This supports the participation of all and allows engagement in public decision making by those individuals with a disability who exercise their right to not join an association.
- There may also be contexts in which an individual will have specific local knowledge or lived experience which adds particular value to a consultation or fills a gap which is necessary to achieve the objectives of a particular consultation, and in this case it may be relevant to seek to engage these individuals. Engaging with disabled

---

<sup>71</sup> The NDA has outlined more detail on the suggested role of this mechanism later in this report.

individuals outside of a DPO structure does not replace the requirement to consult with DPOs.

The above approach reflects the right of individuals to participate in decisions affecting them, while recognising that individuals give their own personal opinions, while organisations bring together the voices of a wider community and offer a position that is accountable to their members.

### **Capacity building and funding**

Capacity-building and funding are inextricably linked to meaningful consultation and engagement. The NDA recommends the following:

**Recommendation 3:** Consider a project funding stream for the development of capacity building programmes for DPOs, with the various types of capacity building needed identified by DPOs in line with their organisational requirements. Organisations or individuals from any sector<sup>72</sup> with expertise in a relevant area could be eligible to apply to deliver capacity-building programmes to DPOs. (See page 79 for more details). Were the DPCN to continue it could have a role to play in relation to capacity building.

**Recommendation 4:** Support the growth and development of DPOs through various strategies to support their access to the necessary funding to develop their governance systems where necessary, grow their membership, improve their capacity to advocate for disability rights, and engage effectively in consultation, including:

**4 (a):** Consider developing a once-off programme of supports to assist those DPOs who need to develop the requisite governance structures to attract State funding. The programme design detail should be discussed with DPOs but could for example include some financial support and access to expertise in governance and organisational development.

**4 (b):** Consider how State funding such as the Disability Participation and Awareness Fund could be made more accessible to DPOs. For example, reducing barriers in funding criteria, giving due regard to the State's responsibility to ensure good governance of public money, and by ensuring the application and reporting processes are accessible.

**4 (c):** Consider developing a model of multi-annual core funding to which DPOs that meet required governance requirements and can demonstrate

---

<sup>72</sup> Including DPOs with relevant expertise.

a capacity to deliver on agreed strategic objectives could apply. For example, consider looking at models from other sectors such as the Community and Voluntary sector fund administered by Pobal, and other relevant examples (See page 82 for more details). Any scheme would have to respect the independence of the DPO space by, for example, not requiring a DPO to report into a non-DPO disability organisation.

**4 (d):** While some DPOs work towards establishing their governance structures, consider interim measures which would support access to funding for these organisations. For example, allowing organisations to apply collaboratively with another established organisation for funding in which one organisation acts as a conduit organisation which distributes the funding to another DPO, as has been the case with the grant to the DPO Network from DECDIY to support the DPO Network's participation in the DPCN.

### **Other issues for consideration**

**Recommendation 5:** Consider undertaking the following scoping exercises which could be included as actions under the next UNCRPD strategy:

**5 (a):** Explore how to map and maintain a list of all national and local DPOs for the purposes of supporting officials to identify relevant organisations for consultation and engagement.

**5 (b):** Consider how to define and measure progress in relation to article 4.3 as part of the new UNCRPD strategy. For example, consider developing indicators with DPOs to measure implementation of article 4.3, informed by General Comment 7 and OHCHR guidance. (See page 80 for more details).

**5 (c):** Explore whether the introduction of national legislation and policies that recognise the right to participation and involvement of DPOs would be appropriate in an Irish context, given that some other EU countries have introduced such measures (See page 80 for details). This could take place in the context of any future reviews of disability legislation.

**5 (d):** Consider how to promote DPO consultation and engagement at the local level including potential linkages between local and national structures of engagement.

**5 (e):** Explore how the development of child and youth DPO(s) could be supported by the State. In the interim, explore alternative mechanisms to ensure that disabled children and young persons' views are included in consultative fora, for example, by supporting the inclusion of disabled children in mechanisms of engagement for the UN Convention on the Rights of the Child.

## **Conclusion**

The NDA considers that development of Ireland's first UNCRPD strategy in 2023 is an opportune time to articulate the vision for DPO engagement in Ireland and to clearly define and communicate their role and the role of other stakeholder groups including other disability organisations and individuals and to communicate this across government. The NDA considers that these recommendations could form the basis of key targets within the new UNCRPD strategy.



## Appendix

### **Recent concluding observations by the UNCRPD Committee in relation to article 4.3**

#### **New Zealand, 2022**

##### Areas for Concern

The Committee is concerned about:

- (a) The lack of recognition, across all government portfolio areas, that disability is a whole-of-government responsibility, the lack of engagement with organizations of persons with disabilities outside the ministry of disability portfolio, and the lack of appropriate resourcing for organizations of persons with disabilities to build capacity to meaningfully engage in legislative and policy processes;

##### Recommendations

The Committee recommends that the State party: Develop strategies to strengthen commitment across all government portfolio areas to ensure disability is recognized as a cross-cutting issue, that meaningful partnerships are developed with organizations of persons with disabilities to ensure close consultation and active involvement in legislative and policy processes to implement the Convention, including co-design, co-production and co-evaluation, and that organizations of persons with disabilities are appropriately resourced to build capacity to participate in partnerships across government portfolio areas;

#### **Switzerland, 2022**

##### **Areas for Concern:**

The Committee notes with concern:

- (a) The lack of involvement of persons with disabilities through their representative organizations, including diverse organizations of persons with disabilities, in decision-making processes concerning laws, policies and programmes, including in the implementation of the 2030 Agenda for Sustainable Development and efforts to achieve the Sustainable Development Goals.
- (b) The lack of information about formal mechanisms to ensure the participation of persons with disabilities and their representative

organizations in monitoring of implementation of the Convention. (Art 33.)

**Recommendations:**

Recalling its general comment No. 7 (2018), the Committee recommends that the State party:

- a) Strengthen mechanisms at the federal, cantonal and municipal levels to ensure effective support and consultations with diverse organizations of persons with disabilities – including organizations of persons with intellectual disabilities, autistic persons, persons with psychosocial disabilities, women with disabilities, children with disabilities and lesbian, gay, bisexual, transgender and intersex persons with disabilities – in design, reporting and monitoring with respect to legislation and policies aimed at implementing the Convention and achieving the Sustainable Development Goals.
- b) Ensure that persons with disabilities, including children with disabilities, through their representative organizations, are effectively involved and participate fully in monitoring of implementation of the Convention. (Art. 33)

**Japan, 2022**

**Areas for Concern:**

The Committee is concerned about:

- (a) The insufficient involvement of persons with disabilities through their representative organizations in consultations concerning legislation and public policies, including those carried out by the National Consultative Council of Persons with Disabilities and by the municipal and intermunicipal committees on accessibility.

**Recommendations:**

Recalling its general comment No. 7 (2018) on articles 4 (3) and 33 (3) of the Convention, the Committee recommends that the State party:

- (a) Ensure active, meaningful and effective consultations with the diverse range of representative organizations of persons with disabilities at the national and municipal levels, including by means of alternative communication, accessibility and reasonable accommodation, in public decision-making processes, paying attention to self-advocates with disabilities, to organizations of persons with intellectual disabilities, of persons with psychosocial disabilities, of autistic

persons, of women with disabilities, of LGBTIQ+ persons with disabilities, and of persons with disabilities living in rural areas, and to those requiring more intensive support, including in the implementation and monitoring of and reporting on the Sustainable Development Goals.

### **Republic of Korea, 2022**

Areas for Concern:

The Committee is concerned about:

(a) The Committee is concerned about the lack of participation of persons with disabilities, through their representative organizations, including diverse organizations of persons with disabilities, in decision-making processes concerning laws, policies and programmes that affect them.

Recommendations:

The Committee recalls its general comment No. 7 (2018) and recommends that the State party:

(a) strengthen and implement mechanisms for the effective involvement of persons with disabilities, through their representative organizations, in public decision making processes, and ensure that meaningful consultations are held with the whole range of organizations of persons with disabilities, including children with disabilities, persons with psychosocial disabilities and/or intellectual disabilities, intersex persons with disabilities, women with disabilities, refugees and migrants with disabilities, autistic persons, lesbian, gay, bisexual, transgender and gender-diverse persons with disabilities and persons with disabilities requiring higher levels of support.

### **France, 2021**

Areas for Concern:

The Committee is concerned about:

a) The limited involvement of persons with disabilities, through their representative organizations, in consultations concerning legislation and public policies, including those carried out by the National Consultative Council of Persons with Disabilities, and the municipal and intermunicipal accessibility committees.

Recommendations:

The Committee recalls the recommendations made by the Special Rapporteur on the rights of persons with disabilities in the report on her visit to France, 5 and recommends that the State party:

a) Adopt a comprehensive national strategy to implement the State party's obligations under the Convention and promote strategies in the overseas territories, in close consultation with organizations of persons with disabilities, ensuring a coordinated disability-support administration system across the State party, including at the regional, departmental and municipal levels and in the non-metropolitan areas;

The Committee recalls its general comment No. 7 (2018) and recommends that the State party:

(a) Revise the provisions in article 1 of Act No. 2005-102 with a view to strengthening and implementing transparent mechanisms to consult closely with and involve actively persons with disabilities, through their representative organizations, in public decision-making processes at all levels, including in implementing, monitoring and reporting on the Sustainable Development Goals;

(b) Ensure meaningful and effective support and consultations with the diverse organizations of persons with disabilities, as outlined in general comment No. 7, paying attention to organizations of persons with intellectual disabilities, autistic persons, persons with psychosocial disabilities, women with disabilities, lesbian, gay, bisexual, transgender and intersex persons with disabilities, persons living in rural areas, Roma persons with disabilities and those requiring high levels of support.

## **Estonia, 2021**

### **Areas for Concern:**

The Committee notes with concern:

(a) The lack of effective involvement of persons with intellectual disabilities, persons with psychosocial disabilities and persons with autism, through their representative organizations, in decision-making processes concerning disability-related laws, policies and programmes, including in processes related to the implementation of the 2030 Agenda for Sustainable Development and its Sustainable Development Goals.

### **Recommendations:**

The Committee recalls its general comment No. 7 (2018) and recommends that the State party:

- (a) Strengthen and implement mechanisms for the effective involvement of persons with disabilities, through their representative organizations, in public decision-making processes, including for monitoring and reporting on the implementation of the Sustainable Development Goals. The State party should ensure that meaningful consultations are held with the whole range of organizations of persons with disabilities, including organizations of children with disabilities, persons with intellectual disabilities, persons with psychosocial disabilities, intersex persons with disabilities, women with disabilities, persons with disabilities living in rural areas, persons with autism, Roma persons with disabilities, lesbian, gay, bisexual, transgender and gender diverse persons with disabilities and persons with disabilities requiring higher levels of support;

### **Australia, 2019**

The Committee is concerned about

5. (d) The weakness of the mechanisms and the limited funding available under the National Disability Strategy and the National Disability Agreement for the full and effective engagement of persons with disabilities, through their representative organizations, in policy development, implementation and monitoring of actions relating to the Convention;

The Committee is concerned that there are no permanent or effective mechanisms to ensure the active participation of persons with disabilities, through their representative organizations, in the implementation and monitoring of the Convention.

8. The Committee recommends that the State party, in line with the Committee's 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, establish formal and permanent mechanisms to ensure the full and effective participation of persons with disabilities, including children with disabilities, through their representative organizations, in the development and implementation of legislation and policies to implement the Convention, ensuring adequate resources and the provision of the necessary support. It recommends that the State party involve Aboriginal and Torres Strait Islander persons with disabilities and their representative organizations in particular in all aspects of the design, implementation, monitoring and evaluation of the Australian Government Plan to

Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability.

### **Cyprus, 2017**

While noting the existence of a law regulating the obligation of public services to consult with the Confederation of the Disabled People Organization, the Committee remains concerned about the insufficient financial and other resources provided to and inadequate collaboration with representative organizations of persons with disabilities regarding all disability-related issues. The Committee is also concerned by the absence of a representative organization of persons with intellectual disabilities. Furthermore, the Committee is concerned that contributions by representative organizations of persons with disabilities into national decision-making processes are not acknowledged appropriately. 8. The Committee recommends that the State party urgently, effectively and substantially increase the support to, collaboration with and impact of all representative organizations of persons with disabilities in capacity-building and in cross-sectoral development, implementation and monitoring of policies, laws and programmes. It also recommends that the State party provide support for the creation of a representative organization of persons with intellectual disabilities.

### **Belgium, 2014**

The Committee notes that persons with disabilities are represented by the National Higher Council for Persons with Disabilities at the federal level. However, it regrets the absence of advisory councils in the Flemish Region and in the French- and German-speaking Communities. 10. The Committee urges the State party to establish, and allocate adequate resources to, advisory councils in all regions. These advisory councils should be closely involved in the development, implementation and monitoring of legislation and policies