

# **NDA Working Paper on Engagement with Disabled Persons' Organisations**

October 2020

## **Executive Summary**

This paper sets out the National Disability Authority's advice in respect of working towards effective and meaningful engagement with persons with disabilities, through the establishment of sustainable infrastructure. The NDA has considered commentary by the UN Committee on the Rights of Persons with Disabilities, as well as its General Comment No. 7 in order to gain a comprehensive understanding of what the Committee's definition of appropriate and effective engagement with persons with disabilities looks like in practice.

The NDA has examined the current Irish landscape, in order to explore the existing methods of collecting the lived experience, expertise and opinions of persons with disabilities. These methods, while numerous, often do not contain elements which allow for the structured, resourced, sustainable engagement with Disabled Person's Organisations as defined by the Committee on the Rights of Persons with Disabilities.

In appraising current methods in place to facilitate the involvement of persons with disabilities in the development of policies and practices, the NDA has looked at approaches used in various jurisdictions. In this advice paper, the NDA has identified and examined several elements of DPO engagement that have worked effectively elsewhere. The NDA advises that the Department could consider the inclusion of such elements when drafting Terms of Reference for the Participation and Consultation Network, and when reviewing the outcome of the first 12 months of operations of the Network next year.

The NDA advises that the elements below have been shown to be critical to the long-term success of a sustainable, effective and meaningful participation model for DPOs, all of which are explored in greater details later in the advice paper:

- A clear mandate
- A consistent and continuous funding model
- Membership that represents various disabilities, as well as others factors such as gender, location and age

- Capacity-building
- Buy-in from all relevant Government Departments
- Innovative methods of engagement.

## Introduction

The National Disability Authority (NDA) is an independent statutory body with a duty to provide information and evidence-informed advice to Government and officials in the public sector on disability matters, and to promote Universal Design. Currently, the NDA has a specific duty to advise the Minister for Justice and Equality and this paper is particularly relevant to the Department of Justice and Equality, as it continues to act as the focal point for the UN Convention on the Rights of Persons with Disabilities until the transfer of functions to the Department of Children, Disability, Equality, Integration and Youth is complete.<sup>1</sup>

The aim of this advice paper is to highlight good practice in other jurisdictions in respect of effective participation and consultation with Disabled Persons' Organisations, which can offer learning for the Irish context. This good practice pertains to both the development and implementation of legislation and policies designed to implement the UNCRPD and to other decision-making processes concerning issues relating to persons with disabilities. The NDA has examined the approach taken by the Committee on the Rights of Persons with Disabilities to clarify what effective participation looks like, both in respect of its commentary on States Parties' implementation of Articles 4(3) and 33, and its adoption of General Comment No. 7 on "Participation with persons with disabilities in the implementation and monitoring of the Convention".

The NDA has also examined the current Irish landscape, sign-posting existing relevant disability organisations, and identifying the gaps that remain between the standard set by the Committee on the Rights of Persons with Disabilities and the reality in Ireland.

The NDA notes that the Department of Justice and Equality is currently in the process of establishing a Consultation and Participation Network. The NDA advises that the Department of Justice and Equality put in place a process for

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<sup>1</sup> The NDA recognises that, when the transfer of functions from the Department of Justice to the Department of Children, Disability, Equality and Integration is completed, the latter will act as focal point for the UNCRPD. The NDA also recognises that it will have a specific duty to advise the Minister for Children, Disability, Equality, Integration and Youth, rather than the Minister for Justice, following that transfer.

capturing the learning from the first phase of establishing a Consultation and Participation Network, which, when combined with the learning and recommendations in this paper, could inform development of a sustainable, effective pathway for DPOs to develop, strengthen and participate in decision-making processes. To do this, at the end of this paper, the NDA has identified certain elements from various jurisdictions that it understands have led to successful and effective engagement with disabled persons' organisations and people with lived experience. This paper will consider how these elements might be put in place and carried out successfully, incorporating work carried out to date by the Department of Justice and Equality. These elements include:

- A clear mandate
- A consistent and continuous funding model
- Membership that represents various disabilities, as well as others factors such as gender, location and age
- Capacity-building
- Buy-in from all relevant Government Departments
- Innovative methods of engagement

## **UN Convention on the Rights of Persons with Disabilities**

The aim of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) is to empower persons with disabilities and their representative organisations to become active citizens and provide moral and practical leadership in society and work towards solutions for contemporary problems including issues that affect persons with disabilities. It was ratified by Ireland in March 2018, and the first State Report, outlining the State's efforts to promote and protect the rights contained in the Convention, will be submitted by the Government in Q4 of 2020.

Of all the Conventions adopted by the UN, no other is as clear as the UNCRPD on the issue of participation and engagement of those people who will be directly impacted by the obligations contained therein. Both Articles 4(3) and 33 of the UNCRPD explicitly encourage meaningful engagement with persons with disabilities. The former obliges States Parties to 'closely consult with and actively involve' persons with disabilities in relation to the development and implementation of legislation and policies concerning issues relating to disability. The latter compels States Parties to ensure that persons with disabilities and their representative organisations participate fully in the monitoring of the Convention.

The Committee on the Rights of Persons with Disabilities (the Committee) regularly comments on a State Party's efforts to implement Articles 4(3) and 33 in its Concluding Observations. Recent recommendations to States Parties include:

- Allocate financial resources to support DPOs
- Establish mechanisms to secure the full participation of DPOs in the design and implementation of strategic policies aimed at implementing the Convention across the State Party, through objective, measurable, financed and monitored strategic action plans
- Establish formal and permanent mechanisms for consulting with representative DPOs in an effective and result-oriented manner at all levels of administration
- Ensure that a broad range of persons with disabilities that reflect the diversity of people's backgrounds, including age, sex, faith, race, sexual orientation, migrant status and impairment groups, meaningfully participate in an inclusive and accessible manner in direct decision-making processes
- Provide sufficient financial support to build the capacity and enable the autonomous participation of DPOs in all decision-making processes
- Ensure sustainable and adequate funding for the meaningful engagement of persons with disabilities and their representative DPOs in the implementation and monitoring of the Convention
- Involve and financially support civil society organisations, in particular representative DPOs, in the preparation of its periodic report

In initial commentary on State Party Reports submitted between 2010 and 2017, the Committee believed that an “important gap between the goals and the spirit of articles 4 (3) and 33 (3) and the degree to which they have been implemented” existed.<sup>2</sup> It stated that this was due to, among other things, the “absence of meaningful consultation with and involvement of persons with disabilities, through their representative organisations, in the development and implementation of policies and programmes”. Because of this gap, the Committee adopted a General Comment in October 2018 in order to provide further clarity of how Articles 4(3) and 33(3) should be implemented. By defining DPOs and according

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<sup>2</sup> Committee on the Rights of Persons with Disabilities (2018) **General comment No. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention**  
[https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en)

them special recognition, the Committee creates an obligation on governments to engage directly with persons with disabilities through DPOs on the issues that impact on their lives. It should be noted that while the guidance contained in a General Comment is not binding, the Committee regularly relies on it when examining a State Party's implementation of the Convention.

## **General Comment No. 7: Participation with persons with disabilities in the implementation and monitoring of the Convention**

According to General Comment No. 7, a Disabled Persons' Organisation (DPO) is a civil society organisation of persons with disabilities that is led, directed and governed by persons with disabilities. A clear majority of its membership should be persons with disabilities. The organisation should be rooted in, committed to and fully respect the principles and rights recognised in the UNCRPD.<sup>3</sup>

DPOs should be distinguished from organisations "for" persons with disabilities, which provide services and/or advocate on behalf of persons with disabilities. The Committee has also said that while DPOs are a specific type of civil society organisation, there is also a distinction, as the term "civil society organisation" comprises different kinds of organisations, including research institutes, organisations of service providers and other private stakeholders.

The General Comment provides further characteristics of a Disabled Person's Organisation:

- They are established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities and be generally recognised as such
- They employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves
- They are not affiliated, in the majority of cases, to any political party and are independent from public authorities and any other non-governmental organisations of which they might be part/members of
- They may represent one or more constituencies based on actual or perceived impairment or can be open to membership of all persons with disabilities

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<sup>3</sup> Appendix 2 contains a checklist of criteria necessary to qualify as a DPO. This checklist was developed by the DPO Coalition in New Zealand and is applicable in a New Zealand context. It is included in this paper for information.

- They represent groups of persons with disabilities reflecting the diversity of their backgrounds (in terms of, for example, sex, gender, race, age, or migrant or refugee status). They can include constituencies based on transversal identities (for example, children, women or indigenous people with disabilities) and comprise members with various impairments
- They can be local, national, regional or international in scope
- They can operate as individual organisations, coalitions or cross-disability or umbrella organisations 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 organisations and private entities.

Among the different types of disabled persons' organisations that the Committee has identified in the General Comment are:

- Umbrella organisations of persons with disabilities. An umbrella organisation should be organised, led and controlled by persons with disabilities, and should speak on behalf of its members in respect of matters that are of mutual interest and collectively decided upon.
- Cross-disability organisations, which are made up of persons representing all or some of the wide diversity of disabilities. They most frequently organise at the local and/or national levels, but can also exist at the regional and international levels
- Self-advocacy organisations representing persons with disabilities in different, often loosely and/or locally formed, networks and platforms. They advocate for the rights of persons with disabilities, especially persons with intellectual disabilities. Their establishment, with appropriate (sometimes extensive) support to enable their members to express their opinions, is of fundamental importance to political participation and participation in decision-making, monitoring and implementation processes.
- Organisations 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 organisations. In such cases, these organisations should be included in consultation, decision-making and monitoring processes. The role of parents, relatives and caregivers in such organisations should be to assist and empower persons with disabilities to have a voice and take full control of their own lives. Such organisations 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

- Organisations of women and girls with disabilities, which represent women and girls with disabilities as a heterogeneous group. The diversity of women and girls with disabilities should include all types of disabilities. Ensuring the participation of women and girls with disabilities is indispensable in consultations addressing specific issues that exclusively or disproportionately affect women and girls with disabilities, and issues related to women and girls in general, such as gender equality policies
- Organisations and initiatives of children and young persons with disabilities, which are fundamental for the participation of children in public and community life and for their right to be heard and their freedom of expression and association. Adults have a key and supportive role to play in promoting an environment that enables children and young persons with disabilities to establish and act, formally or informally, within their own organisations and initiatives, including through cooperation with adults and other children and young persons.

Ireland's focal point under the UNCRPD has indicated that Ireland accepts the definition of a DPO as outlined in the Committee's General Comment.<sup>4</sup>

Therefore, all efforts to establish, develop and maintain a Participation and Consultation Network should reflect the definitions and recommendations contained in the General Comment.

## **Disability organisations in Ireland**

In order to understand the current landscape of disability organisations in Ireland- both those **of** persons with disabilities and those **for** persons with disabilities- a comprehensive (but not exhaustive) list of disability organisations is outlined in Appendix I. The list includes DPOs (both of members with disabilities and family-led organisations) and organisations for persons with disabilities. There is currently no national funding mechanism for bodies or organisations to cover running costs where they are solely advocacy bodies (as opposed to those offering services).

Research has been carried out which helps to set the Irish context for the learning contained in this advice paper. Working Group 3 was a Group established under the government's Transforming Lives programme in 2015. It was tasked with developing a plan, underpinned by a set of values and strategies

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<sup>4</sup> At the time of writing, Ireland's focal point is the Department of Justice and Equality.

that would support effective participation. Its report, **Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places**, looks at particular barriers that prevent persons with disabilities in participating effectively in decision-making.<sup>5</sup> These barriers include:

- Low expectations which focus on persons with disabilities as patients rather than active agents capable of affecting change in their own lives
- Inaccessible transport networks, inaccessible buildings and inaccessible facilities which pose real obstacles to inclusive participation in decision-making processes
- Inaccessible communication methods which restrict understanding of information and are disempowering

The Working Group's report also looked at the supports that were needed to be put in place for effective engagement, and the set of values that were necessary to underpin any participative infrastructure.

### **Structured engagement with representative groups on disability matters**

In Ireland, there are a number of clear examples of structured engagement with persons with disabilities in respect of legislation, policies and practices that directly impact their lives.

However, it is important to note that none of the examples of structured engagement below could be considered as engagement with DPOs as understood by the UN Committee. The Disability Stakeholders Group, the Disability Advisory Committee and the National Women's Council of Ireland Women with Disabilities Group do not qualify as DPOs, as defined by the CRPD's General Comment No. 7. They are not civil society organisation of persons with disabilities that are led, directed and governed by persons with disabilities.

#### **Disability Stakeholders Group**

The Disability Stakeholders Group (DSG) is a group of 24 individuals, appointed by the Minister of State for Disability Issues, to monitor the implementation of the National Disability Inclusion Strategy (NDIS). The 24 individuals include persons with a lived experience of disability as well as members of disability organisations. The DSG is currently in its fifth iteration (DSG5) and each member's tenure is as long as the Strategy they are monitoring - the current DSG was established to monitor the implementation of the NDIS 2017-2021.

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<sup>5</sup> Working Group 3 (2018) **Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places** <http://52.169.106.200/eng/services/publications/effective-participation-in-decision-making-final.pdf>



The current group includes representation of several different types of disability and a wide geographical spread. It is important to note that the DSG members are volunteers, and are not remunerated for their participation, aside from travel and subsistence costs.

The DSG members carry out their role by meeting to review and discuss the implementation of the Strategy, participate in the national steering group and in meetings of departmental Disability Consultative Committees (DCC). There are nine government departments that have such committees which operate to review implementation of Strategy actions at department and agency level, and meet quarterly. The DCC meetings are each attended by 2-3 DSG representatives, department officials and other stakeholders, such as agencies of that Department or disability organisations. DSG members attend these meetings and request information from the Department regarding the progression of the actions for which it is responsible. The DSG representatives then meet each other, also four times a year, to discuss any issues arising, in meetings chaired by an independent Chairperson. The NDA, while not a member of the Group, provides secretariat support to the DSG and a small budget to cover costs of travel and subsistence for members. The DSG representatives report to the Chairperson on how each Department is progressing the actions under the NDIS.

The DSG members also sit on the national steering group tasked with supporting the implementation of the Strategy and monitoring progress on same. The National Disability Inclusion Strategy Steering Group is chaired by the Minister of State for Disability. Other members of that Steering Group include officials from most government departments and some key government agencies, and the NDA within its independent advisory role. The DSG presents its views and suggestions at these meeting through their Chairperson, but also includes input by individual members. The Steering Group also considers future reviews of the Strategy, including with regard to implementing the requirements of the UNCRPD.

The DSG also provides input to the Comprehensive Employment Strategy (CES) Implementation Group, Similar to the NDIS, the CES is a cross-government strategy that brings together actions by different departments and state agencies in a concerted effort to address the barriers and challenges that impact on employment of persons with disabilities. As part of this programme, each relevant government department reports on its implementation of the CES to an implementation monitoring committee, which meets quarterly and which is made up of officials from relevant departments and agencies, representatives from the NDA and nominated members of the DSG. The CES Implementation Group is chaired by an independent Chairperson.

## **Disability Advisory Committee**

In December 2018, the Irish Human Rights and Equality Commission (Ireland's independent monitoring mechanism under the UNCRPD) established a Disability Advisory Committee (DAC), comprising eleven people. A majority of the DAC are persons with disabilities representing a range of disability types.

Appointments to the DAC are for a three-year term and follow an open competitive process. The role of the DAC is:

- To assist and advise the Commission on matters related to its function of keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of people with disabilities;
- To advise the Commission on the fulfilment of its independent monitoring role under the UN Convention on the Rights of Persons with Disabilities.

The Committee met five times during 2019 and in its work has considered specific rights set out in the UN Convention, including:

- The right to political participation;
- The right to independent living and participation in the community;
- The right to participate in monitoring the Convention;
- The right to participate in the implementation of the Convention; and
- The right to inclusive education.

IHREC covers the costs of travel and subsistence for DAC members.

## **National Women's Council of Ireland**

In 2020, the National Women's Council of Ireland (NCWI) established the Women with Disabilities Group. The Group has held thematic meetings, during which it has discussed violence against women (in respect of which they plan to develop a short paper), economic equality, the right to personal assistance and participation in the women's movement. There are currently approximately 35 women with disabilities participating, following a nationwide call launched by NCWI in 2019. Some are involved in disability organisations such as ILMI and CRC.

The purpose of the group is:

- To work with NCWI to ensure women with disabilities are more effectively represented across all our work
- To strengthen NCWI's advocacy and campaigning work
- To champion spaces where women with disabilities take the lead.

The group is a space for disabled women to come together to share information and ideas, to help shape the women's equality movement in Ireland and to support disabled women's leadership. The role of NWCI within the group is a facilitative role not a leading role; it is about supporting and creating spaces for the direct voices, activism and participation of women with disabilities, understanding the intersection of gender and disability. The NCWI has recently launched a call for more women with intellectual disabilities to take part.

### **Department of Children and Youth Affairs**

In 2015, the Department of Children and Youth Affairs launched the Government's first National Strategy on Children and Young People's Participation in Decision-Making 2015-2020, becoming the first country in Europe to do so.

The goal of the strategy was to ensure that children and young people had a voice in their individual and collective everyday lives across the five national outcome areas set out in *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People, 2014-2020*, namely:

- To be active and healthy;
- To be achieving in all areas of learning and development;
- To be safe and protected from harm;
- To enjoy economic security and opportunity; and
- To be connected, respected and contributing.

The strategy focused on the everyday lives of children and young people and the places and spaces in which they are entitled to have a voice in decisions that affect their lives, including in community, education, health and well-being, and legal settings. The strategy was primarily aimed at children and young people under the age of 18, but also embraced the voice of young people in the transition to adulthood.

In the strategy, HSE Disability Services committed to developing a framework document on how children's voices will inform the design, implementation and evaluation of disability services. This commitment was finalised in Year 3 of the strategy. By the end of 2019, 93% of actions had been completed. Children with disabilities participated in the strategy, especially those with mental health difficulties and learning difficulties, but not as much those with sensory impairments or intellectual disabilities.

The Department of Children and Youth Affairs is currently preparing a new Strategy, and the NDA has engaged with departmental officials regarding effective approaches to engaging children and young people with disabilities.

## **Department of Justice and Equality**

The NDA notes that the Department of Justice and Equality has recently issued a call for expressions of interest to develop a Disability Participation and Consultation Network.

The Network is intended to 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 newly established Disability Participation and Consultation Network will enable persons with a disability to be involved in the development of policy and legislation. The network will also be open to individuals and groups (non-grant funded) who will take part in network and ensure that as many persons with disabilities as wish to can input into its work.

Funding is available for an organisation representing persons with disabilities to administer the network as an Organising Member. A limited amount of separate funding is also available for organisations to become grant-funded members. Individuals and other organisations will also be able to become non-grant-funded members, thereby creating three categories of members.

Consultation on Ireland's Initial State Report to the UNCRPD is an immediate task for the Network.

## **Other existing forms of participation**

Other forms of participation that currently exist and are used to seek the views of persons with disabilities in respect of national policy and practice include:

- **Public Participation Networks:** A Public Participation Network (PPN) is a network that allows local authorities to connect with community groups around the country. A PPN is a resource for all local authorities who wish to benefit from community and voluntary expertise in their area. There are currently 31 PPNs around the country, many of whom have persons with disabilities as members. Several PPNs work together on the PPN Disability Network, which hosts seminar, makes submission and carries out disability awareness training. For example, the Bray Area Partnership facilitates a forum for local disability groups, services and relevant statutory agencies, called the BAP Disability Network. The forum provides space for members to network, discuss common issues and identify local service gaps/policy issues to take joint action to promote the full and equal participation of persons with disabilities in the local community.
- **Social Inclusion and Community Activation Programme:** The Social Inclusion and Community Activation Programme (SICAP) 2018 – 2022 provides funding

to tackle poverty and social exclusion through local engagement and partnerships between disadvantaged individuals, community organisations and public sector agencies. The programme is managed at a local level by 33 Local Community Development Committees (LCDCs), with support from local authorities, and actions are delivered by Programme Implementers (PIs). One example of engagement was a SICAP-funded Development Officer who facilitated Access for All, a collaboration between a number of agencies and community groups, to highlight access issues in Galway City and to campaign for changes to improve access and facilities for people with disabilities.

- Local Implementation Groups: HSE Local Implementation Groups (LIGs) have been set up across the country to provide local vehicle for the development of Primary Care Teams and Health and Social Care Networks in CHO. The LIG's objective is to promote the vision of Primary Care Teams and Health and Social Care Networks in the CHO in line with national framework, policies, procedures and guidelines so as to enhance the delivery of primary care services to the local population and to work in partnership with general practice and other key stakeholders in realising this objective. Under the Progressing Children's Disability Services Programme, each CHO established a Local Implementation Group, which includes representatives of children's disability services, parents and other relevant stakeholders. The LIG's task is to plan the development of Children's Disability Network Teams. This includes agreeing how the teams are going to be managed and operate and how existing staff will be allocated to each team. Then the LIG must plan very carefully for the transfer of children and their families from the current services to the new teams and ensure the changes happen as smoothly as possible. The HSE advises that at least two parent/service-user representatives sit on each LIG.
- Strategic Policy Committees: Strategic Policy Committee (SPCs) are local authority committees in city and county councils whose membership includes elected councillors, representatives of business, farming interests, environmental/conservation groups, trade unions and community and voluntary members. It is the task of the SPCs, as committees of the council, to advise and assist the council in the formulation, development and review of policy. The SPC system is intended to give councillors and relevant sectoral interests an opportunity for full involvement in the policy making process from the early stage. Several council have a Social Development/ Community Inclusion SPC, which looks at disability matters through a local government lens.
- The Mental Health Reference Group: The HSE's Mental Health Division established a Reference Group to make recommendations on the structures and mechanism for Service User, Family Member and Carer Engagement, in

the context of A Vision for Change. The membership comprised of nine service users and four family and carer representatives. In line with their Terms of Reference, the group worked from August 2014 to July 2015, making recommendations for promoting widespread and regular engagement and consultation with service users, family members and carers at local and national level.<sup>6</sup> By January 2019 there were 35 local Mental Health forums across 9 CHO areas. These fora act as a resource for service users and family members, carers and supporters to voice their experiences, raise issues and be consulted and involved in mental health services developments in their area. Many of the themes arising out of the fora have been worked on through national service improvement projects supported by the HSE's Mental Health National Project Management Office. The fora are reported to be meeting regularly throughout the country. Attendance is reported to range from 5 to 20 people and the meetings are facilitated by the Area Lead for Mental Health Engagement.

## Examples of good practice in other jurisdictions

In 2014, 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.<sup>7</sup> The analysis showed that in nearly half (13) of EU Member States, constitutional or legislative provisions are in place that provide for DPOs' engagement in developing laws and policies:

- Constitutional: In Sweden, the constitution stipulates that the State must consult DPOs when developing disability law and policy.
- Legislative (focused): In Austria, Cyprus, Malta and Spain there is relevant disability-focused legislation.<sup>8</sup>

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<sup>6</sup> HSE Mental Health Division (2015) Partnership for Change: Report of the Mental Health Reference Group <https://www.healthpromotion.ie/hp-files/docs/HMT00982.pdf>

<sup>7</sup> European Union Agency for Fundamental Rights (2014) **DPO Involvement: Indicators on political participation of persons with disabilities** <https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/dpo-laws>

<sup>8</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 policy-making. Cyprus defines the Confederation of Organisations of the Disabled, made up of nine DPOs, as

- Legislative (general): 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 consult with DPOs.<sup>9</sup>

In the remaining 15 EU Member States, the law does not require consultation and involvement of DPOs in developing laws and policies. In 11 of these Member States, there are mechanisms in place for consultation with DPOs.<sup>10</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. Other governments have non-binding guidance regarding the involvement of civil society. For example, Estonia has the Good Engagement Code of Practice in Estonia, which states that government authorities have to include interest groups affected by a planned law during the drafting process. The government sends affected interest groups a draft of the planned law so that they comment on it.

### **European Union**

The European Disability Forum is an umbrella organisation of persons with disabilities that defends the interests of over 100 million persons with disabilities in Europe. It is an independent non-governmental organisation (NGO) that brings together representative organisations of persons with disabilities from across Europe. It is run by persons with disabilities and their families, who come together to present a strong united voice of persons with disabilities in Europe. Disability Federation of Ireland is a full member of the EDF.

Created in 1996 by member organisations who wished to ensure that decisions at European level concerning persons with disabilities were taken with and by persons with disabilities, the EDF has since established regular channels of advocacy to European institutions including the European Parliament, the European Commission, and the Council of the EU.

In 2018, the EDF's annual budget was approximately €1.8m. Approximately 70% was provided by the European Union. 30% was provided by a combination of

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the social partner of the state and the government consults with the confederation on decisions that directly or indirectly affect persons with disabilities.

<sup>9</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.

<sup>10</sup> Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, Ireland, Latvia, Luxembourg and the UK.

other donors and partners. EDF membership fees contributed over €174,542. EDF also runs a number of projects which brought in a combined income to the EDF of more than €500.000 in 2018.

## **New Zealand**

The New Zealand government has two distinct forms of engagement with DPOs. The first is with the DPO Coalition, a group of DPOs who come together to engage with the Government and its agencies on policies and practices relating to disability issues. The second is with the Convention Coalition Monitoring Group (CCMG), which forms part of New Zealand's UNCRPD Independent Monitoring Mechanism. Both forms of engagement are funded by the Government, and the same DPOs are involved in both the Coalition and the CCMG.

In 2011, the Minister for Disability Issues announced that the Government of New Zealand had established an independent tripartite framework to monitor implementation of the Convention in New Zealand. The Independent Monitoring Mechanism (IMM) comprises the following bodies and organisations:

- The Human Rights Commission (the national human rights institution)
- The Ombudsman
- The Convention Coalition Monitoring Group (CCMG). This is an umbrella group of DPOs, funded by the Government and consisting of representatives of eight national DPOs who have come together to participate in this tripartite framework. It is overseen by the DPO Coalition, whose work is broader than just the monitoring of the UNCRPD but involves the same DPOs.

As well as monitoring the UNCRPD, additional functions of the IMM include:

- Developing indicators in consultation with public and private sector agencies
- Identifying priority areas by drawing on their existing programmes of work
- Measuring progress by analysing legislation, policy, and practice affecting disabled people and
- Engaging with the government to establish a comprehensive reporting process in relation to the UNCRPD that includes engagement with civil society, integration across public agencies, and clear accountability for publicising reports and following up recommendations.

The IMM has a composition that is fully in line with the provisions of the Convention, in terms of its independence, involvement of DPOs and its mandate to promote, protect and monitor. Each component of the IMM has its own role. The Human Rights Commissioner identifies disability issues and seeks solutions.



The Ombudsman investigates complaints about state agencies regarding violations of the rights of persons with disabilities. The CCMG group governs the persons with disabilities-led component of the IMM. It provides a point for persons with disabilities to participate in the monitoring process. It coordinates an ethical mechanism for collecting the input of persons with disabilities to monitor disability rights. The approach comprises qualitative research and a monitoring programme that collects data directly from persons with disabilities.

The inclusion of the CCMG in the IMM has been welcomed and praised, both nationally by persons with disabilities in New Zealand and internationally by the Committee on the Rights of Persons with Disabilities. The Committee specifically praised the country on a number of strengths of the New Zealand IMM related to the CCMG including:

- The clear mandate and funding for the CCMG set out in a 2010 Cabinet Paper
- The support for disabled people-led monitoring from the two other IMM agencies, the wider disability sector and government
- A process for monitoring the experiences of disabled people through primary data collection.

The Office for Disability Issues in New Zealand commissioned a review of the monitoring mechanism in 2017.<sup>11</sup> The review outlines specific opportunities for strengthening monitoring in the future by undertaking certain tasks, such as:

- Revisiting and strengthening governance arrangements and investing further in developing the governance skills of CCMG members
- Further developing the structure of the monitoring through consultation and drawing on monitoring expertise to develop a monitoring framework to provide a foundation for the data collection, analysis and reporting
- Refining data collection methods to provide more opportunities for individuals and organisations of different types to participate. One suggestion was to consider including other perspectives which are currently underrepresented (for example families of persons with disabilities, youths, various ethnic groups)
- Building on the good work done on reporting in order to engage a wider audience with the monitoring findings

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<sup>11</sup> Malatest International (2017) **Review of disabled people led monitoring of the UNCRPD** <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/report-on-the-review-of-disabled-people-led-monitoring/>

- Developing a monitoring framework in partnership with disability sector stakeholders that sets out monitoring priorities and appropriate monitoring measures to deliver the objectives.

As a result of this review (especially the last bullet point above), the DPO Coalition procured a provider to implement a new approach to disabled person-led monitoring. In 2018, the Donald Beasley Institute was appointed by the DPO Coalition and the Government of New Zealand as the research partner to carry out monitoring research.<sup>12</sup>

Over three years the Institute will conduct inclusive and accessible research on behalf of the DPO Coalition that enables disabled people to share their experiences of human rights in New Zealand. The Institute will also be monitoring the progressive realisation of the Convention at a systemic level. This means investigating systems and policies that have resulted in the violation of disabled people's rights.

In 2019, the Institute began by interviewing more than 70 persons with disabilities and their families about their experiences of housing. The next cycle of monitoring will investigate disabled people's experience of health and wellbeing services. This research is led entirely by disabled people. From the Project Lead and Research Assistant, to monitors, transcribers, and participants, this project promotes effective engagement and participation at every stage of the research process.

In terms of funding, the Human Rights Commission and the Office of the Ombudsman receive funding for UNCRPD responsibilities. The Office for Disability Issues has two funding streams for DPOs. One funding stream is available to the CCMG to fund a contract for the disabled people-led monitoring of the implementation of the UNCRPD in New Zealand, as part of the IMM. The CCMG receives \$275,000 (€157,000) per year.

The second funding stream is to enable DPOs to work and meet together as a coalition. The New Zealand DPO Coalition provides collective advice to the government and engages in the governance of the Disability Action Plan with government officials. Since 2015/2016, about \$100,000 (€57,508) to \$120,000 (€69,014) per year has been budgeted for those meetings, to cover travel, accommodation, secretariat support and Sign Language interpreters.

The Disability Action Plan presents priority work programmes and actions developed through a co-design process by government agencies, persons with

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<sup>12</sup> <https://www.donaldbeasley.org.nz/projects/disabled-person-led-monitoring-of-the-uncrpd/>

disabilities and their representative organisations. The work programmes and actions aim to advance implementation of the UNCRPD and the New Zealand Disability Strategy 2016-2026 (from which the Action Plans flow). The Disability Action Plan 2019-2023 was launched in November 2019 and it responds to the main issues identified by persons with disabilities, the DPO Coalition and government agencies working together during consultations. The DPO Coalition continues to play a key role, providing feedback on progress and advice on implementing the work programmes.

The DPOs have additional funding streams through donations, membership fees and government contracts, which cover the individual organisations' operational expenses.

In comparison to Ireland, New Zealand has more and larger national DPOs, with more stable funding and more experience of contributing to human rights monitoring. For example, representatives from the majority of the DPOs in the New Zealand Coalition were involved in negotiations on the drafting of the CRPD, whereas in Ireland, only a few activists participated in negotiations.<sup>13</sup> Because Ireland does not have many examples of large national DPOs and lacks experience of human rights monitoring, it may not be able to immediately replicate New Zealand's example of the CCMG, but could explore other options in the interim such as seeking individuals to represent the broad diversity of the disability community in Ireland, or bringing DPOs together through the Disability Participation and Consultation Network. Both options require funding, capacity-building and a clear mandate.

## **Iceland**

The Organisation of Disabled in Iceland (ÖBÍ) is the national DPO umbrella group, comprising 43 member DPOs which cover a vast range of disabilities, from sensory to intellectual to physical. It also includes a DPO focusing on children with disabilities. However, some of the member DPOs focus on illness and medical conditions rather than disability (for example, HIV-Iceland, Icelandic Diabetes Association and the Icelandic League against Rheumatism). ÖBÍ's role is to represent persons with disabilities and to safeguard their interests, for example regarding the development of legislation and the implementation of law and regulations. The organisation furthermore provides consultation for disabled persons and their relatives. ÖBÍ is a member of the European Disability Forum, which is an umbrella organisation of DPOs in Europe. ÖBÍ does not receive

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<sup>13</sup> Irish Human Rights and Equality Commission and NUI Galway (2016) **Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of Persons with Disabilities** <https://www.ihrec.ie/app/uploads/2016/05/Establishing-a-Monitoring-Framework-CRPD-WEB-151020119.pdf>

funding from the State. ÖBÍ has submitted a shadow report on Iceland's implementation of the UNCRPD.

Iceland provides a good example of the impact of DPOs in the drafting of core disability legislation to align Icelandic law with the UNCRPD. 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 legislation a second time, and invited additional comments 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 and developed 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 and policy. The new strategy was more successful. The united front of the working group and its in-depth knowledge of the UNCRPD were crucial factors in its success. 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.

The Icelandic example illustrates how a collaborative, united approach to the work of a DPO umbrella group is a factor that can lead to successful and effective engagement which results in effecting policy and legislative change.

## **Denmark**

The Disabled Peoples Organisation (DPOD) is the national umbrella organisation of persons with disabilities in Denmark. Established in 1934, DPOD is the umbrella group of 33 national democratic persons with disabilities organisations. DPOD is a member of the European Disability Forum. The Danish Institute for Human Rights, Denmark's national human rights institution and independent monitoring mechanism of the UNCRPD, regularly collaborates with DPOD.

DPOD has representation on the Danish Institute's board as part of the independent monitoring framework for the UNCRPD. DPOD engages in the legislative process to implement the UNCRPD 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. DPOD received approximately €120,000 from the government to cover costs of coordinating and drafting the alternative report of civil society for the initial review of Denmark

for the CRPD Committee. This allocation of funding allowed DPOD to carry out the workload of drafting a comprehensive and systematic report on the Conventions implementation. When asked what conditions would be necessary to improve its involvement in policy and decision-making processes, the DPOD highlighted that in the ideal case, the State would recognise and consider their opinions as well as providing them with education, financial support to carry out their work and transparent and accessible communication.<sup>14</sup> Education should focus on democracy and techniques to improve representativeness of DPOs. DPOD defined necessary knowledge, sufficient resources, adequate complaint procedures and advisory services as prerequisites for the active and effective involvement of civil society.

As well as financing the coordination and drafting of the shadow report, the Ministry of Foreign Affairs supported activities through a Framework Agreement administered by DPOD (DKK 7.5m (approx. €1m) in 2017) and a Disability Fund managed by DPOD (DKK 31m (approx. €4.2m) in 2017) from which its member organisations can obtain funding for their respective development interventions. Since the beginning of 2018, the support from the Danish MFA has been provided under a single, consolidated grant of DKK 43.5m (approx. €5.85m) under which DPOD continues to operate as fund administrator and implementer of its own projects and programmes.

In 2018, the Ministry of Foreign Affairs issued a tender for a review of the DPOD.<sup>15</sup> The overall objective of the review was to assess DPOD's performance in delivering results in relations to its engagements with the MoFA during the period 2014-2017.<sup>16</sup>

## **United Kingdom**

In the UK, there was financial support to develop DPOs from 2005 to 2015 but not thereafter. In the context of wider austerity measures and welfare cuts, many DPOs and ULOs (user-led organisations) closed when Local Authorities withdrew funding. There is no statutory requirement on public bodies in England to engage with or fund DPOs. While the Social Services and Wellbeing Act 2014 in Wales requires local authorities to promote the involvement of persons using

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<sup>14</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

<sup>15</sup> <https://um.dk/en/about-us/procurement/contracts/short/contract-opportunitie/newsdisplaypage/?newsid=b7e33539-22cf-4ed7-9c1f-476f2daa6244>

<sup>16</sup> Unable to find results of the Review- awaiting response from the project lead in Denmark.

care, support and preventative services in their design and operation, there is no such requirement under the Care Act for English councils. However, the Equality Act 2010 contains a public sector equality duty, which requires public bodies to have due regard to the need to reduce inequality, including between disabled and non-disabled people. The 2010 Act has motivated public bodies to fund ULOs and DPOs through the duty's requirement for agencies to encourage participation by disabled people in cases where it is disproportionately low.

In 2010, the Independent Mechanism in Northern Ireland<sup>17</sup> explored strengths and weaknesses of four established models for engaging with stakeholders:

- An advisory forum based on a 10-12 member panel
- Geographical roundtable focus groups
- A network model
- An annual public consultation.

It concluded that States need a combination of each of these models to fulfil all the requirements of Article 33 and to address the weaknesses of any single approach.<sup>18</sup>

In its Concluding Observations on the UK's initial State Report in 2017, the Committee on the Rights of Persons with Disabilities expressed concern about the lack of support for DPOs and the absence of mechanisms to ensure their effective participation.<sup>19</sup> In May 2018, the Government established an Inter-Ministerial Group on Disability and Society. However, the terms of reference for the inter-ministerial group did not refer to the UNCRPD or the Committee's concerns and did not specifically provide for the participation of DPOs or persons with disabilities.

In 2018, the Office for Disability Issues announced it would create a Regional Stakeholder Network to listen to the voices of persons with disabilities. The

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<sup>17</sup> The Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission jointly perform the role, under Article 33 (2) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), of "Independent Mechanism" in Northern Ireland (IMNI) to promote, protect and monitor the implementation the Convention. Together with the Equality and Human Rights Commission (EHRC) and the Scottish Human Rights Commission (SHRC), they are designated as the United Kingdom Independent Mechanism (UKIM).

<sup>18</sup><http://www.equalityni.org/ECNI/media/ECNI/Publications/Corporate/IMNI%20meetings/2010/CRPD-2-5-Final-engagement-model-paper-23Apr10.pdf>

<sup>19</sup> Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland <file:///H:/Downloads/G1728929.pdf>

Regional Stakeholder Network seeks to bring the views of disabled people, local disability organisations, disabled people led organisations, and organisations that represent disabled people closer to government. It facilitates face-to-face forums and provides a channel for people to share their views about policies and services that affect them. In late 2019, nine regional Chairs were appointed. However, it seems as though many of the Chairs are directors and CEOs of services and agencies, and it cannot, therefore, be seen as a DPO.

## **Germany**

In Germany, the national human rights institution was appointed as the Monitoring Body in respect of the UNCRPD. The Monitoring Body hosts consultations with civil society three times a year. Each consultation focuses on one issue that is of concern to the Monitoring Body at that time. Topics the Monitoring Body has focused on include legal capacity, women and girls with disability, and housing. Over 60 groups are invited to participate in these consultations, including DPOs, service providers, and groups representing family members of those with disabilities.

Germany also has a formal mechanism for civil society participation in its coordination mechanism, within government, a body known as the Advisory Council on Inclusion. This Council is responsible for liaising with broader society and representing the coordination mechanism. The Council acts as a meeting place for civil society, the focal point, and the monitoring mechanism. Most of the members of the Advisory Council are people with disabilities, with most other members being representatives of focal points or other state bodies involved in implementation.

## **Creating meaningful and sustainable engagement**

Aside from being an obligation under Articles 4(3) and 33 of the UNCRPD, effective participation of and engagement with persons with disabilities leads to a number of benefits. Participatory processes can be educational for both government officials and for persons with disabilities. The processes may help government officials to understand the extent of the barriers faced by persons with disabilities by virtue of a particular policy or practice. Government officials develop first-hand knowledge of the capabilities of persons with disabilities and the structures that are in place that either support or hinder those capabilities. New policies can incorporate accessibility considerations- be they environmental or communication considerations- from the beginning of the decision-making process.

Equally, the increased visibility of persons with disabilities provides role models for others and instils confidence in policies and practices developed through engagement. The inclusion of persons with disabilities in decision-making makes issues real and provides clear, relevant objectives to be achieved.

The NDA notes that support for DPOs would also be a contribution to fulfilling the legal duty on all public bodies in Ireland to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans, under the Public Sector Equality and Human Rights Duty.

Transforming Lives' Working Group 3 identified a range of supports necessary to facilitate the effective participation of persons with disabilities, including:

- Changing and challenging attitudes through disability and equality awareness training for all
- Making communication accessible for everyone and addressing physical and structural accessibility deficits
- More efficient meetings through advanced planning, facilitated chairing and small group discussions
- Achieving change using proofing and feedback systems

All of these supports are provided for in the highlighted elements below.

Working Group 3 also promoted the idea of building a national infrastructure to strengthen the representation of people with a disability in the development of strategy, policy and practice. As noted above, the Department of Justice and Equality has commenced the search for members to populate a Participation and Consultation Network. The NDA recognises that funding will be provided to this Network for 12 months, and that a review will take place thereafter. The NDA also notes that the first mandated task of the Network will be to carry out a consultation on the State Report, to be submitted to the Committee on the Rights of Persons with Disabilities before the end of the year.

The NDA notes that the establishment of this Network creates a very positive opportunity for the Department to shape the future of consultation and participation. The NDA advises that this Network be seen as the starting point of an on-going journey of engagement. In order to do so, the Department should have a clear idea of the characteristics required to develop strong, functioning and effective networks to engage with. The NDA advises that these characteristics are borne in mind when creating Terms of Reference for the Participation and Consultation Network.



The characteristics listed below are a consolidated list of traits that have allowed for positive engagement and successful results following engagement in other jurisdictions.

### **A clear mandate**

Established DPOs that engage with government departments on a regular basis understand their mandate. From that mandate, they are able to identify goals and objectives within their remit, methods to achieve them and deadlines to frame their work. The NDA suggests that the setting of tasks (including a consultation to the State Report) for the Network will allow for the creation of a clear mandate, but recommends that the Network itself is also afforded the opportunity to frame its mandate. However, in order to instil confidence in the members of the Network, the NDA believes that the mandate should also include tasks around drafting the Shadow Report and consultation for same, which, the NDA believes, would be a priority of many of the members. By only including tasks around immediate consultation on the State Report, it may create the impression that the Network is being established to carry out one specific task, rather than being established with a wider mandate which includes planning for future tasks.

### **A consistent and continuous funding model**

DPOs need to have confidence that they will be funded to carry out their mandate. They will need to be aware of budgets when it comes to work-planning. The confidence in knowing how much funding they will receive, and when it will be received allows organisations to carry out their functions comprehensively and effectively. As an example, we can look to the National Platform for Self-Advocates. While the Platform carries out important work, most of its communications over the last two years have related to requests for funding and concerns around how long it could continue to operate. The reassurance of continued funding leads to positive output and future planning for the organisations in question.

### **Membership**

Successful DPOs ensure that all disabled voices in society are heard. All disabilities are represented, and other traits such as age, gender and location are also well represented. Not only should the Network strive to represent as many disabilities as possible but it should also seek to include members with relevant skills, such as governance expertise and monitoring and research expertise.

By representing so many various disabilities, DPOs may struggle to speak in one united voice. There are many organisations in Ireland advocating on behalf of one single disability that is relevant to their members or service users. It may be difficult for a body to bring representative organisations together to speak in one

voice, and consideration should be given as to how the Organising Member and other members of the Network will achieve this. As mentioned above, a clear mandate will certainly help this objective. However, the NDA emphasises that members should be aware that, when they join the Network, they are there to engage on behalf of all persons with disabilities.

### **Capacity-building**

In other jurisdictions, DPOs have illustrated their need for organisational, leadership and data skills, access to pertinent information, education and training in human rights, law, advocacy, research methodology, policy advice, negotiation, democracy, technology and accessible communication in order to participate in UNCPRD implementation and monitoring. Capacity-building may be needed in respect of enhancing the ability of different organisations to come together and work towards a shared goal. Also, like any other organisation funded by public money, accountability, transparency and governance are critical, and appropriate training should be put in place to allow the Network to carry out its responsibilities in this respect.

It may not be the case that DPOs and other organisations in the Network will have the skills to immediately engage with Department officials, in a way to which Department officials are accustomed. Time and support will need to be afforded to them to learn the processes around decision-making and the development of legislation and policy.

However, it should be noted that capacity-building should also be considered for the Department officials who will be engaging with the Network. Just as Network members may not have experience of interacting with Government officials, public servants may not be aware that interactions with persons with disabilities are different to interactions with colleagues. They may have to consider their way of working when it comes to engaging with the Network. Accessibility of information and communications will have to be considered, and innovative methods may need to be invoked for meetings, to enhance participation. It should be noted that disability awareness training for all public servants is committed to by all relevant departments in the National Disability Inclusion Strategy 2017-2021.

### **Buy-in from all relevant Government Departments.**

In the information circulated along with the call for Expressions of Interest to join the Participation and Consultation Network, the Department of Justice and Equality noted that this Network would engage with various Government Departments and bodies. This will require a shared understanding of the role and purpose of the Network and a commitment to support and engage with the Network.

### **Innovative ways of engaging**

While technology has recently become the basis of many people's work, it has not always been the way, and the challenges in adopting it (both practical and logistical challenges as well as reluctance of the individual or their caregiver to use technology) have led to the exclusion of many individuals and organisations who are not in a position to travel to one central location for meetings. As the Network will be engaging extensively with local and regional groups, and perhaps with individuals who are not connected to any existing organisations or services and are therefore 'harder to reach', it will need to have a good sense of how it can use technology and other innovative methods to enhance engagement. Social media may be a feature of its engagement. It should also show awareness of the 'digital divide' that exists, especially when it comes to individuals living in residential settings, for whom access to technology cannot be taken for granted.

However, the NDA notes that technology may not always be the most appropriate method of facilitating engagement. Multiple methods of engagement will be required, in order to gather the experiences of as many persons with disabilities as possible.

## **Conclusion**

The NDA believes that the creation of the Network is an important first step in the development of a new culture of engagement, that reaches far beyond the UNCRPD, beyond the focal point of the Department of Justice and Equality and effectively realises the true meaning of Article 4(3), which is that persons with disabilities are afforded meaningful involvement in policies and laws that impact their lives.

The NDA emphasises the importance of gathering learning from the Network and examining it critically when the 12-month review is carried out. Identifying the learning and good practice will assist the Department in building on the foundation of the Network and supporting a long-lasting and sustainable method of engagement and participation going forward.

The NDA is happy to continue to input and advise the Department of Justice and Equality as relevant and appropriate to assist in devising methods for effective engagement with Disabled Persons' Organisations going forward.

## Appendix I: DPOs and Disability organisations in Ireland

### Disabled Persons Organisations

A number of organisations in Ireland have declared themselves to be Disabled Persons' Organisations, meeting the criteria outlined by the UNCRPD and General Comment No. 7. These include:

- **AsIAm:** AsIAm provides a portal of information about Autism and a platform for people affected by Autism to share their stories and views. It also provides for the concerns of the Autism community.
- **Disabled Women of Ireland:** The only dedicated organisation to advocate for the rights of women, trans and non-binary people with disabilities in Ireland. The organisation believes the only way to achieve real change is to advocate from an inter-sectional feminist approach. It hopes to break down the barriers which marginalise and isolate women with disabilities - be they legislative, policy based or social.
- **Independent Living Moving Ireland:** Independent Living Movement Ireland (ILMI) is a national cross-impairment Disabled Person's Organisation (DPO). It works collectively, at a local, national and international level from the basis of the Social Model to ensure that all disabled person's voices are heard. Its core values of Independence, Options, Rights and Empowerment are the foundation of the organisation. It recognises and promotes equality within its members, in terms of gender, sexuality, ethnicity, age, marital status, socio-economic status and impairment.
- **Irish Deaf Society:** The Irish Deaf Society works to bring equality and human rights to members of the Deaf Community through advocacy and empowerment as full citizens. It hopes to achieve this through the promotion of Irish Sign Language and its related culture and norms.
- **National Platform of Self-Advocates:** The National Platform of Self Advocates is an independent organisation run by people with intellectual disabilities for people with intellectual disabilities. It is a membership organisation with an elected steering committee working on its strategic plan.
- **Physical Impairment Ireland:** PII promotes the interests of Physically Disabled people in Ireland. Its aim is the full integration of disabled persons into society.
- **Voice of Vision Impairment:** VVI advocates for the rights and needs of people who are blind and partially sighted in Ireland. All VVI members and representatives have a visual impairment.

In 2020, these seven organisations came together to form the Coalition of DPOs, in order to develop Ireland's first shadow report on the implementation of the UNCRPD in Ireland. Having completed that task, the Coalition disbanded in November 2021. Five of the organisations came together again in December 2021, to work collectively as a network of DPOS. They include:

- AslAm
- Disabled Women of Ireland
- ILMI
- Irish Deaf Society
- National Platform of Self-Advocates.

## **Disability Organisations**

The following lists organisations that may not meet the DPO criteria set out by the UNCRPD and General Comment No. 7:

- **Ability West:** The Galway Association is dedicated to enabling people with an intellectual disability realise their dreams and ambitions.
- **Acquired Brain Injury Ireland:** ABI Ireland is a provider of community-based rehabilitation services for people living with an acquired brain injury in Ireland.
- **ADHD Ireland:** ADHD Ireland provides up-to-date information, resources and networking opportunities to individuals with ADHD, parents of children with ADHD and the professionals who serve them.
- **AHEAD:** AHEAD is an independent non-profit organisation working to create inclusive environments in education and employment for people with disabilities. The main focus of its work is further education and training, higher education and graduate employment.
- **Áiseanna Tacaíochta:** AT is a user-led network that seeks to provide leadership and support in Ireland to empower those who have disabilities to direct their own lives.
- **Alzheimer's Ireland:** The Alzheimer Society of Ireland is the leading dementia specific service provider in Ireland. The Alzheimer Society of Ireland works in local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers.
- **Anne Sullivan Foundation for people who are deafblind:** The Anne Sullivan Foundation (ASF) is a national organisation that was established to

help children who are deafblind throughout Ireland. The Anne Sullivan Centre aims to facilitate adults who are deafblind to pursue meaningful, active and fulfilling lives by providing care, advocacy and support services in partnership with people who are deafblind, their families, statutory and non-statutory organisations and local communities.

- **Arts & Disability Ireland:** The national development and resource organisation for arts and disability.
- **Aspire- The Asperger Syndrome Association of Ireland:** Aspire provides services and information to support people with Asperger Syndrome and their families. It works to promote an understanding of Asperger Syndrome in schools, colleges, workplaces and the wider community.
- **Bluestack Special Needs Foundation Ltd:** The Foundation is a voluntary, not for profit organisation run predominately by parents of children with special needs and professionals who not only work, but have a personal interest in the field. The Foundation supports a registered family base of 132 families.
- **Brí- The Acquired Brain Injury Advocacy Association:** Brí is dedicated to advocating for all those affected by acquired brain injury and to providing support through strength and understanding.
- **Care Alliance Ireland:** Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. It supports 85 member organisations in their direct work with Family Carers through the provision of information, developing research and policy in the field, sharing resources, and instigating opportunities for collaboration.
- **Caring and Sharing Association:** CASA builds friendships and supports between able-bodied people and people with disabilities through various projects and activities including local social events, holiday centres, respite care and Lourdes pilgrimages.
- **Catholic Institute for Deaf People:** The aim of the Catholic Institute for Deaf People is to work with, enable and serve the Deaf Community by working in partnership with other Deaf organisation and public bodies to provide services for Deaf People.
- **Central Remedial Clinic:** The CRC is national centre established for the care, treatment and development of children and adults with physical disabilities. It works with over 4,000 persons with disabilities throughout Ireland.
- **Cheeverstown House Ltd:** Cheeverstown House provides residential day and support services to over 400 persons with an intellectual disability and to their families in Cheeverstown Centre and in the local community.

- **Children in Hospital Ireland:** Children in Hospital Ireland, a National Organisation aims to ensure all sick children, either in hospital or in the community are cared for appropriately. Works collaboratively with parents, professionals and other organisations.
- **Childvision:** Childvision offers a service to Ireland's young visually impaired population.
- **Chime:** As a National Charity for deafness and hearing loss, Chime supports adults, parents, children, teenagers and families with services, technology, events and resources.
- **Clare Leader Forum:** The Clare Leader Forum is an independent group of people with disabilities who work to provide a voice on disability issues in Clare. With the support of the Center for Independent Living (CIL) they prioritise issues for action at local and county level, while also feeding into the national disability agenda.
- **CoAction West Cork Ltd:** CoAction West Cork provides services to support children and adults with an intellectual disability, and children with autism.
- **COPE Foundation:** COPE Foundation provides a comprehensive service to 1,600 persons with an intellectual disability from Cork City and County.
- **Crosscare Cedar programme:** The aim of the Cedar Programme is to raise awareness and change attitudes of people to those with disabilities within Parish Communities and throughout the Diocese.
- **Cystic Fibrosis Association of Ireland:** The aim of the Association is to provide back-up services for young people with cystic fibrosis.
- **DCA Warriors:** DCA Warriors is an organisation of family members and relatives that aims to improve the quality of life of families affected by disability by providing support, information, promoting equality and inclusion as well as raising awareness in the community by being a voice for our members. They are representative of many varied and complicated conditions and disabilities.
- **DEBRA Ireland:** The aim of the organisation is to fund medical research into epidermolysis bullosa (EB), to provide specialist care and welfare to patients and their families and to educate the general public and health care professionals about EB.
- **Disability Federation Ireland:** DFI is the national umbrella body for Ireland's main organisations of and for people with disabilities, with 66 member organisations offering a wide range of services to people with a disability. These services range from information and support services to education, training, housing, accommodation, respite care, para-medical and

other professional services. The membership of DFI are involved with all disability groupings and cover all ages.

- **Disabled Drivers Association:** The Association promotes independence and equal opportunity through mobility for people with physical disabilities.
- **Disabled People of Ireland:** Disabled People of Ireland is a group of disabled people who have come together to develop an organisation for disabled people and disabled peoples' organisations (DPOs) in Ireland. It comprises all types of disability. Membership is only open to DPOs and persons with disabilities. Family-led organisations do not qualify for membership. Disabled People of Ireland was established in 2016, however its website has not been updated in 3 years and there is no information about the work it has undertaken or its membership. However, its website notes that DPOI is "slowly and carefully building the organisation because [it] has been very aware of the need to avoid the mistakes of other efforts to create national DPOs in the past".
- **Down Syndrome Ireland:** Down Syndrome Ireland is the primary source of information and support to people with Down syndrome, their families and the professional community, working towards an improved quality of life for its members.
- **Dyslexia Association of Ireland:** Dyslexia Association of Ireland promotes public awareness of specific learning disability and promotes the welfare of people with this difficulty.
- **Dyspraxia Association of Ireland:** The Dyspraxia Association was formed in 1995 with the aim of raising awareness of dyspraxia in Ireland and to create a better understanding of the difficulties children and parents face.
- **Enable Ireland:** Enable Ireland is a non-profit state-funded organisation that works to enable and empower children and adults with disabilities to achieve independence, choice and inclusion in communities across Ireland.
- **Epilepsy Ireland:** Epilepsy Ireland aims to improve the quality of life for people with epilepsy, their families and carers through the provision of information, advice and counselling.
- **Experts by Experience:** Experts by Experience is a Social Enterprise set up in 2013, led by people with lived experience of mental ill health. It seeks to improve the lives of people with mental health difficulties through engagement, education and training.
- **Extra Care:** Extra Care is the largest, not for profit domiciliary care provider in Northern Ireland and the Republic of Ireland. Extra Care provides a range of domiciliary care services and carer support services to promote independent living.



- **Family Carers Ireland:** Family Carers Ireland is a registered charity that represents fairness for carers.
- **Féach-** Féach works to improve the education, training and communication of blind and visually impaired children. The organisation provides support for parents, and is involved in lobbying for the needs of blind and visually impaired children.
- **Fighting Blindness:** Fighting Blindness is an Irish patient-led charity funding and enabling world-leading research into treatments and cures for blindness. It provides a professional counselling service to support people and families affected by sight loss.
- **Galway Autism Partnership:** Galway Autism Partnership (GAP) is a community based charity that supports individuals and families living with autism in Galway city and county. The GAP mission is to improve quality of life experience for individuals and families living with autism by providing and facilitating quality peer support, information, social activities, training and education.
- **GROW:** Grow works to promote mental health and well-being for all to prevent mental ill-health for people who are at risk and to support people with mental health problems during their recovery.
- **Headway Ireland:** Headway is an Irish registered charity and a brain injury services organisation that supports adults who are affected by brain injury. It provides a range of community-based rehabilitation support services and information for people affected by brain injury.
- **i.C.A.R.E:** Inishowen Children's Autism Related Education (i.C.A.R.E) aims to provide a framework within which families, carers , professionals and tutors have access to training, support and any other help or service necessary in order to help children and young people with Autistic Spectrum Disorders realise their full potential
- **Inclusion Ireland:** Inclusion Ireland provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to government, statutory bodies, other relevant groups as well as the general public. Inclusion Ireland campaigns for changes in services and legislation that will improve the quality of life and participation of people with an intellectual disability.
- **Inclusion Ireland Self-Advocacy Committee:** This group has 3 board members of Inclusion Ireland on it and meets once a month. It is a very active issues-based advocacy group. There are 9 members on the group.
- **Irish Society for Autism:** The Society was formed with the goals of creating awareness about Autism, and convincing the authorities that early

diagnosis and specialised education would greatly enhance the quality of life for people with Autism.

- **Irish Wheelchair Association:** Irish Wheelchair Association (IWA) works with, and on behalf of, people with physical disabilities to drive positive change in Ireland through the influencing of public policy, the provision of quality services and enabling accessibility to all aspects of society. It advocates for the needs of people with physical disabilities and provides services and support to over 20,000 members in their homes and communities throughout Ireland.
- **KARE:** KARE provides a comprehensive range of quality services to individuals with intellectual disabilities and their families in County Kildare, East Offaly and West Wicklow.
- **Leap:** Leap is a family-led, non-profit organisation that works on behalf of children and adults with disabilities and their families. It works with families, their supporters and allies, people with disabilities, service providers and others. They focus their efforts on increasing expectations of what is possible in the lives of people with disabilities.
- **Leitrim Association of People with Disabilities:** The Association aims to empower and enable people with disabilities to take control of their own lives by providing training, a personal assistant service and creating awareness of needs in the public arena.
- **Livability:** Livability offers a wide range of innovative services to support and empower disabled people throughout their lives. They also provide community organisations with the resources, advice and confidence to impact their neighbourhoods.
- **Mental Health Reform:** Mental Health Reform is Ireland's leading national coalition on mental health. It coordinates over 70 member organisations to work together to drive progressive reform of mental health services and supports in Ireland.
- **MindFreedom Ireland:** MindFreedom Ireland is a voluntarily run, psychiatric survivor-led organisation which campaigns to abolish the power of psychiatry within the present 'mental health' system. MindFreedom Ireland explores and promotes healing alternatives to the mainstream psychiatric/medical model.
- **Muscular Dystrophy Ireland:** MDI provides support to persons affected by muscular dystrophy and their families through the provision of a range of services.
- **National Advocacy Service:** NAS provides a free and confidential advocacy service to adults with a disability, aged 18 years and over. NAS has a particular remit to work with people with disabilities who are in vulnerable

situations, such as people who are isolated from their community of choice or mainstream society, may communicate differently and who have limited formal or natural supports.

- **National Council for the Blind of Ireland:** NCBI is a not-for-profit charity, which offers support and services to people of all ages who are experiencing difficulties with their eyesight.
- **National Federation of Voluntary Bodies:** The national umbrella organisation for voluntary/ non-statutory agencies who provides direct services to people with intellectual disabilities.
- **North West Parents and Friends Association:** The North West Parents and Friends Association are a voluntary locally based community association, which is dedicated to the support of facilities and communities, working towards the fulfilment, needs and rights of people with intellectual disabilities and special needs
- **Not for Profit Business Association:** Not for Profit Business Association Limited consists of the 9 leading organisations supplying services, principally to people with physical and sensory disabilities. The association was formed to represent the business interests of its members as service providers, particularly in view of the need to combine the care ethos of the past with a commercial ethos to deal with current and emerging market forces.
- **Not so Different:** Not so Different is a social enterprise promoting equality and inclusion for people who are neurodiverse, such as those on the Autism Spectrum and their families. They support people to realise their full potential through education and employment and to live a good life in the community.
- **Rehab Group:** The Rehab Group is an independent, not for profit, non governmental organisation, operating across national boundaries, which is dedicated to promoting social integration, economic independence and equal opportunities especially for people with disabilities.
- **Saor:** Saor is a Disabled Persons Organisation (DPO) owned and controlled by disabled people, which supports persons with disabilities to achieve independent living.
- **Seasamh:** Seasamh is a self-advocacy forum for people with intellectual disability. They are an independent organisation and they are run by people with disabilities for people with disabilities in the south east.
- **Sharing the Journey:** Sharing the Journey is an independent, national parent to parent support network, supporting parents of Deaf and Hard-of Hearing (D/HH) children in Ireland. Sharing the Journey is a voluntary organisation and does not avail of statutory funding. Established in 2010, Sharing the Journey offers support and advocacy for parents while also engaging with and working

alongside D/HH agencies and Government Departments to ensure that parents' voices are heard.

- **Special Needs Parents Association-** this Association wound up in July 2020.
- **Special Olympics:** A sports organisation for people with an intellectual disability from the age of 4 years old with no upper age limit.
- **Spina Bifida Hydrocephalus Association:** The Association's primary and long term aim is to complement, support and provide for the various stages of development in the lives of its members with disabilities, their families and friends.
- **St Catherine's Association:** The Association promotes the welfare of young people of all ages with special needs throughout Co. Wicklow.
- **St Gabriel's School and Centre:** The Centre provides educational and therapy services for children and young adults with physical and multiple disabilities.
- **St Michael's House:** St. Michael's House aims to deliver a quality service that is influenced and shaped by the people it serves and to empower people with a learning disability and their families to make choices on the type of education, work, recreation and living arrangements they require.
- **The Carers Association:** The Carers Association aims to provide family carers with on hand and practical supports; to promote the interest of family carers and those receiving care in the home through effective partnership, lobbying and advocacy and to gain recognition and social justice for carers invaluable contribution to Irish society.
- **WALK:** An organisation that aims to benefit the community through empowering people with disabilities to live self-determined lives in an equal and inclusive society, in particular by providing assistance to people with disabilities in accessing education, training, employment opportunities and in areas of community living and by acting as a support for the full and equal participation of persons with disabilities concerning all aspects of their lives.
- **Western Care Association:** Western Care Association works to empower people with a wide range of learning and associated disabilities in Co. Mayo to live full and satisfied lives as equal citizens. The organisation has a Service Level Agreement with the Health Service Executive on whose behalf it provides supports and services to people with intellectual disabilities in Co. Mayo.

## Appendix 2: DPO Attributes

The New Zealand DPO Coalition developed a checklist of attributes an organisation should have to qualify it as a Disabled Persons' Organisation. It is important to note that these attributes were developed for the New Zealand context, and not all may be applicable in an Irish context but could be useful in developing a similar list here.

No.	DPO Attributes	Yes/No
1	The organisation has a legal existence i.e. must demonstrate it exists as a group of individuals with certain rules that bind them to a common purpose or goal	
2	The organisation has a national structure and focus. If the organisation has a regional focus, it demonstrates that there is no national organisation that speaks on behalf of its members	
3	The organisation upholds and promotes the philosophy that people with disabilities have the right to participate collectively in decisions that impact on our lives (Nothing about Us without Us)	
4	The organisation's primary goal, objectives and operations reflect and support the primary purpose of the Convention	
5	The organisation functions effectively and demonstrates it is putting into practice its constitutional requirements	
6	The organisation may focus on a single disability or it may be a multi-disability organisation. It is open to all disabled people who meet its membership criteria	
7	The organisation must be governed by a significant majority of disabled people who reflect its community of interest and meet its membership criteria	
8	Only disabled people who meet the organisation's membership criteria may elect and vote for its governing body	
9	A significant majority of the organisation's members are disabled and reflect its community of interest	

<b>No.</b>	<b>DPO Attributes</b>	<b>Yes/No</b>
10	The organisation demonstrates that it has a mandate or authority to speak on behalf of its members and this remains paramount over any other obligations including direct service provision	
11	The organisation responds to and is driven by the collective voice of its disabled members who reflect its community of interest	
12	The organisation demonstrates that it has strong links to its members throughout the country, or throughout the region for a regional organisation	
13	The organisation has a variety of ways to ensure its members are informed of key decisions at both a local and national level	