Engaging and consulting with disabled people in the development and implementation of legislation and policy

A note for Government officials and staff of public bodies

June 2022[[1]](#footnote-1)



## Note on terminology

In this report, the terms “persons with disabilities” and “disabled people” are used interchangeably. The term ‘disabled people’ is recognised by many within the disability rights movement in Ireland to align with the social and human rights model of disability, as it is considered to acknowledge the fact that people with an impairment are disabled by barriers in the environment and society. However, we also recognise that others prefer the term “persons with disabilities” because of the inherent understanding in the term that they are first and foremost human beings entitled to human rights. This reflects the language used in the UNCRPD. Finally, we recognise that some people do not identify as being disabled.

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# Introduction

Engagement and consultation with persons with disabilities ensure that the lived experience of disability is used to inform the development and implementation of legislation and policies, and other decision-making processes concerning issues relating to persons with disabilities. The meaningful participation of disabled people in the co-production of the outputs of these areas of work is also important although it happens less frequently than consultation. Increasingly in Ireland, disabled persons are represented by Disabled Persons’ Organisations (DPOs).

This paper seeks to briefly explain the landscape of disability stakeholders in Ireland, the growing role of DPOs, the obligations that government and public bodies have in consulting with persons with disabilities through their representative organisations, and advice on same. For those interested in reading more about DPOs, the NDA has previously published a research paper and a working paper giving more detail about DPOs, such as how they are defined, the current landscape of DPOs in Ireland, and examples of good practice in other jurisdictions.[[2]](#footnote-2)

# Obligations on the State to engage with persons with disabilities

Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. Article 4(3) of the UNCRPD states that:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, **through** their representative organizations.[[3]](#footnote-3)

The Articles contained in the UNCRPD are binding on those States Parties that have ratified the Convention. It should be noted that the UNCRPD has not been incorporated into domestic law, as, for example, the European Convention on Human Rights (ECHR) was, via the ECHR Act 2003. This means that a person cannot commence legal proceedings against the State for an alleged violation of their rights under UNCRPD. However, if a State Party has ratified the Optional Protocol to the UNCRPD, a citizen of that State may make a complaint regarding violation or non-implementation to the Committee on the Rights of Persons with Disabilities. Ireland has not yet ratified the Optional Protocol but both the Minister for Children, Equality, Disability, Integration and Youth, and the Programme for Government commits to ratifying it following the first CRPD reporting cycle.[[4]](#footnote-4) Clarification on the Government’s timeframe for the ‘first reporting cycle’ is awaited.[[5]](#footnote-5)

In 2018, the Committee on the Rights of Persons with Disabilities adopted General Comment No. 7, in order to provide States Parties with guidance on how to implement Article 4(3). One of the reasons for the adoption of General Comment No. 7 was:

“[T]he absence of meaningful consultation with and involvement of persons with disabilities, through their representative organizations, in the development and implementation of policies and programmes.”[[6]](#footnote-6)

As we can see, the language is consistent in placing “through their representative organisations” after “persons with disabilities”, both in the Convention itself and in the accompanying General Comment. This particular phrasing implies that DPOs should be prioritised in consultation and engagement processes. The General Comment goes on to say:

The involvement and participation of persons with disabilities through “representative organizations”, or organizations of persons with disabilities, is inherent in both articles 4 (3) and 33 (3).[[7]](#footnote-7)[[8]](#footnote-8)

The term “organisations of persons with disabilities” is an explanation of the term “representative organisations” which is included in the UNCRPD. “Disabled Persons’ Organisation” is a term that pre-dates the UNCRPD. All three terms mean where persons with disabilities constitute a majority of the overall staff, board, and volunteers, and whose principles are rooted in the UNCRPD. The NDA tends to use the term ‘Disabled Persons’ Organisation’.

It is important to note that, unlike the Convention itself, the General Comment is not binding on States Parties. It is the Committee’s interpretation of a particular Article and States Parties are encouraged to apply it. The Minister for Children, Equality, Disability, Integration and Youth, Roderic O’Gorman TD mentions General Comment No. 7 in a September 2021 Parliamentary Question, and outlines how his Department hopes to fulfil Articles 4(3) and 33(3) (and the guidance on these articles provided by General Comment No. 7) through the Disability Participation and Consultation Network (more on this below).

While the UNCRPD is currently the most prominent instrument obliging the State to engage and consult with persons with disabilities, it is not the only instrument. Appendix 1 looks at the wider context of our duty to engage effectively and inclusively including through the Public Sector Duty and EU initiatives. These create a foundation for a human rights-based, inclusive approach to engaging with disabled people from the earliest stage possible.

# Disability stakeholder landscape in Ireland

The landscape of disability stakeholders in Ireland can broadly be divided into six groups

* Disabled Persons’ Organisations
* Umbrella groups of DPOs
* Formal government appointed and funded consultative groups
* Non-DPO disability organisations and umbrella groups of (non-DPO) disability organisations
* Disability service provider organisations
* Individuals with a disability

Each of these are discussed in turn below but please note that there may be overlap between different groups.

## Disabled Persons’ Organisations and their umbrella groups

General Comment No. 7 defines a Disabled Persons’ Organisation (DPO) and this definition is outlined in Appendix 2 of this document. In summary, they are civil society organisations of persons with disabilities that are 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.

In Ireland, there is no organisation or Government Department designated to determine whether an organisation qualifies as a DPO. DPOs currently self-declare as a DPO. In other jurisdictions, a checklist of criteria is applied to disability organisations to determine their status as a DPO. An example of such a checklist, developed jointly by the New Zealand government and various DPOs, has been included in Appendix 3. This example may assist Departments when they are considering with whom they should engage. Please note that this checklist is only an example of good practice from another jurisdiction and has no agreed role in the Irish context. It should be noted that this checklist is not perfect; for example, it states that organisations should be national or regional in scope, in order to achieve DPO status, despite paragraph 11 of General Comment 7 including organisations that are local in scope. The NDA agrees with General Comment 7 in this regard, that DPOs may be local in scope. Departments should use their judgement when considering with whom they might engage on a particular piece of work.

In 2020, a new umbrella group called the DPO Coalition was established. It comprised six organisations that considered themselves to meet the criteria set out by General Comment No. 7.[[9]](#footnote-9) They included:

* AsIAm
* Disabled Women of Ireland
* Independent Living Movement of Ireland
* Irish Deaf Society
* National Platform of Self-Advocates
* Voice of Vision Impairment

A seventh group, Physical Impairment Ireland, joined the Coalition at a later stage.

The DPO Coalition’s main purpose was to develop a shadow report to Ireland’s initial State Report to the Committee on the Rights of Persons with Disabilities. The DPO Coalition was a recipient of funding under the Irish Human Rights and Equality Commission’s (IHREC) Human Rights and Equality Scheme 2020-21 to carry out this work. They were also successful in being appointed as a grant-funded member of the Disability Participation and Consultation Network (see next section).

In late 2021, the DPO Coalition disbanded but some of the members are involved in a new network that plans to work together based on the shared values of dignity, respect, participation and inclusion.

It should be noted that organisations that have not been involved in either the DPO Coalition or the network of DPOs may consider themselves to be a DPO.

## Formal government appointed and funded consultative groups

Two groups are discussed under this heading:

* Disability Participation and Consultation Network
* Disability Stakeholders Group

### Disability Participation and Consultation Network

The Disability Participation and Consultation Network (DPCN) was established by the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) in 2020, to ensure that persons with disabilities are involved in the development of policy and legislation. It is a three-tier network, with the first two tiers funded (one Organising Member at the top tier, Inclusion Ireland, and four grant-funded members at the second tier including Mental Health Reform, AsIAm and Disability Federation Ireland.[[10]](#footnote-10) The third tier comprises non-funded members, including persons with disabilities, Disabled Persons’ Organisations and disability organisations. All funding is provided for by DCEDIY.

The Organising Member administers the network, the four grant-funded members provide training and support to persons with disabilities to be involved in the network and the non-funded members provide the views and opinions of persons with disabilities living in Ireland on law, policy and other important issues.

It is envisaged that the DPCN will become a long-term, sustainable resource for all Departments and public bodies to avail of when they are developing relevant policy and legislation.[[11]](#footnote-11) The DPCN’s first piece of work was to conduct consultations on Ireland’s initial State Report under the UNCRPD, which was submitted to the Committee on the Rights of Persons with Disabilities in November 2021. The DPCN was also consulted on the development of the National Housing Strategy for Disabled People 2022-2027, which was launched in January 2022.

It should be noted that, while the DPCN involves DPOs (both as funded members and non-funded members), its Organising Member (Inclusion Ireland) is not a DPO. The DPCN, therefore, cannot be considered a DPO umbrella group. However, the DPCN remains a very useful resource and should be considered by Departments for advice in relation to contacting and consulting with DPOs.

### Disability Stakeholders Group

The Disability Stakeholder Group (DSG) is a group of 26 individuals, appointed to monitor the implementation of the National Disability Inclusion Strategy (NDIS).[[12]](#footnote-12) It is made up of voluntary members with lived experience and representatives of disability organisations and DPOs. Members of the sixth iteration of the DSG (DSG6) were recruited in late 2021, and the Group now includes five representatives of DPOs. Their term will last for three years, and their meetings are convened and run by an independent Chair.

DSG members carry out an important role in respect of monitoring the implementation of NDIS actions and corresponding policies, programmes and plans flowing from those actions. Members take part in one or more Departmental Disability Consultative Committees (DCCs) to discuss the specific NDIS actions of a Department. They also participate in the quarterly NDIS Steering Group meetings.

However, the DSG cannot be considered a DPO. It is not “led, directed and governed by persons with disabilities”. Its members have been appointed to the Group by the Minister of State with responsibility for Disability, and its remit is determined by the parameters of the National Disability Inclusion Strategy.

The NDA provides secretariat support to the DSG. NDA staff members interact with and sit alongside DSG members at DCC and NDIS steering group meetings.

## Non-DPO disability organisations and their umbrella groups

The term ‘disability organisation’ is a wide term and encompasses organisations that are **for** persons with disabilities rather than **of** persons with disabilities (which is what a DPO is). They range from small advocacy organisations to large umbrella organisations that represent a range of smaller disability organisations. Historically, the State has consulted with these disability organisations in the absence of DPOs. They represent a wide range of disabilities and sectoral areas, and often have funding to engage in the policy space. However, while their views are often informed by their disabled members, they are rarely directly conveyed by persons with disabilities in the policy arena.

These groups can still be involved in consultation, as they hold important and valid points of view, but they should not be engaged with instead of DPOs.

## Disability service provider organisations

There are many large and small service provider organisations in Ireland, some of which can be included in the category above. Again, this group can be involved in consultation but not at the expense of DPOs. Those organising the engagements should be mindful that service providers come from a different perspective and will have operational imperatives to consider as well as the needs of those to whom they provide services.

## Individuals with a disability

A disabled person may choose not to join a DPO or may not have access to a representative DPO. The voices of individuals with disabilities can be used to inform a consultation, however, it should be noted that disabled persons give their own individual and personal opinions. DPOs bring together the voices of a wider community of persons with disabilities and strive to offer a view that is representative of their members.

## Role of the National Disability Authority

The National Disability Authority should not be considered a representative organisation. We are the independent statutory body that provides information and advice to the Government on policy and practice relevant to the lives of persons with disabilities. We have a role to assist the Minister for Children, Equality, Disability, Integration and Youth in the co-ordination of disability policy. While some members of staff and of our Board have disabilities, we do not provide a representative voice, nor do we advocate on behalf of persons with disabilities. While we sit on several advisory and working groups in various Departments and agencies, we do not seek to sit on them at the expense of representative organisations or disabled people. We frequently remind Departments and agencies of this point, and advise them to broaden membership of working and advisory groups to include DPOs and disabled individuals who can offer a lived experience perspective.

The work of the NDA work is generally informed by lived experience, derived from direct consultation, engagement and events, but also from what we learn from our representative on working groups, advisory committee and Departments Consultative Committees.

# Advice for Government and public sector staff

## When to consult with DPOs and other disability stakeholders

Article 4.3 of the UNCRPD states

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

Decision-making processes may include developing policy advice, strategies, standards and codes of practice, designing processes, services, public infrastructure and public spaces, and carrying out research projects. However, these are not exhaustive examples.

Guidance from the Department of Public Expenditure and Reform advises that officials should recognise that involving stakeholders from the earliest possible stage in the policy development process will promote transparent and comprehensive participation.[[13]](#footnote-13)

## How to consult and engage with DPOs and other disability stakeholders

The NDA is currently working on a revision of the ‘Ask Me’ Guidelines for Effective Consultation with People with Disabilities[[14]](#footnote-14), which will provide practical advice on effective and meaningful consultation. The Guidelines are being informed through wide consultation with DPOs.

Government Departments and public bodies have historically engaged with persons with disabilities in a number of ways, including:

* Large and small consultation meetings/focus groups on particular themes with disability stakeholders
* Steering groups or advisory groups for particular projects. This approach has tended to include a mix of people with particular skills, such as research skills or subject matter expertise. To date, persons with disabilities have not always been included in these groups even when the project is specifically related to disability
* Consultation through surveys or through calls for written submissions on particular topics open to all or selected stakeholders
* Departmental Disability Consultative Committees where NDIS actions are discussed
* Consultation through seeking feedback on draft reports
* Informal consultation through phone calls and e-mails seeking advice and information – usually through personal contacts.

However, despite the examples of consultation outlined above, the obligations on Departments and public bodies as outlined earlier require more concerted efforts in this area with DPOs as the first port of call in any consultation. The UNCRPD obliges Departments and public bodies to move towards processes where DPOs are actively involved. From the beginning of the development of a piece of legislation, a policy or strategy, project managers should consider that project’s approach to consultation with DPOs.

The method of consultation with DPOs should be determined on a case-by-case basis, depending on which DPO might be best placed to add meaningful input to the work in question. The NDA advises Departments and public bodies to seek out whether an organisation fits within the definition of a DPO as outlined by the CRPD (set out in Appendix 2), or seems to align with the traits set out in Appendix 3. This process of deciding on whom might be appropriate for the Department to engage with should be documented. Officials can also ask organisations if they self-declare as a DPO and on what grounds.[[15]](#footnote-15) On this final point, the NDA reiterates that there is no authority in Ireland tasked with determining who qualifies as a DPO and who does not.

In designing or organising consultation, it is important to recognise the intersecting identities of the people at whom it is aimed. Disabled people will face different barriers depending on their various identities. An older woman with disabilities will face particular challenges, as will a disabled member of the Traveller community. The barriers faced by an asylum seeker with disabilities may be different to disabled members of the LGBTI+ community. Consultations should result in comprehensive, rounded views of all persons who will be affected, and the outcomes should be informed by all experiences and identities.

It may be the case that DPOs or the DPCN will not have capacity to engage, due to constraints placed upon them by their current workloads, however they should still be contacted, and their potential involvement should be explored. It may be the case that the work is not of such urgency that it cannot be put on hold for a short while until a DPO is in a position to engage. Where it is not possible for a DPO to engage during the time required, other channels to engage the disability community should be pursued to seek effective engagement with individuals or other organisations as appropriate. However, the distinction between this form of engagement and engagement with DPOs should be clearly recognised, and documented in any subsequent consultation report. Engagement with non-DPOs is not a substitute for engagement with DPOs.

Although the UNCRPD prioritises engagement with DPOs, this engagement is not exclusive. The positive, rich relationships that have been cultivated with disability organisations and individuals with disabilities and their family members should not be discounted, but their distinction from the views of DPOs should be clearly recognised. Disabled people who choose not to join a DPO should not be excluded from voicing their experiences.

While all efforts should be made to engage with DPOs, it may be the case that a contribution of specific lived experience may be required. It may be the case that an individual with a specific disability, of a certain age and living in a particular location may be able to offer a point of view that is not offered by a national DPO. There are some situations where Departments and public bodies may have to adopt a pragmatic approach to consultations, particularly as the landscape of DPOs in Ireland is not yet as well developed as in some other countries.[[16]](#footnote-16)

Departments and public bodies should document their efforts to identify a DPO and their rationale for adopting the consultation process that they adopted.

## Considering the views of DPOs

Taking together the language of Article 4(3), Article 33(3) and General Comment No. 7, the NDA interprets the UNCRPD as saying that DPOs should be consulted in the first instance and that all efforts should be made to ascertain their views in the ways outlined above. Due regard and consideration must be given to the views of DPOs and officials should recognise, and utilise, the valuable input of people’s lived experiences, offered by DPOs through their representative role.

Following (and during, where appropriate) engagement, those responsible for carrying out consultation should provide feedback to all participants on how views were considered and taken on board and for significant policy issues explaining why they were not taken on board. This feedback steps helps to make the consultation process more meaningful and reduces the feeling that can exist post consultation that people are not listened to. Guidance on consultation from the Department of Public Expenditure and Reform in 2016 notes that the provision of feedback should be considered on a case-by-case basis, and should not impose an unreasonable burden on a public body.[[17]](#footnote-17) It states that feedback does not have to be given on an individual basis but can be done in other ways. For example, a public body or Department may develop a consultation report that summarises the number of submissions received, key points raised in the submissions, whether these were taken on board or not, and future plans (if any) for further engagement, is important to encourage active participation. Public bodies should be able to respond should any individual or DPO request feedback in an alternative format, in so far as is practicable.

A relevant situation arose in the UK in January 2022, which should be watched closely.[[18]](#footnote-18) The National Disability Strategy was launched in July 2021. This Strategy was allegedly informed by a National Disability Survey, which had been made available in January 2021. The Survey invited the views of disabled people on their everyday experiences, and received 14,000 responses. It comprised 109 multiple-choice and four open-ended questions such as: "What are the top-three changes that would make your life better?"

An application for judicial review was brought against the Survey on the basis that it did not meet the requirements of a lawful consultation at common law. The government argued that this had been an information-gathering exercise and not a consultation.

The High Court found that, whilst the Secretary of State did not have a legal duty to consult on this matter, she had voluntarily chosen to do so and therefore was subject to the common law rules. On review by the Court, the consultation had fallen short of compliance with these rules in a number of ways. The failure of the Secretary of State to provide sufficient information on the proposals of the Strategy meant that it was impossible to answer the survey in a meaningful way. The heavy reliance on a multiple choice format for questions, with freeform answers also being word limited, further reduced the ability of respondents to the survey to fully communicate their thoughts.

The government has indicated its intention to seek permission to appeal against the ruling to the Court of Appeal.

The obligation on Ireland to effectively engage and involve disabled people in decision-making processes and development of legislation and policy, put in place by the UNCRPD, is well recognised and understood by DPOs and disabled people. Departments and public bodies can expect to be challenged in respect of projects, initiatives, policies and strategies and all other relevant work that has not been subject to effective and meaningful consultation and engagement.

## Explore participatory processes

There is scope in Ireland to explore the use of more participatory processes in the development of legislation, policies, and guidelines relevant to the lives of persons with disabilities. When revised, the ‘Ask Me’ Guidelines for Effective Consultation with People with Disabilities will include a section on how to carry out a meaningful participation process, rather than seeing consultation as a once-off event.

The CEUD, in collaboration with the National Standards Authority Ireland (NSAI), has been working with organisations on implementation of I.S. EN 17161: Design for All - Accessibility following a Design for All approach in products, goods and services - Extending the range of users’. This is a European process standard about using a Universal Design approach at all levels in organisations to continuously improve and manage the accessibility and usability of the products and services they provide.

This standard can be used as part of complying with accessibility legislation and to help advance corporate social responsibility. The standard specifies requirements and recommendations that enables an organisation to extend their range of users by: identifying diverse user needs, characteristics, capabilities, and preferences; by directly or indirectly involving users; and by using knowledge about accessibility in its procedures and processes.

In other jurisdictions, such as Australia, public sector co-designing is an emerging field of practice that takes a participatory approach and provides the opportunity for creative and innovative ideas. [[19]](#footnote-19) With co-design, engagement commences at the earliest possible stage of the design process and continues throughout, even after the design or policy is created. It builds a feeling of involvement and ownership and generates a shared language between participants and policy makers. Participatory engagement is being reframed, not just as an issue of access and representation, but as a rights and justice issue, as people with disabilities have the right to co-design the policies and programs that will affect their daily lives.

The meaning of co-design currently lacks a shared understanding, especially in policy-making. Co-design in various forms, from participatory design to co-creation, has attracted the interest of many people, companies, and organisations, and is growing rapidly. Most of the growth is taking place at the early front end of design, also known as the ‘fuzzy front end’, where the strategy and direction and the “what” of the development effort is decided. Co-design is practiced using a ‘designing-with’mind-set. There is growing interest in and support for this mind-set that the end-users are the experts of their future lives and that designers/design teams can design withthe people that will be using the service or product. It is a growing recognition of and skill at involving end-users in design processes as “experts of their experience,” and a recognition that this requires a process rather than a one-shot reaction.

# Conclusion

The obligation on Departments and public bodies under Article 4(3) to engage with DPOs in the development of policy and legislation is very well understood by the disability community. The NDA, Government Departments and public bodies can expect to be held to account if they do not engage with DPOs.

In addition to their obligations under the UNCRPD, all public bodies in Ireland have a responsibility to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans. This is a legal obligation, called the Public Sector Equality and Human Rights Duty, as per Section 42 of the [Irish Human Rights and Equality Act 2014.](http://www.ihrec.ie/download/pdf/ihrec_act_2014.pdf) Meaningful engagement with DPOs helps to fulfil this duty. In addition, the legal obligations under Section 28 of the Disability Act support consultation with individuals with disabilities, by requiring communications published by public bodies to be accessible in alternative formats on request for those with hearing or visual impairments, or with intellectual disabilities.

While the Disability Participation and Consultation Network will, ideally, become an invaluable resource to Government Departments and public bodies, it is not yet developed enough to play that role now. Therefore, Departmental officials and public body staff should consider which DPO(s) might be best suited to engage on a particular project, and approach them bilaterally. Until a clear path to effective, inclusive engagement is identified, officials should use their judgement and experience, while also being open to new and innovative methods of engagement, with existing and new networks and to embrace more active participation of DPO members. This will be a decision for each Department and public body to decide for themselves, in light of the work in question. It will be important for Departments and public bodies to document the process they took when identifying organisations and individuals with whom to engage. The NDA has advised that the NDIS Steering Group dedicate a meeting in 2022 to discussing the, status, role and future work-plan of the Disability Participation and Consultation Network.

There is an important issue around the need for capacity-building, in respect of Department officials, members of DPOs and other individuals with disabilities in order to be able to effectively engage with one another. It is beyond the scope of this paper to provide advice on this issue. However, the NDA is currently updating its ‘Ask Me’ Guidelines for Effective Consultation with People with Disabilities, which provide practical advice on how to undertake inclusive consultation processes with people with disabilities. The updated guidelines will take into account the new role played by DPOs, will provide a ‘how to’ in respect of the actual carrying out of consultations and will examine the area of capacity-building of all parties.

# Appendix 1: Other obligations in respect of consulting and engaging

### Section 28, Disability Act 2005

Section 28 of the Disability Act 2005 obliges a public body, in its communications with people, to ensure that the contents of the communication are made available in a form that is accessible to the person concerned, if that person has a hearing or visual impairment and requests for information to be provided in a particular form. A similar obligation is put on a public body where the communicated is made in electronic form; the head of that public body must ensure that the communication may be accessed by a person using adaptive technology. Finally, the head of a public body must ensure that information relevant to persons with intellectual disabilities is made available in a clear language that is easily understood by those persons.

### Public Sector Duty

The Public Sector Equality and Human Rights Duty (the Duty) places a statutory obligation on public bodies to eliminate discrimination, promote equality of opportunity and protect the human rights of those to whom they provide services and staff when carrying out their daily work. It puts equality and human rights in the mainstream of how public bodies execute their functions. To that end, it has the potential to positively transform how public bodies engage with members of the public, and their own staff.

The Duty has been part of Irish law since 2014, and is set out in Section 42 of the Irish Human Rights and Equality Commission Act 2014. The Irish Human Rights and Equality Commission has a mandate to give guidance to, and encourage, public bodies in developing policies and good practice in relation to human rights and equality.

Engagement and consultation with both staff and service users is a key element of a successful implementation of an organisation’s Public Sector Duty. IHREC’S ‘Implementing the Public Sector Equality and Human Rights Duty’[[20]](#footnote-20) guidance document states that engagement and consultation should consist of:

* An inclusive approach which encourages a diversity of voices, as appropriate;
* Targeted and appropriate consultation methods which take into account how to reach and engage different audiences;
* A transparent, open and accountable approach, which can indicate how the consultation has informed the issue
* Clear, concise communication providing clear guidelines outlining the objectives and timeline of the consultation;
* Accessibility including a commitment to providing information about, and advertising, the consultation in a way that takes into account the needs of people with disabilities, literacy issues and English as a second language;
* Reasonable accommodation and positive action measures including a commitment to:
* ensuring that people with disabilities can notify the public body of particular supports required to participate in the consultation;
* responding to requests for reasonable accommodation for people with disabilities, as appropriate;
* identifying the need for targeted approaches to support participation of disadvantaged groups or to cater for the needs of specific categories of people within the consultation process.

### Our Public Service 2020

Our Public Service 2020 is the framework for development and innovation in Ireland’s public service. It was preceded by two public service reform plans beginning in 2011. These plans have embedded a range of new approaches to governance, people management and service delivery, and have made the work of the public service more transparent, decision-making more accountable, and service delivery more effective.

Action 4 of Our Public Service 2020 aims to enhance engagement and accountability around the delivery of public services, so that the public and businesses have greater input into the planning, design, implementation and review of public services.

Our Public Service commits public service organisations with continuing to improve engagement with the public and businesses through mechanisms such as open policy debates, focus groups, seminars, social media and crowd-sourcing solutions from the public, academics, practitioners and experts. The learnings from these platforms will allow the development and application of new approaches to policy design, evaluation, consultation and implementation. The framework also states that public service organisations will continue to improve engagement with individuals on those services where better outcomes can be achieved by designing the service around the specific needs of the individual.

Under Our Public Service, CEUD and DPER developed the Customer Communications Toolkit for the Public Service - A Universal Design Approach, which has guidance to inform the design and procurement of customer communications across the Public Service. The Toolkit is based on a Universal Design approach promoted by the CEUD which ensures that all communications- be they verbal, written, signed or digital- are designed to be easy to understand, accessible and usable by everyone but in particular by persons of any age, size, ability or disability.[[21]](#footnote-21)

### Disability Impact Assessment

In 2012, the Department of Justice published Disability Impact Assessment guidelines.[[22]](#footnote-22) Disability Impact Assessment is the process used for carrying out disability proofing. It involves a comprehensive examination of how any proposed policy, legislation, programme or service impacts on a person with a disability. The analysis should consider all potential impacts, both positive and negative.

By carrying out a Disability Impact Assessment, Departments progress Ireland’s social justice goals, achieve efficiency and effectiveness, and address their legal obligations to combat discrimination.

The Cabinet Handbook, an internal Government guide to assist Ministers and officials in the preparation of matters, requires that all substantive Memoranda should indicate the impact on people with disabilities. ‘Substantive Memoranda’ includes:

* A change in policy
* The introduction, abolition or significant change in an existing scheme
* A decision which impacts on the public at large, or on a significant subset of that population
* A decision to draft or to approve legislation
* A decision involving expenditure increases or reductions, or changes in taxation.

In order to gather evidence to assess whether a piece of substantive memoranda will affect persons with disabilities, the Impact Assessment advises that consultation with persons with disabilities takes place as early as possible in the process, recognising that this early engagement may indicate the need for an alternative approach to the project than originally envisaged.

### European Union obligations

The ‘**Better Regulation Agenda’**, launched by the European Commission in 2018, is about evidence-based policy-making, designing and evaluating EU policies and laws transparently, taking into account the views of those who will be affected, and focusing on delivering where it matters the most. The Commission requires consultation to be a key part for any policy development process that has an equality dimension.

The European Commission has sought to encourage and support a practice of equality mainstreaming at Member State level. This work includes the publication of a compendium of practices in non-discrimination/equality mainstreaming in 2011.[[23]](#footnote-23) It also includes the adoption of regulations governing the European Structural and Investment Funds, and good practice exchanges among the members of the Governmental Expert Group on Non-Discrimination of the European Commission and the High Level Group on Disability.

The European Commission has defined equality mainstreaming as the “systematic incorporation of non-discrimination and equal opportunity concerns” on the grounds of gender, racial or ethnic origin, disability, age, religion or belief and sexual orientation into all policies and stages of the policy process.

The Commission has also provided guidance on the use of equality impact assessment, a key part of which is consultation and engagement.

The **European Disability Strategy 2021-2030**, launched in February 2021 reinforces the ‘Better Regulation Agenda’ and states that effective policy-making implies consultation and participation of persons with disabilities and their representative organisations throughout the process and the provision of information about relevant policy initiatives and consultations in accessible formats. In the new Strategy, the Commission commits to reinforcing the Better Regulation toolbox to enhance disability-inclusiveness for ensuring UNCRPD consistency, and to ensuring the coherent inclusion and assessment of disability matters in impact assessments and evaluations where relevant.

### United Nations obligations

The 2030 Agenda for Sustainable Development, or **Sustainable Development Goals** (SGDs), sets out a vision for sustainable development grounded in a human rights-based approach, putting equality and non-discrimination at the centre of its efforts and encompassing not only economic and social rights but also civil, political, and cultural rights, and the right to development.

Universal values are what enable the SDGs to be truly transformative, by placing the person and their inherent dignity at the heart of development efforts, empowering all people to become active partners in this endeavour. One of the approaches used to operationalise the values of the SGDs is active and meaningful participation.

The SDGs state that active and meaningful participation of stakeholders, including the human rights community and civil society, women, children and vulnerable groups, must be ensured in all phases of the design, implementation and monitoring of the new Agenda, and any projects which fall within its remit. Meaningful participation will ensure that the most marginalised are identified and taken into account in policy development.

The UN urges its institutions and States Parties to establish strong partnerships with civil society and other stakeholders, to create consistent space and resources for informed and empowered participation.

# Appendix 2 – Definition of a DPO

General Comment No. 7, adopted by the Committee on the Rights of Persons with Disabilities in 2018, contains a list of the characteristics of a Disabled Persons’ Organisation:

(a) They are established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities and should be generally recognized as such;

(b) They employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves;

(c) They are not affiliated, in the majority of cases, to any political party and are independent from public authorities and any other non-governmental organizations of which they might be part/members of;

(d) They may represent one or more constituencies based on actual or perceived impairment or can be open to membership of all persons with disabilities;

(e) They represent groups of persons with disabilities reflecting the diversity of their backgrounds (in terms of, for example, sex, gender, race, age, or migrant or refugee status). They can include constituencies based on transversal identities (for example, children, women or indigenous people with disabilities) and comprise members with various impairments;

(f) They can be local, national, regional or international in scope;

(g) They can operate as individual organizations, coalitions or cross-disability or umbrella organizations of persons with disabilities, seeking to provide a collaborative and coordinated voice for persons with disabilities in their interactions with, among others, public authorities, international organizations and private entities.[[24]](#footnote-24)

# Appendix 3: New Zealand DPO Checklist

Alongside collaborating with Government agencies to agree on priorities in the New Zealand Disability Action Plan 2014-2018, the New Zealand DPO Coalition developed a set of attributes that distinguish Disabled People’s Organisations from other organisations in that jurisdiction.

The NDA emphasises that this should not be considered an official checklist by Government Departments and public bodies in this jurisdiction, as it has no legislative basis in Ireland. It is intended to act as an examples of good practice for Departments, for when they are considering with which organisations they should engage. The NDA reiterates that there is no authoritative body in Ireland that determines which organisations may be considered DPOs; it is up to organisations themselves to show that they reach the threshold set by the UNCRPD.

The New Zealand checklist notes that an organisation must have the following characteristics to be considered a DPO:

* 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 (refer appendix for additional information).
* 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.
* 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).
* The organisation’s primary goal, objectives and operations reflect and support the primary purpose of the Convention
* The organisation functions effectively and demonstrates it is putting into practice its constitutional requirements
* 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.
* The organisation must be governed by a significant majority of disabled people who reflect its community of interest and meet its membership criteria.
* Only disabled people who meet the organisation’s membership criteria may elect and vote for its governing body.
* A significant majority of the organisation’s members are disabled and reflect its community of interest.
* 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
* The organisation responds to and is driven by the collective voice of its disabled members who reflect its community of interest
* The organisation demonstrates that it has strong links to its members throughout the country, or throughout the region for a regional organisation
* The organisation has a variety of ways to ensure its members are informed of key decisions at both a local and national level.[[25]](#footnote-25)

1. A version of this paper was circulated to Government Departments on 17 June 2022. It was amended, to include two points of correction on 24 June 2022, and re-uploaded to the NDA website. [↑](#footnote-ref-1)
2. Both papers are available at this link. <https://www.nda.ie/publications/others/uncrpd/nda-working-paper-on-engagement-with-disabled-persons-organisations-and-related-research-report.html> [↑](#footnote-ref-2)
3. Emphasis added. [↑](#footnote-ref-3)
4. https://www.oireachtas.ie/en/debates/question/2020-12-09/167/ [↑](#footnote-ref-4)
5. It may mean the development and submission of the first State Report, or the full process of submission of the State Report, receipt of the List of Issues from the Committee on the Rights of Persons with Disabilities, the subsequent interactive dialogue with the Committee and receipt of its Concluding Observations. If it is to be the latter, it may be three or four years before the full reporting cycle is complete. [↑](#footnote-ref-5)
6. General Comment No. 7, paragraph 8. [↑](#footnote-ref-6)
7. General Comment No. 7 can be found here: <https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2pjFYzWLBu0vA%2bBr7QovZhbuyqzjDN0plweYI46WXrJJ6aB3Mx4y%2fspT%2bQrY5K2mKse5zjo%2bfvBDVu%2b42R9iK1p> [↑](#footnote-ref-7)
8. Article 33(3) also obliges States Parties to engage with representative organisations, but solely in respect of the monitoring of the implementation of the Convention. Therefore, Article 33(3) is not discussed in this note, which offers guidance on engagement in respect of the development and implementation of policy and legislation. [↑](#footnote-ref-8)
9. A seventh organisation, Physical Impairment Ireland, joined the DPO Coalition in 2021. [↑](#footnote-ref-9)
10. In January 2022, an advertisement went live, intending to recruit a fourth grant-funded member to replace the DPO Coalition following its disbandment. It stipulated that the fourth member had to be a DPO. This recruitment process is currently ongoing. [↑](#footnote-ref-10)
11. It should be noted that the Network is in the very early days of development and it is unlikely that it will have the capacity to take on all requests for consultation it receives. [↑](#footnote-ref-11)
12. <https://www.gov.ie/en/organisation-information/e9122-disability-stakeholder-group/> [↑](#footnote-ref-12)
13. Department of Public Expenditure and Reform (2016) Consultation Guidance and Principles, para 12. https://assets.gov.ie/5579/140119163201-9e43dea3f4b14d56a705960cb9354c8b.pdf [↑](#footnote-ref-13)
14. The existing 2002 guidelines are available here <https://nda.ie/policy-and-research/research/research-publications/-ask-me-guidelines-for-effective-consultation-with-people-with-disabilities.html> [↑](#footnote-ref-14)
15. For some organisations it will be straightforward to determine as the organisation is led by persons with disabilities and their membership is largely made up of persons with disabilities. However, General Comment No. 7 also recognises that organisations of parents, family members and carers of children with disabilities or people with intellectual disabilities or dementia may also be considered DPOs if their role is primarily to assist and empower persons with disabilities to have a voice and take full control of their own lives. [↑](#footnote-ref-15)
16. Please note that some DPOs would disagree with this approach and maintain that DPOs are the only organisations that should be consulted on CRPD related matters. [↑](#footnote-ref-16)
17. Department of Public Expenditure and Reform (2016) Consultation Guidance and Principles, para 26. https://assets.gov.ie/5579/140119163201-9e43dea3f4b14d56a705960cb9354c8b.pdf [↑](#footnote-ref-17)
18. https://www.bbc.com/news/disability-60138437 [↑](#footnote-ref-18)
19. Rieger J (2020) Right to Participate: Co-designing Disability Policies in Australia.

    QUT Centre for Justice Briefing Paper, pp. 1-4, December 2020. <https://eprints.qut.edu.au/208220/1/Briefing_paper_series_Dec_2020_Issue12.pdf> [↑](#footnote-ref-19)
20. <file:///H:/Downloads/IHREC_Public_Sector_Duty_Final_Eng_WEB.pdf> [↑](#footnote-ref-20)
21. <https://www.ops.gov.ie/news/Resources/customer-communications-toolkit-for-the-public-service/> [↑](#footnote-ref-21)
22. <http://www.justice.ie/en/JELR/20120305%20DIA%20Guidelines.pdf/Files/20120305%20DIA%20Guidelines.pdf> [↑](#footnote-ref-22)
23. https://op.europa.eu/en/publication-detail/-/publication/1c934780-2913-4061-a2be-7a86a33279c6 [↑](#footnote-ref-23)
24. Criteria of a DPO, as set out in General Comment No. 7. [↑](#footnote-ref-24)
25. <https://www.odi.govt.nz/guidance-and-resources/disabled-peoples-organisations/> [↑](#footnote-ref-25)