

Participation Matters

Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making





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	Table of acronyms
DPO	Disabled Persons' Organisation
GDPR	General Data Protection Regulation
IHREC	Irish Human Rights and Equality Commission
ISL	Irish Sign Language
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
NDA	National Disability Authority
ILMI	Independent Living Movement Ireland
SLIS	Sign Language Interpreting Service
PECS	Picture Exchange Communication System
LGBTQI+	Lesbian, Gay, Bisexual, Transgender, Queer and Intersex+
DPER	Department of Public Expenditure and Reform
WCAG	Web Content Accessibility Guidelines
SEB	Standard English Braille
UEB	Unified English Braille
PPN	Public Participation Network

Foreword

I am very pleased that the National Disability Authority is publishing its updated guidance for government departments, public bodies and local authorities on how to effectively engage with disabled people in decision making processes.

Ireland ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. This means that Ireland has made a commitment in international law to protect and promote the rights of disabled people. The Convention outlines obligations on Government to ensure the meaningful participation



of disabled people, and Disabled Persons' Organisations, in the development, implementation and monitoring of policies and legislation and in other decision making processes.

Too often, disabled people and their organisations face barriers to their full and effective participation. These include inaccessible physical and online environments, inaccessible information and communication, and negative attitudes and stereotypes.

These guidelines provide practical information to support public officials to address these barriers in order to meaningfully consult with and actively involve disabled people and their organisations in decision making. They support officials to take a universal design approach to all public consultation and participation processes so that disabled people can participate on an equal basis with others.

It is time to ensure the systematic inclusion of disabled people in decision making, and to recognise that their participation is not a 'tick the box' exercise. When carried out meaningfully, it adds enormous value by making laws, policies and services more responsive to the needs of disabled people. In doing so, it contributes towards achieving a more inclusive society for all.

Ireland's effective implementation of UNCRPD, and the realisation of the rights of disabled people, depends on the quality and accessibility of our public participation processes. I am certain that this guidance will support Government to achieve this.

Anne Rabbitte T.D.

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Minister of State at the Department of Children, Equality, Disability, Integration and Youth

Acknowledgements

These guidelines were developed by the National Disability Authority (NDA). The NDA would like to acknowledge and thank representatives from a number of Disabled Persons' Organisations, voluntary, community and statutory organisations, Departmental and local authority officials, and disabled individuals who provided input and feedback during the consultation.

Disabled Persons' Organisations

- As I Am
- Disabled Women Ireland
- Independent Living Movement Ireland
- Independent Living Movement Ireland Youth Collective
- Irish Deaf Society
- The National Platform of Self Advocates
- Physical Impairment Ireland
- Voice of Vision Impairment

Public officials from:

- Department of Children, Equality, Disability, Integration and Youth
- Department of Education
- Department of Enterprise, Trade and Employment
- Department of Environment, Climate and Communications
- Department of Justice
- Department of Transport
- Higher Education Authority
- Donegal County Council
- Dublin City Council
- Wexford County Council
- Wicklow County Council

We also acknowledge those individuals and organisations who made public submissions. We extend our thanks to the Anne Sullivan Foundation, Cairde, Carlow Universal Access Movement, Disability Federation of Ireland, the Disability Participation and Consultation Network, Epilepsy Ireland, Galway Access for All, Inclusion Ireland, the National Council for the Blind, and all individuals who made a submission.

Statement on language

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

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

Please see the NDA advice paper on disability language and terminology for further information.

Introduction

What are these guidelines?

These guidelines are a practical resource to support public officials at national and local level to meaningfully consult with and actively involve disabled people and their representative organisations in policy development and other decision making processes to meet obligations set out under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). These guidelines support officials to take a Universal Design approach to all public consultation and participation processes so that disabled people can participate on an equal basis with others. This guidance is an update to the NDA's 2002 publication "Ask Me: Guidelines for Effective Consultation with People with Disabilities."

Who are these guidelines for?

These guidelines are for public officials from government departments, public bodies and local authorities. They are useful for officials whose roles have a strategic remit and for those whose roles have an implementation or administration remit. They may also be useful to other organisations who wish to consult with and actively involve disabled people and their organisations.

How were the guidelines developed?

The guidelines were prepared by the National Disability Authority and informed by consultation with Disabled Persons' Organisations, other stakeholders across the disability community and public officials from departments and local authorities. Details of the consultation process are outlined in the consultation report which is available on the NDA website.

How to use these guidelines

The guidelines are divided into four sections.

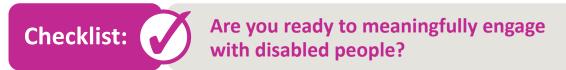
Section 1 contains quick guides with important background information on key legislation, policies, and concepts which are essential to know about when engaging with disabled people and their organisations.

Section 2 outlines the stakeholder landscape, and in particular the central role of Disabled Persons' Organisations in participation processes. It outlines when to consult with Disabled Persons' Organisations and how to reach them. It also provides information about the role of other kinds of organisations and individuals in participation processes.

Section 3 includes practical information about designing a meaningful and accessible participation process. It outlines the principles of meaningful participation and some examples of tokenism to avoid. It provides information about how to use some common participation and consultation methodologies, both in-person and online, such as meetings, focus groups, surveys and submissions processes.

Section 4 outlines some good practice for inclusion of disabled people. This includes guidance around respectful language and terminology as well as guidance for Chairs and facilitators regarding how to create an inclusive environment for disabled people in meetings and workshops.

The **Appendix** contains checklists which can be used for planning your participation process. It also contains contact information for the Disabled Persons' Organisations who contributed to the development of these guidelines as well as some useful links and resources.



This checklist will help you understand what you need to know in order to carry out a meaningful participation process with disabled people.

I am familiar with my obligations regarding the participation of disabled people in decision making under the UN Convention on the Rights of Persons with Disabilities (page 10)	
I am familiar with Disabled Persons' Organisations, I understand their role in participation processes, and I know how and when to contact them (page 12; page 18)	
I understand the different role of other stakeholder groups such as civil society organisations, organisations of family members of disabled people, and the National Disability Authority in participation processes regarding disability (page 20)	
I understand the principles that underpin a meaningful participation process and how to recognise and avoid tokenism (page 23)	
I know the steps for an effective participation process and have a plan for engaging with disabled people at each stage (page 24)	
There is senior level commitment in my Department, public body, or local authority to take forward the recommendations of stakeholders where practicable (page 24)	
Staff involved in the participation process at all levels have received Disability Equality Training from a human-rights based perspective (page 25)	
There is sufficient budget, time and staff resources allocated to carry out this process meaningfully (page 26)	
I know how to make each stage of the process accessible to disabled people (page 31)	
I have a plan for how feedback will be delivered to stakeholders both throughout the process and at the end (page 34)	
I understand how to evaluate the effectiveness of the participation process (page 35)	
I know how to speak and write about disability in a respectful manner (page 38)	
I feel confident that I can facilitate an inclusive and accessible consultation activity, meeting, or event taking place online or offline (page 40)	

Section 1: Quick Guides

What is UNCRPD?

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international human rights treaty.

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. (UNCRPD Article 1)

Ireland ratified the Convention in 2018. The Articles contained in the UNCRPD are binding on those States Parties that have ratified the Convention. This means that Ireland has made a commitment to protect and promote the rights of disabled people.

Ireland must report to the UN on how well it is implementing the Convention. The Committee on the Rights of Persons with Disabilities is a body of independent experts who monitor the implementation of UNCRPD by State parties. States must report within one year of ratifying the Convention. After submitting their initial report, States parties have to present periodic reports every four years.

The Department of Children, Equality, Disability, Integration and Youth is responsible for co-ordinating disability policy across Government and acts as the national focal point for the Convention. The focal point oversees the process of the implementation of the UNCRPD. States are also required to designate an independent monitoring mechanism. In Ireland, this role will be carried out by the Irish Human Rights and Equality Commission (IHREC). The National Disability Authority will have a role to support IHREC with data and information. Civil society, in particular disabled people and Disabled Persons' Organisations (DPOs), must be involved in the monitoring process. (See page 12 for information about DPOs).

Civil society stakeholders may also submit a shadow report to the UNCRPD Committee which will be considered as part of the reporting cycle. Shadow reports are a way for civil society organisations (including DPOs, NGOs, or independent human rights bodies) to provide the Committee with supplementary or alternative information to that which is included in the State report.

The Optional Protocol to the UNCRPD establishes a procedure which allows individuals to bring a petition to the UNCRPD Committee in order to claim a breach of their rights under the Convention. Ireland has not yet ratified the Optional Protocol, but the Government has committed to ratifying it following the first UNCRPD reporting cycle.

UNCRPD and the participation of disabled people in decision making

The UNCRPD outlines obligations on Government for how they include disabled people in the development, implementation and monitoring of policies and legislation and other decision making processes. It applies at the local, national and international level.

Article 4(3) of the UNCRPD states that:

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

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

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

The UNCRPD Committee can also issue something known as a "General Comment" which seeks to clarify Articles in the Convention and provide practical guidance on how to implement it. These General Comments are not legally binding, but are the interpretation of the Committee on a particular Article and countries are encouraged to apply them.

General Comment No. 7 on the participation of persons with disabilities was issued in 2018 to provide States Parties with guidance on how to implement Article 4(3) and Article 33. General Comment 7 states that the rights under these Articles are civil and political rights and therefore of immediate application.¹

General Comment No. 7 elaborates on what it means to closely consult with and actively involve Disabled Persons' Organisations.²

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

¹ Social and economic rights can be implemented through progressive realisation, while civil and political rights are of immediate application.

² UNCRPD, General Comment No. 7 (2018), paragraphs 21 – 23.

What is a Disabled Persons' Organisation?

Disabled Persons' Organisations (DPOs) are a type of civil society organisation which are led, directed and governed by disabled people. A clear majority of its membership must be disabled people. The organisation should be rooted in, committed to and fully respect the principles and rights recognised in the UNCRPD. You may also see the term "Organisations of Persons with Disabilities" (OPDs) used, particularly in international documents. However, DPO is the preferred term in Ireland.

General Comment No. 7 states that Disabled Persons' Organisations are the representative organisations of disabled people. There are other kinds of organisations which work on disability rights issues, or which provide services to people with disabilities, which are not DPOs. It is important to understand the difference, because of the specific obligation under UNCRPD to actively involve DPOs in decision-making processes relating to disabled people. Other organisations can be involved, but including them instead of DPOs does not meet UNCRPD obligations. See Page 20 for more information about the role of other disability stakeholders in participation processes.

There are certain criteria an organisation must meet in order to be considered a DPO.

- DPOs should be committed to the principles and rights outlined in the UNCRPD.
- DPOs can only be organisations that are led, directed and governed by persons with disabilities.
- A clear majority of their membership should be disabled people themselves.
- They are independent of political parties, public authorities or other non-governmental organisations.
- They can represent certain impairment groups or be open to all people with disabilities.
- They can represent certain groups such as women with disabilities, children with disabilities, migrants with disabilities or other groups based on age, race, geographic location, gender and so on.
- They can be local, national, regional or international in scope.
- They can operate as individual organisations or as coalitions or umbrella organisations.

See page 17 for more information about engaging with DPOs.

What is disability?

There are many different definitions of disability. In Ireland, there are different definitions of disability contained in different legislation.³ Different legal definitions are used because they have a particular purpose under a particular law. For the purposes of the participation of people with disabilities in decision making, a social model, UNCRPD-informed definition of disability should be used, which is explained below.

³ See for example, the Disability Act 2005, the Equality Acts, the Education for Persons with Special Educational Needs Act 2004.

UNCRPD Article 1 states

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

An important part of this definition of disability is the recognition that barriers in society and in the environment prevent the full participation of disabled people. Barriers include things like inaccessible buildings, documents provided in inaccessible formats, negative attitudes and stereotypes towards disabled people, and so on.

This highlights that a person's 'impairment' is not what prevents participation. Instead, it brings our focus towards how we must remove the social and environmental barriers that prevent inclusion. This approach also recognises the importance of a disabled person's gender, class, ethnic background and other intersectional lived experiences. This approach is known as the **social model of disability**.

An older approach to understanding disability, which can often still be prevalent, is known as **the medical model of disability**. The medical model focuses on an individual's impairment as a problem to be fixed or cured. This approach sees the impairment as the reason an individual cannot participate fully, and does not examine how improving accessibility in the environment promotes the right of disabled people to participate.

Using a social model definition of disability when planning your participation process means focusing on identifying and removing any barriers to participation at all stages of your consultation process (See Section 3). Never ask someone for medical documents or proof of a diagnosis in order to take part.

What is participation?

There are many ways of understanding participation. Broadly, it means ways in which citizens can give their views and be heard in order to shape the policies, services, and processes that affect their lives. It also includes participation in monitoring how well policies, services and processes are working.

People can participate in decisions which affect them individually, for example decisions about the health, education or social care they receive. People can also participate in decisions which affect people as a group, for example in the development of national legislation and policies. This is known as public participation. These guidelines focus on this kind of collective participation.

There are different approaches to participation which vary in terms of the extent to which power over the process and outcome of the initiative is shared. In all cases, participation is never a once-off 'event'. It is a process which requires two-way communication and feedback.

Consultative approaches are often characterised as being initiated by public officials. Under this approach, the views of disabled people are sought and participants do not have control over the outcomes. Although led by public officials, this approach recognises that disabled people have expertise and experience to contribute to decision making. It's important that transparent and accessible feedback is given to participants on how their inputs were used in order to ensure that a process following a consultative approach is meaningful.

Collaborative processes are often initiated by public officials, but empower disabled people to influence the process and outcome. These processes take a partnership approach with disabled people.

Citizen-led initiatives, led by disabled people, are characterised by disabled people identifying the issue of concern and controlling the process, with public officials acting as facilitators and providers of information and advice rather than leading the process.

Different approaches may be appropriate in different contexts. All three of the above approaches can be carried out in a meaningful way. See page 23 for how to ensure the process is meaningful, whichever of these approaches is followed.

What is Universal Design?

Universal Design is defined in Irish law under the 2005 Disability Act. It is also defined under UNCRPD Article 2 as follows

"Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

At the national and European level, there is now a European Universal Design Standard that demonstrates how an organisation can be more inclusive in its decision making. This will be underpinned by the upcoming European Accessibility Act.⁴

All participation and consultation processes should be underpinned by the principles of Universal Design. This means designing a process that is as inclusive as possible from the outset, rather than trying to add it in later or having a separate, accessible 'disability process' that is additional to the main participation process. There will sometimes be a need to have focused consultation with disabled participants only, but this should not be a substitute for making all mainstream participation processes accessible.

⁴ See Appendix C, Useful links and resources.

What is Irish Sign Language?

Irish Sign Language (ISL) is a visual and spatial language with its own linguistic and grammatical structure. It is not a signed version of English or Irish. Different countries have different sign languages that are distinct from each other. The Irish Sign Language Act 2017 recognises the right of ISL users to use ISL as their native language. Under the Act, public bodies are required to provide free ISL interpretation to people using or seeking access to statutory entitlements and services.

ISL interpreters are hearing people who translate between ISL and English. Deaf interpreters are different to ISL interpreters. A Deaf interpreter is a Deaf person who works in tandem with an ISL interpreter to further translate nuances or cultural meanings which may otherwise not be understood. For example, the skills of a Deaf interpreter may be required to support with translation for Deaf foreign nationals or Deaf people with little knowledge of English.

Public bodies must only use accredited interpreters. The Sign Language Interpreting Service (SLIS) has a referral service to help organisations find an appropriate interpreter.

Section 2: Stakeholder engagement: Why, when and who



Why consult with and actively involve disabled people in decision making?

There are many reasons why the participation of disabled people in decision making is important and beneficial for your department, public body or local authority.

Participation is a fundamental right within the UNCRPD and other human rights treaties. In addition to meeting UNCRPD obligations, improved participation processes help to meet obligations under other international, European and national laws and policy commitments.⁵

Beyond meeting obligations, there are also several benefits to engaging with disabled people in decision making. It makes government more responsive to the rights of people with disabilities and makes laws, policies and services more effective by taking account of the lived experience of those affected. Good participatory processes lead to increased transparency in the development of legislation and policy which improves trust and builds relationships which last beyond the timeline of the consultation. Meaningful engagement may also lead to a sense of ownership of the topic in question by disabled people, and may lead to enhanced buy-in of the policy or strategy.

What kind of participation processes should involve disabled people?

There is a twin approach needed for involving disabled people in public participation processes.

1. Closely consult with and actively involve DPOs on issues relating to persons with disabilities

The UNCRPD is clear that DPOs, as representative organisations of disabled people, must be closely consulted with and actively involved in decision making processes concerning issues related to people with disabilities. Public authorities must systematically and openly approach, consult with and involve DPOs in a meaningful and timely manner.

Engagement with DPOs must take place on legislation and policies to implement the Convention, and in other decision-making processes relating to persons with disabilities. Other decision making processes include, for example, research projects, developing policy advice, developing strategies, guidelines, standards and codes of practice. Article 33 also says that DPOs must be included in monitoring the implementation of the Convention.

2. Persons with disabilities must have access to all the spaces of public decision-making, on an equal basis with others

Disabled people have a right to participate in any public consultation initiative that is open to citizens. That means that as standard, consultation and participation processes at all levels of government must be accessible and underpinned by the principles of Universal Design. While there is a need for disability-specific consultation on certain issues, this should not be a substitute for making all public participation processes accessible.

⁵ For example, the Public Sector Equality and Human Rights Duty, Our Public Service 2020, the European Disability Strategy, the Sustainable Development Goals, the Local Government Reform Act.

How to include DPOs in participation processes

How to contact a DPO?

There is currently no government department or organisation which keeps a register of DPOs in Ireland. This may change in future. A current list of contact information for the national DPOs which took part in the development of these guidelines is included in Appendix B.

New DPOs, both local and national, are likely to form over the coming months and years. If in doubt about whether or not an organisation is a DPO, refer to the list of criteria outlined in General Comment No. 7 (See Section 1, page 12).

Remember that DPOs may receive little or no funding. Their staff members may or may not be paid. Here are some tips for making contact:

- Make contact as early as possible in the process.
- Make sure what you are asking for is clear.
- State that accessibility and reasonable accommodation requirements will be provided.
- Include a contact phone number and email address.
- Allow time for the DPO to consider the request and respond.

How to know which DPOs to engage with?

Which DPOs, and how many you engage with, will depend on what it is you are seeking input on. Think about the objectives you want to meet through your participation process. You can use your judgement and approach the DPOs most relevant to your consultation objectives, which ensures they can meaningfully contribute. You can engage with a DPO one-to-one or you can invite them to be part of an advisory group or other structure in which DPOs engage in an initiative together. A DPO may also approach you if they have identified that they have relevant expertise to contribute.

Consider how you will reach more underrepresented disabled people through DPOs. Some DPOs have a particular focus, such as representing people with intellectual disabilities, or disabled women and non-binary people. Many DPOs in Ireland have made considerable efforts to engage a diverse membership. For example, some national DPOs facilitate groups of young disabled people, disabled Travellers, disabled migrants and disabled members of the LGBTQI+ community. Engaging with DPOs can help you to reach these underrepresented groups. You can also state in your invitation that you wish to engage diverse groups and ask DPOs to demonstrate that they draw from a range of experiences.

What to do if there is no relevant DPO or none available to participate?

It is essential to make every effort to meaningfully include DPOs in relevant participation processes. In some cases, there may not be a DPO that fits with the consultation objectives. For example, you may be carrying out a consultation on a specific local issue and there may not be a local DPO, or a national DPO with local knowledge, which can contribute. There may be a case where there is not yet a DPO in Ireland that fully represents a target group you wish to reach, such as people with a mental health difficulty or deafblind people.

Engagement with non-DPOs is not a substitute for engagement with DPOs. However, there are some situations in which you may have to adopt a pragmatic approach, particularly as the landscape of DPOs in Ireland is not yet as well developed as in some other countries. We recommend these steps:

- Do not assume that the current DPOs in operation do not have the expertise required.
 Make contact with national DPOs and identify with them whether they have the expertise to contribute.
- If they do not, try to identify collaboratively with DPOs any local groups or individuals who may be suitable to take part.

It may also be the case that DPOs 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. We recommend these steps:

- Plan your process in good time and contact DPOs at the earliest stage. Remember that many DPOs have no paid staff, so allow for this when planning timelines. Sending a last minute request does not demonstrate meaningful engagement with DPOs.
- If the planned work is not urgent, consider adjusting the timeline 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, and every effort has been made, then other channels to engage the disability community should be pursued to seek effective engagement with individuals or other organisations as appropriate.

Public officials should document their efforts to identify a DPO and a rationale for engaging with non-DPO stakeholders, if necessary.

Considering the views of DPOs

General Comment 7 of the UNCRPD states that

State parties should **give priority** to the views of organizations of persons with disabilities when addressing issues related to persons with disabilities.

The NDA interprets this as meaning that DPOs should be consulted as a matter of priority and that all efforts should be made to ascertain their views throughout the process, from the earliest stages. Due regard and consideration⁷ 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. Where limited spaces are available for a consultation which addresses disability issues, priority should be given to DPOs as representative organisations of disabled people.

⁶ Please note that some DPOs would disagree with this approach.

⁷ Please note that some DPOs would disagree that 'due regard and consideration' is sufficient to meet the standard set by General Comment No. 7 in terms of giving priority to DPOs. Please see the NDA Consultation report for further information.

When giving due weight to stakeholders' views, keep in mind that promoting and upholding disability rights must remain at the forefront. DPOs as human-rights-based organisations by nature are expected to place human rights above all else, while other kinds of organisations may have business needs that are their first priority. Where the input of stakeholders is not taken on board, feedback should be provided transparently which outlines a rationale for the decision.

The role of other stakeholder groups

Organisations of family members of disabled people

General Comment No. 7 states that

Organizations including family members and/or relatives of persons with disabilities, which are pivotal in facilitating, promoting and securing the interests and supporting the autonomy and active participation of their relatives with intellectual disabilities, dementia and/or children with disabilities, when these groups of persons with disabilities want to be supported by their families as united networks or organizations. In such cases, these organizations should be included in consultation, decision-making and monitoring processes. The role of parents, relatives and caregivers in such organizations should be to assist and empower persons with disabilities to have a voice and take full control of their own lives. Such organizations should actively work to promote and use supported decision-making processes to ensure and respect the right of persons with disabilities to be consulted and to express their own views.

Children and young people with disabilities

UNCRPD Article 7 outlines the rights of children with disabilities to express their views and have their views given due weight in accordance with their age and maturity. General Comment 7 affirms that organisations of children with disabilities are DPOs under the Convention. Adults can have a key and supportive role in promoting an environment that enables disabled children and young people to form and act within their own organisations and initiatives, including through cooperation with adults. Organisations supporting children with disabilities which facilitate their active participation can also be included on this basis.

Non-DPO civil society organisations and service providers

There are many civil society organisations such as non-governmental organisations and disability service providers which advocate on behalf of people with disabilities or highlight issues related to disability rights. These organisations are not DPOs because they are organisations 'for' people with disabilities and not 'of' people with disabilities, and they do not meet the criteria of General Comment No. 7. These organisations often have much more funding than DPOs and many have long-standing relationships with Departments and public bodies. These groups can still be involved in consultation, as they hold important and valid points of view. However, consulting with these organisations does not replace the requirement to consult with DPOs who are the representative organisations of disabled people. The views of non-DPO stakeholders should also be considered in light of any conflict of interest they may have.

The National Disability Authority

The National Disability Authority (NDA) 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 disabled people. We sit on several advisory and working groups in various Departments and agencies, but we do not seek to sit on them at the expense of representative organisations. While the NDA's advice is always informed by our own consultation efforts with DPOs, disabled individuals and other stakeholders, engaging with the NDA does not replace the requirement to consult with DPOs.

Disabled Individuals

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 disabled people and offer a view that is representative of and accountable to their members. However, individuals have the right not to join an association. General Comment 7 also states that disabled people should be able to decide for themselves which organisations they want to represent them and that the existence of umbrella organisations should not hinder individuals from participating in consultations. Engaging with disabled individuals outside of a DPO structure does not replace the requirement to consult with DPOs. However, there may be contexts in which individuals will have specific local knowledge or lived experience which adds particular value to a consultation.

⁸ UN (1948) Universal Declaration of Human Rights, Article 20. The Declaration is recognised in the Preamble of UNCRPD.

Section 3: Participation in practice



Principles of meaningful participation

Participation processes can take many forms, such as working groups, a call for submissions, or a consultation on a particular policy or law. No two processes will look the same. However there are key principles which should underpin any process.

- **Genuine**. There is a commitment to really listen to stakeholders and follow through on recommendations. A clear rationale is provided when recommendations cannot be implemented. Adequate resources are allocated to the process and to implementing the recommendations.
- **Timely**. Stakeholders are engaged from early in the process when they can still have an influence. There is adequate time for stakeholders to prepare and time to respond with their input.
- **Accessible**. The process, materials and environment are accessible to the greatest extent possible by all people. Public officials who are responsible for the participation process understand accessibility, Universal Design, and the social model of disability.
- **Ongoing**. The process is not seen as a once-off event. Feedback is given to stakeholders about how their inputs were used. Consideration is given to how to build and maintain relationships with stakeholders.
- **Transparent**. The process is transparent. Public officials document their rationale for the stakeholders they engage with and the participation process they followed. The outcome of the process is transparent. A rationale is provided for recommendations not taken on board. Outputs, such as reports or minutes, are published in accessible formats, and circulated to stakeholders.

It is also important to know when participation is not meaningful. **Tokenism** happens when organisations want to appear to have engaged with disabled people, or any underrepresented group, but have not done so meaningfully. Tokenism can also happen accidentally when officials lack the understanding of how to meaningfully engage with stakeholders. Below are some examples of tokenism to avoid:

- Disabled participants are consulted too late in the process, when all or most of the decisions have already been made.
- Disabled participants do not have all the information they need in a format that is accessible and understandable to them in order to make an informed contribution.
- Disabled participants have not been informed of the objective of the consultation or how their inputs will be used.
- The views of disabled participants are edited or used to fit into a prescribed view that the consulting body already wishes to take.
- The views of participants with disabilities are not taken on board and no rationale is provided.
- Disabled people are used for a photo opportunity to launch a new policy, service or product but disabled people have not been involved meaningfully in the design.

See Appendix A for a Meaningful Participation Checklist.

Steps for an effective participation process with disabled people

Every participation process will look different and the focus should be on real engagement. Being flexible and adapting the process when needed can be more effective and inclusive than being restricted by a set process.

When planning, it is helpful to think about your process using the following stages.

- 1. Pre-planning
- 2. Planning
- 3. Active engagement
- 4. Analysis
- 5. Feedback
- 6. Taking action
- 7. Evaluation
- 8. Monitoring
- 9. Dissemination

1. Pre-planning

Participation processes work best when supported by a culture of participation across the whole organisation. The pre-planning stage means asking the strategic questions about how participation processes will work most effectively across your Department, public body or local authority.

If you do not have responsibility for these areas in your role, it is still helpful to ask these questions to understand where your participation process may have limitations or where there may be opportunities to share learning.

Obligations and commitments

Think about the legal obligations and policy commitments that the planned participation process can help your Department, public body or local authority to meet. There could be opportunities to join up processes or share learning internally to meet various objectives at the same time. This also makes good use of stakeholders' time.

Senior leadership support

Senior leadership support is needed for participation processes to be most effective. Adequate financial and staff resources need to be allocated to the process. Buy-in is also needed so that recommendations from stakeholders can be implemented.

Communicating how a participation process will help to meet various obligations and commitments can be a way to build support. Some Departments and public bodies have added 'Participation' as an objective in their strategies or developed a participation charter for the organisation.

Staff training

Think about which staff members will be involved, at all levels, in the participation process with disabled people. Has adequate training been provided to them?

Disability Equality training is essential to ensure staff are properly prepared. The term 'Disability Equality' is used here instead of 'Disability Awareness' in the context of training. Disability Equality training goes beyond staff awareness of disability towards a social model and human rights based approach which examines the environmental, social and attitudinal barriers which prevent the full participation of disabled people. Staff should understand how to make the process as accessible and inclusive as possible by removing barriers to participation. Training also helps to combat negative attitudes towards disabled people and low expectations. Such training should ideally be led by, or at least include, disabled people. Officials may also benefit from training or peer learning on the use of participatory methods, inter-cultural awareness and communication.

Depending on the context, there may be a need for tailored training which includes additional elements. For example, those working in city planning may need an understanding of tactile maps. Assess what skills are needed for your context. It's also important to consider how this knowledge will be retained within the organisation.

Capacity building of participants

Not only do public officials require training and capacity-building, but the disabled participants involved in a participation process may also require capacity-building opportunities to enable them to have an effective seat at the table. Depending on the nature of the participation process, there are different ways of providing capacity building support. For example, it could include holding a preparation day in advance in which participants learn about the various mechanisms and process that allow people to influence policy. You could consider working with and funding DPOs or other partners with specialist knowledge to provide capacity-building support to participants in their areas of expertise.

Relationship with stakeholders

The relationship and trust with stakeholders can set the tone for how they will respond to the participation process. Running a transparent and inclusive process and providing feedback will contribute to building trust. Consider whether a long-term plan is needed to build and maintain a relationship with this community.

Timeframes

Timeframes are an important consideration for an effective participation process. Think about the year ahead. If there are initiatives coming up which will require a participation process with the same stakeholders, consider how the timing may impact on their capacity to contribute.

Coordination and collaboration

Coordination and collaboration, both internally and across Departments, public bodies, and local authorities, is another important consideration. Consider how you will share learning from your participation processes with other colleagues internally and externally. Consider asking colleagues for advice or feedback on your planned processes.

2. Planning

The planning stage is when you will identify the purpose and scope of the participation process, the stakeholders to engage, the resources available, the method of participation, how you will address accessibility requirements and practical matters such as managing participant's data, as well as how you will give feedback and follow up on any recommendations.

Defining the purpose and scope of the participation process

Make sure the participation process has a defined objective. For example, it could be a consultation linked to a specific policy issue. For a working group it might mean developing a clear terms of reference. Sometimes the scope will need to be set by the consulting body alone. This means the process will take more of a consultative approach. You can also set the scope of the participation process together with participants to move more towards a collaborative participation approach. For example, working group members could be invited to jointly develop the terms of reference.

Plan how you will ensure that participants are fully aware of how the process will work, any limitations, expected timelines, what will happen with the information they provide and how they will be kept informed during and after.

Identifying the timeline

There are many different elements to consider when planning the timeline of a participation process. Some considerations include:

- Time to prepare the invitation and materials in accessible formats.
- Time to allow DPOs and other relevant stakeholders to consider the request and respond.
- Time to arrange for accessibility requirements to be provided for meetings or workshops.
- Flexibility in the timeline in case you need to adapt the participation process.

Identifying the resources needed

It is important to plan for any costs from the outset. Things to consider include:

- Providing accessible information in different formats. For example, you may need to go to an external provider to produce an easy-to-read document, a Braille document, or a video.
- ISL interpretation. This could be needed for meetings, or you may need a video translation in ISL for survey questions or reports.
- Support person. A person with a disability may require or prefer to bring a support person to a meeting. Consider the transport and subsistence costs of the support person in addition to the participant.
- Transport. If holding an in-person meeting, be aware that inaccessible public transport is a barrier to many disabled people. Providing payment for taxis or mileage can reduce this barrier.

- Other expenses. Besides travel and subsistence, there are other costs that may need to be covered in order to support the participation of disabled people.
- In some cases, Departments, public bodies or local authorities may wish to provide funding to a DPO to carry out consultation with their members. This can be a good approach in terms of collaboration and partnership with DPOs.

Payment of expenses

Expenses incurred by participants should always be paid in order to reduce barriers to participation. Across the public sector, it is common to reimburse travel and subsistence costs. However, there are other expenses that may cause a barrier to participation for disabled people. To make consultation processes as inclusive as possible, we recommend other categories be made eligible for payment of expenses under local arrangement within Departments where possible.

Recommended expense categories include:

- Travel and subsistence.
- Printing and ink (if not providing hard copies of documents).
- Personal Assistance hours.
- Costs of care, including childcare, eldercare, care of a disabled person.

It is not currently practice in public sector organisations to pay people for their participation even when they are not paid by their organisation. However, some DPOs have called for this. There are also administrative barriers faced by public officials in many cases in relation to the payment of individuals taking part in public consultation processes. The NDA advises that a more sustainable solution for the long term is for consistent State funding to Disabled Persons' Organisations to be provided. This approach would contribute towards strengthening the capacity of DPOs to participate in policy making.

Data storage

Plan how you will collect and store data such as personal information or survey responses in line with the General Data Protection Regulation (GDPR). This need not be a barrier to consulting with stakeholders. Under GDPR, the legal basis does now exist to allow public bodies to process equality data.⁹

⁹ IHREC (2020) <u>Public Sector Equality and Human Rights Duty Tool for a Consultative Approach</u>, page 13.

Identifying stakeholders

When you are planning a participation process around a policy, law, or other issue relevant to disabled people, directly or indirectly, it is essential to target DPOs as set out under UNCRPD Article 4(3). Refer to Section 2 for more information about the role of various stakeholders.

Below are some points to consider when identifying stakeholders:

- Which DPO(s) are most relevant to contact?
- How will the process ensure underrepresented disabled people are included?
- Who is directly impacted by this decision?
- Who is indirectly impacted?
- Which other Departments, agencies, organisations or groups may need to be involved?

Inviting stakeholders

- See page 18 for information on contacting DPOs.
- Give enough notice so that stakeholders have time to consider the request.
- Think about the best channels through which to advertise the invitation to participate. Is the invitation and the process of responding to it accessible?
- Think about the language used. Is it appropriate and respectful? See page 38 for guidance on language.
- The invitation should include information about the purpose of the participation process.
- It should state that accessibility requirements will be provided for and ask participants to respond with any additional requirements.
- It should also provide clear information on confidentiality, how the information gathered will be stored and who will have access to it.

Planning the next stages of consultation and active involvement

It is important to look ahead at this stage to the next stage of your consultation and ensure you have a plan in place for each. These include:

- Choosing the method of participation (see page 29)
- Identifying and planning accessibility requirements (see page 31)
- Choosing your method of feedback (see page 34)
- Choosing your method of analysis (see page 35)
- Choosing your method of evaluation (see page 35)
- Considering how you will disseminate the outputs, such as publications or minutes (see page 36).

See Appendix A for a Participation Planning Checklist.

3. Active Engagement

This section outlines some common methods of participation. As you consider the methods you will use, it is also essential to identify any accessibility barriers that these will present for participants. This is further explained on page 31.

Choosing the methods of participation

The methodology you use will depend on your objectives and the stakeholders you wish to engage. You may need to use more than one method to allow participants choice over how to engage. For example, some people may be happy to take part in online meetings, but this method may exclude others. Ask who might be left out and identify any barriers they may face in order to participate. Consider if different approaches or additional resources are needed. It can also be effective to consider a partnership approach, in which DPOs are involved in designing, organising and leading the participation process.

Some suggested approaches include:

- Membership of advisory, steering or working groups
- One-to-one meetings
- Submissions process
- Surveys
- Creative approaches
- Focus groups
- Online meetings and events

Advisory, Steering or Working Groups

Working groups, Advisory groups or other committees can be used for ongoing consultation on a strategy, policy, project or other initiative. The group should have a clear terms of reference. It can be helpful to develop this together as a group. It is good to review membership of committees periodically to ensure there are opportunities for new members to join.

One-to-one meetings

One-to-one meetings with a DPO or other stakeholder can allow you to go deeply into an issue or topic in order to examine an issue. Some DPOs, organisations or individuals may prefer to engage one-to-one rather than as members of a group structure.

Submissions process

The public consultation guidance published by the Department of Public Expenditure and Reform¹⁰ outlines detailed information about running a submissions process. There are some additional considerations for ensuring these processes are inclusive of disabled people. For example:

• Submissions information should be available in accessible formats, including Word, braille, easy-to-read, Irish Sign Language video with captions.

¹⁰ Department of Public Expenditure and Reform (2016), Public consultation principles and guidance.

- Accept submissions in different formats, in addition to traditional written submissions.
 Some people with disabilities might find it difficult to submit a written document but would be able to send in a video or audio file with their opinion, or respond using an easy-to-read form.
- Consider accepting submissions by post, email, or mobile application such as Whatsapp or similar.
- Make sure there is a facility to receive video files. Give guidance on the length of the video. As a general rule of thumb, 5 minutes is equivalent to about 500 words.
- Consider the length of video files and the time it will take for respondents to transfer it. Asking respondents to send a separate video for each question can cut down on the file size making it easier to send.
- If you expect to receive videos in Irish Sign Language, make sure you allow time for these to be translated into English after you receive them.
- Submissions processes with short timeframes make engagement difficult. The more notice that is given, the more of a chance that considerable feedback can be obtained.
- Consider the timing of the submissions process. Holding them during summer months or over public holiday periods such as Christmas is likely to reduce engagement.

Surveys

Surveys can be used to gather information on a larger scale. Some considerations when using surveys include:

- Strike a balance between the information to be gathered and the time it would take someone to complete the survey. It is also important to consider the time it will take to analyse the results.
- If using an online survey tool, make sure it is accessible. It should be usable by a screenreader. It should support the addition of videos to allow for ISL translation.
- Use plain English when writing survey questions. Surveys can also be developed in easy-to-read format.
- Provide clear instructions at the start of the survey.
- List questions in a logical order.
- Group similar questions together under a useful heading.
- Avoid unnecessary or repeated questions.

Creative approaches

Creative approaches can be a good way to get information non-verbally and without requiring participants to write. For example, the use of creative-writing exercises, drama, photography, videos, or drawing can be effective.

Focus Groups

Focus groups generally include no more than seven to eight people per group. It is a method in which a topic can be discussed in a relatively in-depth manner, and if facilitated well, it can be an effective way to generate discussion from various perspectives. It can also be used as a way to provide feedback.

Online meetings and events

Holding a consultation meeting or event online has benefits for many people. It reduces certain accessibility barriers such as inaccessible transport, or sensory stressors associated with travel or attendance in-person. It can be less costly and allow people to manage their time better. It can allow for greater geographic participation as people may attend from anywhere.

It is also important to remember that not everyone wants to or can engage online. Be aware that the 'digital divide' affects the access of disabled people, people living in rural areas, and members of other communities to the internet and technology. It is best to offer various ways, online and offline, for people to engage so they can choose which forum suits them.

The NDA Customer Communications Toolkit contains a supplement with guidance on running an accessible online meeting, including an accessibility checklist. 11 See Section 4 of these guidelines for more information about facilitating an online meeting.

Identifying and planning accessibility requirements

Identifying accessibility barriers that may arise throughout each stage of the participation process is crucial in order to support the participation of disabled people on an equal basis with others.

UNCRPD Article 9 outlines the right of disabled people to accessibility. It includes access to the physical environment, transportation, information and communication, technologies and systems, and to other facilities and services provided to the public.

It is important to identify accessibility requirements with participants. Two people with the same impairment may have different accessibility requirements. One person's accessibility requirements may conflict with those of another person, and therefore solutions should be identified together with those involved. Remember that some participants may have more than one impairment.

Accessible venue

When planning an in-person meeting or event, it's important to visit the building yourself to carry out an accessibility audit. A venue may meet the requirements outlined in Part M of the Building Regulations, but this does not mean it is accessible for all people with a disability. For example, modern power wheelchairs can be wider than certain space requirements outlined in the Part M regulations.

Accessibility includes physical access to the building, within the building, toilets and other facilities including coffee/lunch spaces, accessible parking, availability of accessible transport to the venue, signage, space for service animals, wheelchairs and assistive devices, sensory considerations, and providing adequate information to participants in advance. Ideally it is advised to include disabled people as part of carrying out this audit.

¹¹ NDA (2022), <u>Customer Communications Toolkit for the Public Service – A Universal Design Approach. Supplement on online meeting accessibility.</u>

When choosing a venue, consider also how the setting may impact on participants. For example, it may be better to avoid using clinical spaces or a venue in which participants access disability services.

Accessible online meeting platform

For online meetings, it's important to make sure the meeting platform is accessible. Most online meeting platforms have accessibility information on their website. Check that the platform complies with WCAG 2.1 Standards and EN 301 549 accessibility requirements. If in doubt, Always ask your participants if the chosen platform is accessible to them. Be aware that there is a legal obligation on public bodies to make sure websites and applications are accessible. ¹²

You may choose to work with an external company to manage your event and provide a virtual platform. It is important to make sure the company fully understands accessibility. Don't take their word for it – ask specific questions about the accessibility features provided and arrange a demonstration in advance.

Accessible information

People cannot participate meaningfully in decision making if they are not fully informed of the options available to them and the implications of those options. Publishing reports, submissions, forms, surveys and other documents in accessible formats is essential so that everybody has access to the information they need. Accessible information must also be provided in a timely manner to ensure people have enough time to process the information and to formulate a response.

The EU Web Accessibility Directive also applies to most types of content including; file formats (Word, PowerPoint and PDF documents), videos, and forms.¹³

Some common types of accessible information can include:

Accessible Word document. Many blind and partially sighted people use screenreader technology to read a document. You do not need any complex technical skills to create an accessible document in Word. By using 'Styles' to create a system of headings and subheadings, a person can use their screenreader to jump through different headings to get to the part they need to read. If there are images or tables in the document, you must include a simple 'Alt text' description so that the reader can understand the image.¹⁴

¹² The European Union (Accessibility of Websites and Mobile Applications of Public Sector Bodies) Regulations 2020 was transposed into Irish law on September 25th 2020 and requires public sector bodies to take necessary measures to make their websites and mobile applications accessible.

¹³ European Union (Accessibility of Websites and Mobile Applications of Public Sector Bodies) Regulations 2020.

¹⁴ There is a step-by-step guide on how to create an accessible Word document in the <u>NDA's Customer Communications</u> <u>Toolkit for the Public Service – Universal Design Approach</u>.

Braille document. Braille is a system of reading and writing using raised dots which are read by touch. Some blind and partially sighted people, and some deafblind people, prefer Braille and may request this format. Some things which are difficult to describe and understand in audio, such as tables and diagrams, can be easily read by Braille readers. There are two types of English Braille – Standard English Braille (SEB) and Unified English Braille (UEB). UEB was developed to make a standardised Braille code for the English-speaking world. It was introduced in Ireland in 2013. There are some people who learned to read Braille prior to 2013, who prefer to use SEB format. ¹⁵ If you are producing a document for an individual, check which type of Braille they use.

Large text document. A document with large text can make information more accessible for some partially sighted people.

Easy-to-read document. This kind of document uses a combination of plain language and visual images. It is often used by people with an intellectual disability. It also supports people with low literacy levels and people who prefer visual information. The easy-to-read format can be used for any kind of document including large reports, forms, and surveys. Creating these documents is a specialised skill and best practice dictates that a person with an intellectual disability reviews the document for clarity.

Irish Sign Language video. People who use ISL as their primary language have a right to access public information in ISL. This means providing video versions of reports, forms, surveys and other kinds of information in which an interpreter signs in ISL. Contact the Sign Language Interpreting Service to be connected with a qualified interpreter. Allow at least two weeks to arrange for a video translation, depending on the size of the documents. Remember that ISL users will also need to respond to forms and surveys in the same language, so make sure you have the facility to accept video responses.

Visual and audio. Visual aids, audio or video can be used to complement or substitute for written information. Activities that are supported by visual information are more easily accessible for everyone, for example, pictures, mind maps, visual timetables and 'talking mats'.

Swell symbols are tactile raised lettering or pictures. This is used by some deafblind people.

Accessible communication

People with disabilities may communicate in different ways and consulting bodies should facilitate the choice of the participant to communicate in the way that works best for them. Work with participants to identify their communication preferences. You can find some examples in Section 4 of these guidelines.

 $^{^{15}}$ Note that SEB is no longer produced in Ireland but may be sourced from Northern Ireland or Great Britain.

Accessible Social media

Often social media is used to share information about a consultation process or to launch reports or other outputs. Some disabled people have more challenges than others when it comes to accessing social media. Make sure your social media posts are accessible. ¹⁶ Consider who you might not be reaching through social media and plan alternative ways in which you will share the information with them.

Timeframes

Time is an important accessibility requirement in participation processes. Public officials have to balance moving policy forward with allowing enough time for participants to engage in consultation. Some limitations on the timing and length of consultation may be unavoidable. However, often the time given is not sufficient for disabled people to be meaningfully involved. Plan adequate timeframes from the start.

Pace of meeting

It is important to consider the pace of the meeting. The pace of the meeting will depend on the individuals taking part. For example, Deaf participants cannot passively listen like hearing people, and therefore need breaks from actively following the interpretation. Similarly, a person who communicates non-verbally may have a lot to share but may need more time to do so.

4. Feedback

Feedback is a very important part of the participation process. When participants take part in a consultation and do not hear how their inputs were used (or not used), or if participants in a working group are not clear about how their inputs contribute to the decisions of the group, it risks creating cynicism, disillusionment and 'consultation fatigue' among participants. Consider in your planning how you intend to keep stakeholders informed during and after the process.

Feedback should be given during the process to provide an update, particularly for longer-term processes. It should also be provided at the end of a process to inform participants regarding how consultation inputs were used. It may not be possible to implement every recommendation, but outlining a rationale and recording the decision publicly supports transparency and trust-building.

There are different ways that feedback can be provided, depending on the nature of your participation process. Public bodies should be able to provide feedback directly to DPOs who take part in participation processes, in so far as is practicable. Remember that feedback should be given in a format that is accessible to participants. This may mean using more than one method. Methods of feedback could include:

- Host a feedback meeting with participants.
- Prepare a consultation report in an accessible format. Feedback can be grouped into themes rather than directly responding to each organisation or individual.

¹⁶ See the NDA's Customer Communications Toolkit for the Public Service – Universal Design Approach.

- Have a dedicated webpage for consultation updates.
- Feedback can be disseminated through existing participation structures such as Public Participation Networks or local community groups.

Providing feedback should not create an unreasonable burden on time or resources. Particularly in cases in which a large number of submissions or other inputs are received, it may not be possible to get back to every individual. Where relevant, it can help to set expectations for this at the start by including a line in all communications during the consultation phase that clearly states "We will not be in a position to respond to all submissions individually". Then indicate how you intend to provide feedback in another way.

5. Analysis

During the planning stage, think about whether there will need to be an 'Analysis' stage. For example, this will apply to those carrying out a submissions process, focus groups or other kind of consultative process, or for working groups which intend to produce a report. Some considerations when it comes to analysing inputs include:

- When aggregating consultation findings, upholding rights must not be undermined by
 majority opinion or budgetary concerns. Rights are protected under law. In a consultation
 process, if the majority of stakeholders support a certain position, but that position goes
 against other's legal rights, then the rights-based position must be favoured even if those
 supporting it are in the minority.
- Take care when amalgamating feedback into themes to ensure that specific issues, although perhaps only relevant to a minority, or very specific groups, receive due attention.
- Do not take consultation inputs out of context or alter inputs to fit a prescribed narrative.
- There may be contexts in which it is appropriate to include consultation stakeholders in carrying out the analysis, especially if you wish to move towards a more collaborative participation approach.
- It is advisable, where possible, to share the analysis with stakeholders before circulation of the final output in order to validate them.

6. Take action

Listening and taking action is an important step to ensure participation and consultation processes are meaningful. This includes allocating sufficient time, resources, and personnel to implement recommendations. Consider the use of short, medium, or long term objectives or targets which can be implemented.

7. Evaluation

Evaluating a participation process is a great way to capture good practice and identify areas for improvement. Ideally, the process should be evaluated with your stakeholders and the learning applied to future processes. Below are some suggested approaches.

- Use the participation planning process checklists within these guidelines (see Appendix A) as an assessment tool by choosing the most relevant questions and sharing these with your stakeholders in a survey or other format.
- Assess the scope of participation by looking at the point of engagement and the level of engagement. The point of engagement refers to how early in the process stakeholders were involved. The earlier they are involved, the greater their level of influence. The level of engagement refers to whether the process was consultative, collaborative or citizen-led (See page 14).
- Assess the outcomes by referring to the objectives that you set at the beginning of the
 participation process. This will guide the indicators to be used to measure the extent to
 which the process met the objectives.

8. Monitoring

Public authorities can involve stakeholders not only in the development of a policy, law or service, but also in monitoring how well these are working once they are implemented. Involving stakeholders in monitoring activities strengthens accountability by allowing stakeholders to examine whether the policy, law or service is delivering effective outcomes for its target population. Monitoring structures could include a working group or committee or other similar mechanism.

9. Dissemination

Depending on the kind of participation process you followed, there is likely to be some kind of output such as a report, a video, results of a survey, or meeting minutes from a working group which should be shared. Consider which accessible formats will be needed for publication. All accessible versions of a document must be published on the same day, so that everyone receives the information at the same time.

Some common ways to disseminate outputs include:

- Sharing on social media.
- Publishing documents on your organisation's website in accessible formats.
- Emailing participants and other relevant contacts with the information.
- Inviting stakeholders to attend or co-create an event to launch a report.
- Informing participants when and where the outputs will be shared (e.g. on a particular date, on a dedicated webpage).

Section 4: Good practice for inclusion of disabled people



How to speak and write about disability

The words we use can communicate our respect for disabled people or they can reinforce negative and discriminatory stereotypes. People with disabilities may choose to identify in different ways. Non-disabled people may feel unsure that they will get it right, but if in doubt, it is always best to ask the disabled people concerned.

'Person with a disability' or 'disabled person'?

Some people prefer to refer to themselves as a "person with a disability" while others prefer the term "disabled person". These approaches are often called "person-first" language and "identity-first" or "social model" language respectively.

Person-first language (e.g. "person with a disability") places a reference to the person before the reference to the disability. This approach emphasises that a person is first and foremost a human being entitled to human rights, and is the language found in the UNCRPD. Some people with disabilities prefer this approach. In particular, many people with intellectual disabilities and people with mental health difficulties or psycho-social disabilities¹⁷ use person-first language. But, it's important to know that person-first language is not preferred by all.

Some people prefer "identity-first" or "social model" language (e.g. "disabled person", "autistic person" etc.). People who follow this approach, state that it emphasises that disability is caused by barriers in the environment and in society, rather than the person's impairment. This reflects a social model approach to disability, which shifts the focus from 'fixing' the individual and their impairments towards creating a more inclusive society through changing attitudes and improving accessibility for all.

It is also important to note that some disabled people/people with disabilities do not identify with either term. For example, many older people with an impairment, people with hidden disabilities (including mental health difficulties), and members of the Deaf community do not necessarily identify as disabled people.

Language and the Deaf community

Members of the Deaf community who use Irish Sign Language (ISL) as their preferred language identify as a cultural and linguistic minority group, rather than as people with a disability. There are also deaf and hard of hearing people who do not use ISL, who may or may not identify as disabled. Deaf is sometimes spelled with a small 'd' (deaf) or a capital 'd' (Deaf) to make a distinction between those who use ISL and those who do not.

Deaf with a capital 'd' refers to all people who are deaf or hard of hearing who identify culturally as Deaf, including those who have cochlear implants or hearing aids. This group uses Irish Sign Language as their preferred language. When spelled with a lowercase 'd', this refers to those who have other preferences of communication including English, lip-reading, and writing, and may not use Irish Sign Language or be involved in the Deaf community. In

¹⁷ Ireland's national mental health policy, Sharing the Vision, uses the terminology 'mental health difficulties'. The UNCRPD uses the term 'psychosocial disabilities'.

some cases, the term 'd/Deaf' is used. The use of both the lowercase and uppercase 'd' in this instance refers to all those who identify as culturally Deaf and those who do not. The NDA acknowledges that preferences vary among individuals.

General principles on disability language and terminology

1. Take a contextualised, flexible approach

The NDA recognises both "person with disability" and "disabled person" as valid and legitimate terms. In recognition of varying preferences, the NDA adopts a flexible approach, using both terms interchangeably. Departments and public bodies may consider adding a statement to their documents explaining their choice of language. You can find examples of such statements in the NDA's advice paper on disability language and terminology.

2. Ask people about their preferences

Disabled people are not a homogenous group and may choose to identify in various ways. Furthermore, language changes and evolves over time. DPOs are the organisations best placed to advise with regard to the most up to date language. Many national DPOs have guidelines on language on their websites which were developed collectively with their members. The views of some DPOs may differ from others. A flexible approach which is respectful to all can be adopted. If engaging with a disabled individual in a consultation or meeting, it is always best to ask a person their preference with regard how to refer to them.

3. Avoid medicalised language

Disability is not a health condition that needs to be fixed or cured. Unless in a relevant setting, medical language should not be used. For example, people with disabilities should not be described as "patients" unless under medical care. Neither should disabled people be labelled by a diagnosis. For example, the term "Autism Spectrum Disorder" is offensive to many in the autism community. Instead you can say "autistic person".

There are some settings in which medical language may be appropriate. For example, in a clinical setting or in reference to specific legislation. However, the use of medical language should be limited to those contexts in which it serves a specific and relevant purpose.

4. Avoid stereotypes

The NDA is aware that for many disabled people, using words such as "inspirational" or "courageous" to describe a disabled person doing day-to-day activities, while well-meaning, can imply that it is unusual for people with disabilities to be successful or live a fulfilling life. Similarly, describing someone as having "overcome" their disability can be patronising. Disabled people can and do have the same interests, abilities and achievements as non-disabled people.

¹⁸ Department of Housing, Local Government and Heritage (2022) <u>National Housing Strategy for Disabled People 2022 - 2027</u>, pg. 1 'Disability Terminology'.

Disabled people are often included in the category of "vulnerable groups" in policy frameworks and strategies both internationally and nationally. However, it is important not to depict disabled people as inherently vulnerable. People with disabilities become vulnerable because of the disabling barriers in society, rather than because of an individual's 'impairment'. This approach shifts the perspective from paternalism and protection towards empowerment and the recognition of disabled people as rights-holders.

5. Avoid euphemisms

Euphemisms such as "differently abled" and "dis-ABILITY" (with 'ability' emphasised in capital letters or bold text) can be seen as condescending by some disabled people. While the intention may be to focus on an individual's strengths, it can result in taking the focus away from the social and environmental barriers that create a disabling environment for an individual.

6. Avoid negative language

It is important not to depict people with disabilities as objects of pity. Terms such as "suffers from", "afflicted with" or "wheelchair bound" are inappropriate. They depict disabled people as powerless and suggest a poor quality of life. It also directs the focus towards the individual's impairment instead of highlighting the lack of inclusion or accessibility within the environment or society. Instead, you can say that a person "is disabled", "has a disability" or "uses a wheelchair". Similarly, describing a person's disability in terms of a "disorder" has negative and stigmatising connotations and should be avoided.

Guidance for Chairs and facilitators

Using respectful language must go hand in hand with inclusive behaviour and attitudes. If you are not used to working with disabled people, there are certain inclusive practices with which you may not be familiar. These examples are not exhaustive, but are meant to give an overview of some common ways to include disabled people.

Before the meeting

- Disabled people often have to go to a lot of effort to understand if a process or venue is accessible or not. It is helpful to outline to participants in advance the accessibility measures which will be in place so that they can more easily determine if it is accessible to them. Ask participants to inform you in advance if they have any additional requirements besides those measures already outlined.
- In a group, one person's accessibility needs may conflict with those of another person. Solutions can be found by discussing these together, so allow time for this in advance or at the start of a meeting or workshop.
- Consider the timing of the meeting. For example, some disabled participants may not be able to join during office hours if they are working or in education. Some people have access to their PA only during certain hours, and others may only have internet access while attending a disability day service which has certain opening hours.
- Ensure relevant information is provided in accessible formats as required by participants. Send out documents with sufficient time for the participant to prepare. One week is

- considered the minimum for good practice. However, some people need more time to process information and may require a longer timeframe.
- Remember that it may take some time to prepare accessible documents, so factor this into your planning.
- Don't overload the meeting agenda. More time may be needed to cover the business
 of the meeting while accommodating accessibility requirements. Make sure to schedule
 breaks.
- Consider offering a blended meeting. This can allow participants to choose whether to join in person or online which can facilitate greater inclusion.
- If a disabled person travels to an in-person meeting with a PA or a family member present, it can be difficult to maintain privacy in that situation. Providing an option to join online is a possible alternative, if it is what the participant prefers.
- It's not generally recommended to separate participants into different groups based on their impairment, but there can be exceptions to this. For example, if participants request to be in the same group as those with the same impairment then it is respectful to facilitate that.
- Separating participants by impairment, unless it is their stated preference, could
 perpetuate a medical model approach which defines people in terms of their impairment.
 In addition, some people may have more than one impairment, and would be required to
 choose between them in order to participate.

During the meeting

- Chairs or facilitators should be guiding the discussion, but their voices should not dominate the consultation space or make it difficult for disabled people to contribute.
- It is helpful to begin the meeting by outlining the housekeeping guidelines for the meeting. These can also be sent out in advance and checked with participants at start of the meeting.
- Be welcoming and supportive. While some participants may have experience working with public officials, some may not.
- Be open to other viewpoints. When disabled participants share their lived experience, and/or analysis of the issues under discussion, it will add value to your work.
- Let participants know how their inputs will be used and recorded and whether or not it is confidential.
- Avoid using jargon and acronyms. If you must use them, explain them clearly first.
- Speak directly to the participant and not to their Personal Assistant, carer, interpreter or support person.
- Ensure that participants do not speak over one another. This can make things very difficult for interpreters and participants. Speaking one at a time makes it easier for everyone to follow.
- Ensure everyone has a chance to engage. The facilitator should pay attention to who is sharing and who is not. Create space for people to participate by calling on those who have not spoken yet. It can be helpful to name a few quieter participants at once so that someone does not feel singled out.

- Be mindful that some people may require more time than others to make their contribution. Be patient and supportive of participants who require this.
- Stick to the scheduled meeting time and ensure there are adequate breaks. Sitting in a meeting or event, either offline or online, can be very tiring and also physically uncomfortable for some people. You can ask participants what kind of break schedule suits them. As a general rule, for long meetings of two hours or more, schedule a fifteen minute break. Consider also scheduling short three minute 'stretching breaks' intermittently to allow people to move their bodies.

For online meetings, there are some additional things to consider.

- Ask participants to mute when not speaking. This is to minimise any background noise which can be distracting for participants and difficult for interpreters.
- Have a plan for dealing with technical issues. It is best to identify a colleague who will
 help with technical issues that may arise during the meeting. It is also good to provide the
 contact details of a staff member who is knowledgeable about technology in advance of
 the meeting, so that if any participants are in need of support prior to the meeting they
 will be able to receive the assistance that they require. Allowing participants to log on ten
 minutes early can also help ensure that any technical issues can be addressed.
- Have a plan for how participants will use the chat function. There are some benefits to using the chat, such as allowing people who cannot communicate verbally another way to engage or allowing people who feel nervous to interject a way to more comfortably contribute. However, it can also be very distracting for participants who use a screenreader. The screenreader reads the chat aloud to the participant which can make it hard to follow the conversation taking place at the same time. It is not necessary to turn off the chat function, but it can be helpful to ask participants to minimise the use of the chat. For example, by using it only for questions to the group and not to say hello or have conversations with other participants.
- Consider how participants will use the "raise hand" function. Most platforms offer a "raise hand" button which allows people to signal when they want to ask a question. Using this function can help keep things organised and reduce the uncertainty of knowing when to interject. However, some participants may not be able to use the "raise hand" function. For example, participants using a screenreader may have trouble using this. It can also cause issues for Deaf participants using ISL interpretation. When participants use the "raise hand" button it can cause the ISL interpreters move around the screen, which is distracting. Participants can agree to an alternative such as raising their actual hand, sending a message to the Chair or facilitator, or unmuting and briefly indicating they have a question or contribution to make.
- Allow participants to keep their camera switched off if they prefer.

After the meeting

• Ask for feedback. Encourage participants to share feedback about how the meeting went for them. You could share a link to a short survey, do a poll at the end of an online meeting, or ask participants to email you with their feedback. This will help you understand what is working well and what can be improved for next time. It also helps

- build trust with participants that their full participation is important to you.
- Allow participants to follow up with any other points during a set time period (e.g. 1 to 2 weeks) after the meeting. Some people will appreciate having more time to process the information. It also reduces the pressure on participants if they know they have another opportunity to share points that may come to them later.

Further inclusive practices for Chairs and facilitators

Further inclusive practices are outlined below with additional detail relevant to persons with different impairments. It does not mean that every person will want or require all of these things. Support should always be identified with the person, not for a person. Each disabled person, even with the same impairment, may have different accessibility needs. Remember that some people may have multiple impairments.

Participants with a physical impairment

A participant with a physical impairment may be prevented from accessing the meeting space or from engaging in certain activities unless they are accessible.

- Make sure the venue itself is accessible. This includes the registration area, meeting space, lunch/coffee areas, and the toilets.
- Ramps must in place where there are steps and the slope must be appropriately graded.
- There must be accessible transport to the venue and accessible parking available for those who use private transport.
- Provide information regarding the terrain at the venue (e.g. pathways to the building, floor materials etc.)
- Make sure signage is at eye level for participants of short stature, wheelchair users and others.
- Leave space at tables for wheelchair users and consider how the legs of a tables can obstruct a wheelchair user from sitting.
- Consider that high tables are not accessible for wheelchair users and people of short stature. It can also be difficult for a person using crutches as there is nowhere to prop them up.
- Providing seating with arms allows people to support their posture.
- Ensure adequate seating is provided, allowing for space for PAs, interpreters and so on.
- Consider how participants will move through the building during the day. For example, if meeting rooms and break rooms are on different floors, and there is only one elevator, this is likely to impact negatively on accessibility.
- Provide alternatives to activities which require holding a pen. For example, you could provide an option to audio record answers or provide a scribe to write on someone's behalf.
- Do not touch or lean on someone's wheelchair, touch or move mobility aids, bags or other belongings of a disabled person without asking for permission first.
- Never push someone in their wheelchair unless requested to by the person themselves.

Blind and partially sighted participants

Consider that blind and partially sighted participants may not be able to read text or see visual cues such as photos, or may not be able to read small text. They may use a screenreader, large text or Braille.

- At the outset of a meeting, ask everyone in the room to introduce themselves so that the participant knows who is there, and can begin to recognise their voices.
- In a group, avoid using expressions like "she said that" and mention the person's name instead, so that the participant knows who you are referring to.
- In online meetings, some blind participants may not be able to use the 'raise hand' button built in to many meeting platforms. Again, spend some time at the start of a meeting to find the best approach.
- In online meetings, be aware that activity in the chat box can be distracting for visually impaired participants using a screenreader, which reads the chat aloud to them. It can be helpful to ask participants to minimise use of the chat function.
- Always describe any images or tables that are part of a presentation. It is best practice to send any presentation slides to participants in advance so that they can open it on their own device. Be conscious of your choice of colours when using slides as certain colour combinations (ie. green and red) can be difficult to read particularly for someone with colour blindness.
- It is not necessary to describe your appearance for the benefit of visually impaired attendees unless it is their preference. 19
- If you leave a room, let the visually impaired participant know so that they will not be talking to an empty room. The same goes for an online meeting. If moving into breakout rooms, make sure to state it clearly and ask participants to reintroduce themselves in the breakout room so participants with a visual impairment know who is there.
- Make sure the participant knows where the doors, windows and furniture are located, how to find the toilet, fire exit and other key parts of the building or room.
- Remove any unnecessary obstacles in a room, for example chairs, desks, lamps, plants and so on. If something can't be moved, let the participant know where these obstacles are. Do not move objects around without telling the participant about the change.
- If a participant has a guide dog, make sure there is space for the dog, and an area to set up a water bowl. Let the participant know where the dog can go to the toilet. This may be a grassy area outside the building, so make sure the participant knows the route and that obstacles are removed or reduced.
- Do not feed or distract guide dogs.
- Always ask before providing assistance. The visually impaired person is the expert in what
 assistance they need. Never take a person's arm, but instead, when guiding, allow the
 guided person to hold your elbow or shoulder.

¹⁹ Source: Consultation feedback from <u>Voice of Vision Impairment</u>.

- Ensure that there is adequate lighting in meeting rooms, and that a visually impaired person is comfortable with the seating arrangements. For example, many may be very uncomfortable facing a light source such as a window.
- Ensure that a visually impaired person is offered assistance for refreshments or lunch where such are provided at breaks. Ensure there is assistance available for a participant who wishes to use the bathroom.
- Ensure that a visually impaired person is not left standing or sitting by themselves (unless that is their preference), since they are not likely to be able to make eye-contact or approach anyone they would like to speak to.
- Audio description of videos should be provided.

D/deaf or hard of hearing participants

Remember that there are different things to consider for Deaf participants who use Irish Sign Language as their primary language and deaf people who prefer other kinds of communication such as lip reading, written communication, and so on. Always ask the participant what works best for them. Below are some things you may need to consider.

Deaf participants who use Irish Sign Language

- You must provide ISL interpretation for a Deaf participant. Deaf people must have access to high quality interpretation through a qualified and registered interpreter.
- It is not appropriate to ask parents, siblings, or friends to interpret for someone who is Deaf.
- Providing captioning, while helpful for some people, is not a substitute for providing ISL interpretation. Remember that ISL is not the same as English, it is a different language and does not follow the same structure. There are low literacy levels in English among many in the Deaf community.
- For the same reason, it may be difficult for a Deaf person to read documents in English. Use plain language in all written communication. You can also translate complex documents into Irish Sign Language video format.
- Having an interpreter available when someone checks in for a workshop or conference, or during break times for networking, can improve inclusion.
- Reserve space for Deaf people who require an interpreter in the first few rows so as not to have any distractions, if they wish.

Working with Irish Sign Language interpreters

The Sign Language Interpreting Service (SLIS) provides guidance on working with ISL interpreters in meetings. Below are some of the main points to be aware of.

- Allow a minimum of two weeks' notice to book an ISL interpreter.
- Book two interpreters for meetings of 90 minutes or longer or for meetings with a high volume of information.

- Provide background information and relevant documents such as the agenda and other
 materials to the ISL interpreters in advance of the meeting so they can prepare. It can be
 helpful to prepare a list of commonly used acronyms to share in advance also.
- Discuss in advance with the interpreter how the session will be run and the best way to manage break times and any other practical details.
- Speak as you normally would, but allow for a slight time lag in interpretation.
- Ensure only one person speaks at a time during a meeting.
- Always speak directly to the Deaf person and not to the interpreter.
- Keep meetings to the scheduled time. If a meeting runs over time, the ISL interpreter may need to leave. The meeting cannot continue without an interpreter or the Deaf participant will be excluded.

If you are meeting online, consider the following additional points:

- It is important to ensure that the interpreters are always visible to Deaf participants and that they don't move around the screen.
- Depending on the type of meeting, you should either "pin" or "spotlight" the interpreter. Pinning can be done by the participant. This turns off the active speaker view to allow a participant to focus on one person's video, that of the interpreter. It does not affect the view of any other participants. Spotlighting can usually only be done by the host or cohost. It puts the spotlighted video as the primary active speaker for all participants. This can be useful for webinar-style presentations.
- Often you will be working with more than one interpreter on a call and they will need to swap with each other throughout the meeting. To minimise errors, consider sharing cohosting permissions with the interpreters who will then be able to spotlight themselves at the right times.
- It is advised to do a technical check with the interpreters in advance of the meeting to make sure everything is working correctly.
- If the interpreter's connection or technology fails, the meeting must be paused until this is resolved, so that the Deaf participant(s) are not excluded.

A deaf or hard of hearing participant who does not use ISL

- Always ask the participant which modes of communication work best for them for example captioning, text messaging, hearing loop, FM system. Be aware that many venues may not have a loop or FM system, so if it is required then organisers may need to hire and have these solutions temporarily installed upon request.
- Using visual prompts (pictures, objects, symbols, text) can be helpful.
- Avoid holding activities in places with lots of background noise. If the participant uses a
 hearing aid, hearing loop or other assistive hearing device, the devices usually pick up this
 noise making it difficult for the participant to focus on what is being said.
- Ensure that only one person talks at a time and encourage everyone to talk slowly and clearly.

- Ask participants where they would like to sit to enable them to hear as effectively as possible.
- Always look directly at the participant and do not cover your mouth, or place anything (a hand, a cup) in the way.

Both D/deaf and hard of hearing

- Be aware that deaf people or hard of hearing people may not be alerted when an alarm goes off. Have a visual alarm system in place.
- Have a mobile number or email address available that is monitored which participants can text if there is a technical problem.

Deafblind participants

There are many ways in which a person who is deafblind can communicate, such as through spoken language, Irish Sign Language (ISL), Tadoma, Braille reader, Deafblind Alphabet, Handover-hand, tactile sign language, finger-spelling, Lámh, Objects of reference/symbols, Picture Exchange Communication System (PECS) symbols or pictures, and gestures.

- Understand the individual's preferred communication method.
- Book an interpreter if one is requested. Always communicate to the person directly and not the interpreter.
- As well as communication needs, be aware of the person's sensory and mobility needs.
- The pace of the meeting must be slow to facilitate the inclusion of deafblind participants.
- Always approach a person from the front.
- Get the person's attention by tapping the person on the arm/shoulder upon approach.
- For deafblind people with some vision, you can wave/gesture your hand in their line of sight to get their attention.
- Minimise any background noise and make sure only one person talks at a time.
- Avoid standing in front of a light source.
- Make sure the person can see your face and lips and avoid having anything in your mouth
- Keep your head still and do not look away when speaking to the person.
- Take your time when speaking and signal any change in topic by pausing.
- Do not shout.
- Lipreading and intense listening is difficult. Allow time for the person to take in what you have said.
- Keep checking back to make sure the person is understanding what you are saying.
- When you write something down, use plain English.
- Create visual strategies such as the use of pictures, maps, written material, signed videos.
- For break time, provide lunch on individual plates and not a central plate in the middle of the table as this can be challenging for a person who is deafblind.

Participants with an intellectual disability

- Do not infantilise people with an intellectual disability.
- Work with the participant to identify ways to ensure they are included. For example, if the participant does not feel comfortable interjecting, the Chair could agree to ask whether they want to say anything when they come to each agenda point. Another example could be to schedule regular breaks, allowing the participant to speak with their support person in order to consider the information, and then to contribute a point after the break if they want to.
- It is very important to stick to the meeting agenda. A participant with an intellectual disability may have put lots of time into preparing for the meeting based on the agenda. Allowing other meeting participants to talk about unrelated issues, or skip ahead to topics further on in the agenda, can be disorienting.
- Use plain language, avoid jargon, and explain acronyms the first time they're used.
- Visual images such as photos, drawings, videos can help to promote communication, especially when discussing abstract ideas.
- Ask one question at a time and keep the format of questions short and clear. Allow plenty of time for the participant to answer.
- Include regular breaks to allow participants to relax, as often as needed.
- Provide information in advance in accessible formats. For example, the participant may
 prefer plain English or easy-to-read documents, video with subtitles, audio description or
 other formats.
- If the participant has a PA or support person, remember that they are there to facilitate the participant's views to be understood, and not to speak on their behalf.
- Check in to make sure that the person understands the topic or activity. Be willing to repeat points, questions or answers several times in plain English to be understood.

Neurodiverse participants

Neurodiversity is a term which recognises neurodevelopmental differences as a natural part of human diversity. Autism as well as Attention Deficit Hyperactivity Disorder (ADHD), Dyspraxia, Dyslexia, Dyscalculia, and Tourette's Syndrome, among other differences or disabilities, are examples of neurodiversity.

- Consider sending a photo of the facilitator(s)/speakers to the participant in advance, in addition to the agenda and other documents.
- Stick to the timings outlined on the agenda and take the breaks when scheduled.
- Remember that environmental factors can irritate someone with sensory issues. For example, overpowering smells (e.g. disinfectant, perfume), noise (e.g. alarm going off unexpectedly, people talking in the background, buzzing of electronic equipment), touch (e.g. difficulty handling certain textures), bright or flickering lights.
- Networking sessions and break times can be stressful for some neurodiverse people who
 may or may not wish to interact with other participants. Consider giving coloured dots
 to all participants and using a traffic light system to give participants control over their
 interactions. A red sticker means that the participant does not want to be approached for

- conversation. An orange sticker means the participant is open to speaking to someone they already know. A green sticker means the participant is open to speaking to anyone.
- Some neurodiverse people find applause uncomfortable because it is sudden and its duration is not predictable. One DPO has developed an 'Autism-friendly clap' which involves providing a visual signal to say that applause will begin in 5 seconds, giving people time to put in earplugs if needed. After this there is a countdown of 5 seconds of clapping.²⁰
- Consider putting in place a 'quiet zone' at in-person meetings where participants can go to take a break.

Person with a psychosocial disability or mental health difficulty

Psycho-social disabilities / mental health difficulties are not obvious or visible, and take many different forms, for example, depression, anxiety, schizophrenia, or bipolar disorders. Some people with psycho-social disabilities / mental health difficulties do not describe themselves as having a disability. However they do have rights under the UNCRPD.

- Include a trigger warning at the beginning of a session to make people aware that potentially triggering issues may be discussed.
- Signpost participants towards mental health supports at the beginning and end of the session.²¹
- Have a support person available, or allow the participant to bring a support person, should they become distressed.
- Be flexible and allow for choice and autonomy. A participant may feel anxious, worried or stressed when placed in situations where they lack control or where they feel that people anticipate they will be difficult.
- Have a quiet, safe space available if the person needs to remove themselves from the room.
- Keep discussions calm, speak in a normal tone of voice and do not make the participant feel as though you are anxious to end the conversation or exclude them from interactions.
- Allow flexibility around re-engaging in a Committee or group if the participant has not been able to attend for a while. Follow up with them if you have not heard from them, as they may have difficulty following up.

²⁰ Source: As I Am Consultation feedback.

²¹ For example, <u>HSE mental health supports</u>.

Person with a speech impairment

Below are some tips for including a person with a speech impairment.

- It's very important to speak directly to the participant with a speech impairment and not to their communication support person or PA. It is also important to ensure other participants do the same.
- Be patient. Take time to listen to what the person is seeking to say and avoid cutting them off
- Keep the format of questions short and clear.
- If you do not understand, then it is fine to ask the participant either to repeat or to say "if I understand you correctly, you would like to..." but then give them time to reply or correct what you have understood.
- Ask the participant if they would like to write down their answer, comment or contribution.
- Consider that it may take more time for a participant with a speech impairment to participate and factor that in when planning the timing and pace of the meeting.

Appendices

Appendix A: Checklists

Use the below checklists to assist in your planning. In addition, the NDA's Customer Communications Toolkit for the Public Service contains checklists covering written, spoken, signed and digital communication. This document is available on the NDA website.



Use this checklist to assess whether your process is underpinned by principles of meaningful participation.

Genuine	Is the consultation linked to a defined objective?
	Do the people carrying out the consultation process have the power to follow through on recommendations?
	Is there a commitment, including financial, to implement the recommendations from the consultation?
Targeted	Have relevant stakeholders been targeted?
Accessible	Have stakeholders been asked about their accessibility and reasonable accommodation needs?
	Have accessibility and reasonable accommodation needs been provided for?
	Have public officials had disability equality training?
	Are there different ways for stakeholders to engage in the process? (e.g. online, offline, providing written, verbal, signed feedback)
Timely	Have stakeholders been engaged from early in the process?
	Is there adequate time for stakeholders to prepare?
	Is there adequate time for stakeholders to input?
Ongoing	How will feedback be given to stakeholders?
	Will participants be involved in an evaluation of the consultation process?
	How will this relationship be built/maintained after the consultation process?
Transparent	Is the consultation invitation or advertisement accessible?
	Have stakeholders been made aware of the scope and objectives of the consultation?
	Has a clear rationale been provided for recommendations which are not taken on board?
	How will the outcome be shared with participants and the general public?



Use this checklist to support in planning your process.

Purpose and	Does the participation process have a defined objective?	
scope	Are participants are aware of how the process will work, any limitations, the expected timelines, what will happen with the information they provide and how they will be kept informed during and after?	
Timeline	Has a timeline been mapped out?	
	Is there sufficient time built in for accessible documents to be developed and other accessibility supports to be arranged?	
	Is there sufficient time built in for stakeholders to consider the information and respond?	
Resources	Are there sufficient staff resources to manage and support the participation process?	
	Is there sufficient budget to provide for various accessibility requirements?	
	Is there sufficient budget to provide for payment of expenses?	
	Are there resources available to implement consultation recommendations?	
Data	Is there a plan for storing participant's data in line with GDPR?	
Identifying	Has a relevant DPO been contacted?	
stakeholders	In the absence of an available DPO, have the steps outlined on Page 18 been followed?	
	Have other relevant stakeholders been identified?	

Inviting stakeholders	Is the invitation and the process to respond to it accessible?			
	Does the invitation state the accessibility requirements provided and ask participants to respond with any additional requirements?			
	Has enough notice been given so that stakeholders have time to consider the request?			
	Does the invitation include information about the purpose of the participation process?			
	Does the invitation provide clear information on confidentiality, how the information will be stored and who will have access to it?			
Consultation	Have you chosen the method(s) of participation?			
stage	Have you identified and planned for accessibility requirements?			
Analysis	Have you chosen your method of analysis, if relevant?			
Feedback	Have you planned how you will give feedback to participants, in accessible formats, during and after the process?			
Evaluation	Have you decided how you will evaluate your process?			
Dissemination	Have you considered how you will disseminate the outputs, such as publications or minutes?			
	Have you planned to have all accessible versions of outputs ready to be shared at the same time?			

Appendix B: DPO contact information

Seven Disabled Persons' Organisations contributed to the development of these guidelines. Their contact details are provided here. Please note that this is not an exhaustive list of DPOs in Ireland.

- As I Am (ceo@asiam.ie)
- <u>Disabled Women Ireland</u> (disabledwomenireland@gmail.com)
- Independent Living Movement Ireland (info@ilmi.ie)
- <u>Irish Deaf Society</u> (info@irishdeafsociety.ie)
- <u>The National Platform of Self Advocates</u> (myvoiceireland@gmail.com)
- Physical Impairment Ireland (physiclimpire@gmail.com)
- <u>Voice of Vision Impairment</u> (info@vvi.ie)

Appendix C: Useful Links and Resources

- <u>Decision Support Service.</u>
- European Commission (2019) European Accessibility Act
- European Union (Accessibility of Websites and Mobile Applications of Public Sector Bodies) Regulations 2020.
- General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention.
- NDA (2022) Advice paper on disability language and terminology.
- NDA (2022) Engaging and consulting with disabled people in the development and implementation of legislation and policy.
- NDA Customer Communications Toolkit for the Public Service A Universal Design Approach.²²
- NDA Customer Communications Toolkit A Universal Design Approach. Supplement on online meeting accessibility.
- Principles of Universal Design
- Sign Language Interpreting Service guidance on working with ISL interpreters,
- Standard I.S. EN 17161:2019 Design For All.
- UN Convention on the Rights of Persons with Disabilities.

²² At the time of publication, the NDA is updating its website so the link is not included.

Notes			

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