Consultation Report for “Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making”

September 2022



# Acronyms

CCUAM County Carlow Universal Access Movement

DPCN Disability Consultation and Participation Network

DPO Disabled Person’s Organisation

ESPEN Education for Persons with Special Educational Needs

IDS Irish Deaf Society

ILMI Independent Living Movement Ireland

ISL Irish Sign Language

UNCRC United Nations Convention on the Rights of the Child

UNCRPD United Nations Convention on the Rights of Persons with Disabilities

LCDC Local Community Development Committees

NCBI National Council of the Blind Ireland

NDA National Disability Authority

PPN Public Participation Network

VVI Voice of Vision Impairment

# Executive Summary

## Introduction

This is the consultation report for the National Disability Authority’s (NDA)[[1]](#footnote-1) publication, “Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making”, published in September 2022. These guidelines are an update to the NDA’s 2002 publication “Ask Me: Guidelines for Effective Consultation with People with Disabilities”.

The NDA published “Ask Me: Guidelines for Effective Consultation with People with Disabilities” in order to provide practical advice on how organisations can undertake inclusive consultation processes with people with disabilities. Since the publication of these guidelines in 2002, a number of legislative and policy changes have taken place in relation to disability inclusion, in particular Ireland’s ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. UNCRPD and the Committee’s General Comment 7 outlines guidance regarding States Parties’ obligations to consult with persons with disabilities “through their representative organisations”. Therefore the guidance was updated in consultation with Disabled Persons’ Organisations and other stakeholders to reflect these new obligations.

In addition, updating the guidelines represents an action towards fulfilling the NDA’s commitment under the Mid-term Review of the National Disability Inclusion Strategy 2017 – 2021 to provide guidance for, and capacity building of, Government Departments and public bodies on engaging people with disabilities in policy development and consultation processes.

## Purpose of this report

The purpose of this consultation report is to provide feedback from the consultation process to all interested stakeholders and to promote transparency in line with the public consultation guidance issued by the Department of Public Expenditure and Reform (2016). The emerging recommendations outlined in this report, together with the desk-based research, informed the development of the NDA’s updated guidance for government departments and public bodies in relation to designing and delivering effective participation and consultation processes with persons with disabilities. The views expressed in the consultation report are those of participants in the process. The NDA reviewed and considered these recommendations when updating the guidelines. This report outlines which recommendations are reflected in the new guidelines and includes a rationale for any recommendations which are not included, or which were partially included, in the “Participation Matters” guidelines. This report is divided into two sections.

**Section 1** examines recommendations from Disabled Persons’ Organisations (DPOs), young people and other organisations and individuals under four parts.

**Part 1:** Understanding Disability and Participation.

**Part 2:** How to make participation work for people with disabilities – Understanding Attitudes and Embedding a Culture of Participation.

**Part 3:** How to make participation work for people with disabilities – designing accessible, inclusive and responsive processes.

**Part 4:** Additional points.

**Section 2** examines responses from public officials to the emerging recommendations from stakeholders outlined in Section 1 from an implementation perspective.

## Summary of emerging recommendations from stakeholders

A summary of the emerging recommendations from Disabled Persons’ Organisations (DPOs), young people and other organisations and individuals is presented here under the headings of each of the four parts of this report. Further context for these recommendations from stakeholders is provided in the main body of the report. At the end of each section, the emerging recommendations related to that section are outlined as well as the NDA’s response and rationale for any recommendations which are not included, or which are partially included, in the updated guidelines.

### Part 1: Understanding disability and participation

Participants suggested the following points for consideration:

1. The guidelines should be underpinned by **UNCRPD** and clearly set out the obligations on State Parties with regard to participation and consultation with persons with disabilities through their representative organisations.
2. The guidelines should **align with existing laws and policies** which include obligations that support the accessible and inclusive participation of persons with disabilities.
3. The guidelines should explain the difference between the **social model, and medical model** of disability.
4. The guidelines should be underpinned by a **social model approach** to disability which examines environmental barriers to participation and how to remove them.
5. The guidelines should outline the **context of different** **language** used with regard to disability.
6. The guidelines should outline **language which should not be used**.
7. The guidelines should provide an explanation of **Irish Sign Language** and thecultural and linguistic identity of the **Deaf community.**
8. The guidelines should acknowledge the **evolving nature of language** and that **DPOs** should be consulted regarding appropriate terminology to be used at the collective level.
9. With regard to **individuals** taking part in consultation, the guidelines should recommend that the preferred language of that individual be used when referring to them.
10. The guidelines should explain the **definition and role of a DPO** under UNCRPD and how it is distinct from other stakeholder groups including service providers.
11. The guidelines should outline that in order to meet obligations under UNCRPD Article 4(3), Government Departments and public bodies **must consult with DPOs**. Some stakeholders recommended the guidelines state that DPO views with regard to disability should be **prioritised** over those of non-DPO stakeholders.
12. Departments and public bodies should proactively engage **children and young people** **with disabilities and their organisations** in participation processes in line with UNCRPD and UNCRC guidance.
13. The guidelines should acknowledge the key **supportive role of parents, carers, service providers and other stakeholder groups** - as acknowledged under UNCRPD and UNCRC - while emphasising that consulting with these groups **does not replace direct consultation with DPOs**, and **children and young people** with disabilities.
14. The guidelines should recommend the use of a broad and inclusive **definition of disability** based on the social model when designing participation and consultation processes targeting persons with disabilities.
15. The guidelines should advise that requesting **proof of a diagnosis** in order to be involved in participation and consultation processes is inappropriate.
16. The guidelines should highlight common **barriers to participation.** The most common barriers highlighted by participants are outlined in the body of this report.

### Part 2: How to make participation work for people with disabilities - (a) Understanding attitudes and embedding a culture of participation

Participants proposed the following potential solutions:

1. Address **attitudinal barriers** – recognise people with disabilities, and DPOs as representative organisations, as experts and agents.
2. Recognise the **structural barriers** faced by people with disabilities, and DPOs as representative organisations, in terms of participation.
3. Take an **intersectional approach** to the design of participation and consultation processes to ensure that they are accessible to all and reflect a diversity of experiences across the disability community.
4. The guidelines should recommend that **participation of persons with disabilities must be** **embedded** from the highest, strategic level (including Ministerial and Departmental senior leadership) down to the implementation level.

### Part 3: How to make participation work for people with disabilities – (b) Designing accessible, inclusive and responsive processes

1. The guidelines should state that persons with disabilities should be engaged in a **broad range** of policy consultation and participation processes, not just those deemed ‘disability-specific’.
2. The guidelines should highlight that a universal design approach to consultation design which addresses barriers to participation can be effective if it is understood and applied properly and implemented in consultation with DPOs and other relevant stakeholders.
3. The guidelines should highlight that effective participation processes should be underpinned by transparency, trust and respect, two-way dialogue and ongoing engagement.
4. The guidelines should highlight the importance of **engaging proactively and early** with DPOs in participation and consultation processes.
5. The guidelines should recommend identifying the **most relevant DPO(s)** to engage with based on the subject matter.
6. The guidelines should recommend **raising awareness** of consultation and participation processes among DPOs and other relevant stakeholders, ensuring intersectional groups are also targeted.
7. The guidelines should recommend **reaching relevant stakeholders through DPOs** **in the first instance.** Stakeholders may also be reached through other organisations, service providers, social media, or other methods if necessary. Engagement with individuals and other stakeholder groups does not replace the need to engage with DPOs.
8. The guidelines should recommend that consulting bodies proactively ensure **accessibility** and provision of **reasonable accommodation** in participation and consultation processes.
9. The guidelines should recommend that consulting bodies **proactively inform** stakeholders of accessibility and reasonable accommodation provision, taking the onus off participants to request supports wherever possible, in addition to asking participants if anything additional is needed to ensure their access.
10. The guidelines should recommend that consulting bodies **recognise the heterogeneity** of persons with disabilities and their accessibility requirements.
11. The guidelines should highlight the importance of ensuring accessibility of the **physical environment** for all persons with disabilities.
12. The guidelines should highlight that **physical accessibility includes a broad range of elements** including building access, signage, audio announcements, the sensory environment and more.

The guidelines should highlight barriers caused by **inaccessible transport** and recommend identifying the most appropriate accommodations with stakeholders with disabilities.

1. The guidelines should highlight barriers caused by **inaccessible information**.
2. The guidelines should highlight barriers caused by **inaccessible communication.**
3. The guidelines should highlight barriers caused by lack of access to **internet and technology, including assistive technology.**
4. The guidelines should highlight that **timeframes** should be long enough to facilitate inclusive participation and consultation.
5. The guidelines should highlight the importance of **capacity-building support** for consultation participants.
6. The guidelines should highlight barriers caused by the **cost of engaging in participation and consultation processes** and recommend consulting bodies reimburse expenses incurred. Some stakeholders also suggest **payment** for participant’s time and expertise.
7. The guidelines should highlight the importance of **providing feedback** to stakeholders, in accessible formats, throughout the process and at the end of the process.
8. The guidelines should highlight various **considerations for the analysis** of consultation findings.
9. The guidelines should highlight the importance of **listening and taking action** is an important step to ensure participation and consultation processes are meaningful.
10. The guidelines should highlight ways of **evaluating** participation and consultation processes and mechanisms with DPOs, and other relevant stakeholders, and applying the learning to future processes.
11. The guidelines should recommend engagement with DPOs and relevant stakeholders in **monitoring the implementation** of policies after they have been developed.
12. The guidelines should include **practical tips** for inclusive participation and consultation activities as highlighted by DPOs and other stakeholders.
13. The guidelines should recommend ensuring **detailed planning** of all logistical and accessibility requirements, e.g. booking interpreters, organising transport, etc.
14. The guidelines should recommend public officials consider a partnership approach in which DPOs and other relevant consultation stakeholders **lead or co-facilitate** the consultation process.
15. The guidelines should recommend choosing a variety of **flexible, creative and age-appropriate** participation and consultation approaches.
16. The guidelines should recommend that officials ensure an inclusive **meeting** **pace** and sufficient **break times.**
17. The guidelines should include information about running an inclusive **submissions** process.
18. The guidelines should include information about designing inclusive **focus groups.**
19. The guidelines should include guidance around creating accessible **surveys**.
20. The guidelines should include information about running **inclusive and accessible online meetings.**

### Part 4. Additional points

Participants advised that:

1. The **title** of the updated guidelines should be updated to reflect UNCRPD participation and consultation obligations.
2. The updated guidelines should be made available in various **accessible formats**.

# Consultation process

## Invitation to contribute papers for the literature review

In January 2021, the NDA contacted relevant stakeholders by email to inform them of the NDA’s intention to update the “Ask Me” guidelines. These stakeholders included those involved in consultation on the original guidelines, Disabled Persons Organisations, and other relevant civil society and public sector organisations. Interested stakeholders were invited to give preliminary feedback on the new topics proposed for inclusion in the updated guidelines. Stakeholders were also invited to send any reports or research they wished to have included in the literature review. The NDA then carried out a desk-based review of the literature, including academic and grey literature relating to participation in general, as well as that which relates to participation of persons with disabilities specifically. The desk review considered participation in relation to adults with disability as well as children and young people with disability.

## Interviews with DPOs

The NDA invited national Disabled Persons’ Organisations to take part in one-to-one meetings in which the emerging themes from the desk-based research were shared and discussed. DPO stakeholders were also invited to highlight any additional points of relevance to the new guidelines. Feedback was also sought from DPOs on the public consultation methods and youth consultation. Five national Disabled Persons Organisations took part in these meetings between June 14th and June 25th 2021. The DPOs who took part in the consultation meetings included As I Am, Irish Deaf Society, Voice of Vision Impairment, Independent Living Movement Ireland, and the National Platform of Self Advocates. The themes from the desk-based research and the questions discussed during these interviews are attached in Annex 1 of this report.

## Youth focus groups

The NDA reached out to disabled young people through a national DPO for the purpose of this consultation. The NDA carried out two focus group meetings and one feedback meeting with young people from the Independent Living Movement Ireland (ILMI) Youth Collective. The ILMI Youth Collective is a cross-impairment DPO-facilitated youth group. Its members range in age from 17 to 24 years old. The meetings followed an informal and semi-structured discussion format. The discussions focused on the young people’s experiences of consultation processes, common barriers to participation and solutions they propose for effective engagement with young people with disabilities. Some of the feedback from the ILMI Youth Collective is presented in this report as quotes from individual members, while some quotes are presented as a statement from the group as a whole from the agreed note of the meeting.

## Public submissions process

The NDA launched a public call for submissions which ran from July 26th 2021 until August 16th 2021. The submissions information and questions were available in Word and Easy-to-Read formats and by video with Irish Sign Language and English audio and subtitles. Submissions were accepted by post, email or video.

The call for submissions was shared on the NDA website and Twitter account and by email to stakeholders including: national DPOs; NGOs working on disability, mental health and children and youth; disability service providers; organisations representing women, migrants and the Traveller community; public bodies including the Irish Human Rights and Equality Commission and the Mental Health Commission; the Disability Unit and the Children and Youth Team within the Department of Children, Equality, Disability, Integration and Youth; the national Disability Stakeholder Group; the Disability Participation and Consultation Network; County Councils; local Public Participation Networks. It was also distributed through the ActiveLink Community Exchange and through the Wheel newsletter.

Several organisations and individuals shared the consultation further through their own networks. For example, the NDA was informed that the consultation was shared in the Galway PPN weekly digest; Galway PPN Disability Forum; Wicklow PPN Facebook page; Wicklow Include Us In Facebook page; Wicklow Access and Inclusion Group; Wexford County Council Access Section; Inclusion Ireland newsletter and social media; Inclusion Ireland Self Advocates Group; DCEDIY Disability Policy mailing list; DCEDIY Citizen Participation mailing list which includes 500 people working in youth and early years.

The NDA received 21 submissions in total. Nine submissions were received from individuals and thirteen submissions were received from organisations. The public submission questions are attached in Annex 2. The list of organisations which made submissions is attached in Annex 4.

## Consultation with public officials

The emerging recommendations presented in Section 1 of this report formed the basis for focus groups with public officials from Departments, public bodies and local authorities which took place in January 2022. The purpose of these focus groups was to invite feedback from public officials on these recommendations from an implementation perspective, in order to highlight any perceived opportunities or challenges. Twenty-six public officials from six Departments, one public body and four local authorities took part in the focus groups. The feedback from public officials is summarised in Section 2 of this report.

## Feedback mechanisms

Feedback has been provided to stakeholders in a number of different ways. An interim update on the development of the guidelines was given to DPOs in a meeting with the NDA in December 2021. A feedback meeting with the ILMI Youth Collective took place in autumn 2021. A draft of the guidelines was circulated to all those who took part in the consultation for observations in April 2022. One-to-one feedback meetings were offered to each DPO which took part in the consultation at the end of the process to give feedback on observations shared by DPOs on the draft guidelines. Finally, this consultation report also serves as a mechanism for providing feedback to stakeholders.

## Consultation limitations

Due to the restrictions in place during the COVID-19 pandemic, direct consultation with children was not possible as part of this process. The initial stage of consultation had limited input from organisations representing people with experience of mental health difficulties. The NDA was not aware of any mental health DPO in Ireland at the time of consultation. Efforts were made to share the call for public submissions with mental health organisations, but no submissions were received from this cohort. The NDA recognised that further input was needed in this regard, and the draft guidelines were shared with mental health organisations for input and feedback which was received at this stage.

## Consultation analysis

Different consultation methods and questions were used for different stakeholder groups (see Annex). The analysis is presented thematically in this report. Some quotes have been shortened for length. The DPOs that participated in the consultation and the organisations who sent submissions through the public process are listed in the appendix. Quotes throughout the report are attributed either to a DPO (via a reference number), an organisation who made a public submission or an individual who made a public submission (via a reference number). Names of individuals are not attributed.

# Section 1: Emerging recommendations from stakeholders

Section 1 outlines the emerging recommendations from DPOs, young people and other organisations and individuals.

## Part 1: Understanding Disability and Participation

This section outlines key issues identified by consultation stakeholders in order to understand disability in the context of participation. This section discusses stakeholder views on UNCRPD and other relevant laws and policies regarding disability and participation; the medical model and social model of disability; language and terminology with regard to disability; the role and function of Disabled Person’s Organisations with regard to participation; the inclusion of children and young people in participation processes; the role of other stakeholder groups in consultation processes; the definition of disability and its implications for participation processes; and common barriers to participation faced by persons with disabilities.

### UNCRPD

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) sets out specific obligations on State Parties with regard to participation and consultation with persons with disabilities through their representative organisations. All five DPOs interviewed agreed that these obligations should be set out within the guidelines. DPO interviewees made the following comments:

UNCRPD Article 4 is one of the General Obligations of the Convention. As important as the other parts are, this is most important as it’s the cornerstone. Article 4 has writing above it saying ‘general obligations’ and this writing is not above any other Article. So it’s at the core of UNCRPD and it says so in General Comment 7 also that DPOs are at the heart of UNCRPD. (DPOREF5)

In relation to the UNCRPD it says that you must consult with Deaf people and people with disabilities. It is important to ask us before proceeding on anything. (DPOREF3)

The members of the ILMI Youth Collective also shared this view stating:

The guidelines need [to] have an opening statement and refer to what a DPO is. The guidelines must refer to the UNCRPD in particular Articles 4.3, 29 B, General Comment 7 and explain social model language versus medical model language. (ILMI Youth Collective)

In the public consultation, an individual submission[[2]](#footnote-2) from a person with a disability stated:

The UNCRPD required change from viewing people with impairments as beneficiaries of charity, medical treatment and social protection to view us as: Persons with Rights who are capable of claiming them; Persons who are adept in decision making for our lives based on our ‘informed consent’; Persons who are competent in being ‘active members’ of society.

### Other relevant laws and policies

In terms of other national laws and policies which include obligations and commitments relevant to these guidelines, the DPOs interviewed highlighted the Irish Sign Language Act; the Assisted Decision Making (Capacity) Act; the National Disability Inclusion Strategy; the Public Sector Duty; the EU Web Accessibility Directive; and the European Accessibility Act.

The ILMI Youth Collective members stated:

It is important to set out the different laws and explain them – this isn’t to tell people what disabled people want but to set the context and make the law clear and accessible to people (Article 9).

The ILMI Youth Collective, DPCN and DFI also highlighted the Public Sector Duty as an important framework under which supports should be provided.

The DPCN highlighted the guidelines from the HSE’s Transforming Lives, Working Group 3, “Effective Participation in Decision Making: Planning for Ordinary Lives in Ordinary Places”.

The Disability Federation of Ireland (DFI) in its submission also highlighted the Local Government Reform Act (2014) stating that:

The Act, created new structures. The key change was to provide for decision making and accountability structures on how national and EU funding could be deployed at local level. The Act also makes local government responsible for engagement with all its local citizens on decision making and plans, not only those who are members of community and voluntary groups.

### Models of disability and language

The UNCRPD is underpinned by the social model of disability which emphasises the ‘disabling barriers’ caused by economic and environmental factors. By contrast, the medical model defines disability in terms of a person’s impairment.

All five of the DPOs interviewed in the consultation operate within the social model approach to disability, as opposed to a medical model approach. DPO interviewees recommended that the guidelines explain this distinction and that the guidelines, like UNCRPD, should reflect a social model approach.

A DPO interviewee commented that the medical model often still prevails, stating:

It’s still very medical model, charity model, hiding people with disabilities away from society. No embracing of people with disabilities. (DPOREF4)

The ILMI Youth Collective members stated:

Medical model attitudes and money mean disability gets left out of diversity discussions. We need to shift to a social model of disability where our impairments are not the issues and that it is society, structures, policies etc. that ‘disable us’.

#### The importance of language

All five DPOs interviewed agreed the guidelines should include a section outlining appropriate language to use in relation to disability. Three DPOs outlined their preference for what is often referred to in the literature as ‘identity-first’ language (e.g. ‘disabled person’) as opposed to what is referred to as ‘person-first’ language (e.g. people with disabilities). One DPO had mixed views amongst its members in this regard with some members preferring either ‘disabled person’ or ‘people with disabilities’ and some preferring ‘people with disabilities’ only.

DPO interviewees made the following comments:

[Our] position is that ‘people with disabilities’ reflects a medical model understanding of disability and that the term ‘disabled person’ should be used, reflecting a social model of disability. This is ‘disabled’ as a verb not an adjective. It means people being discriminated against. We want to reclaim the word ‘disabled’ to show that it’s something being done to us. (DPOREF5)

Access to buildings is a perfect example of people being disabled by design. It’s not that the person in the wheelchair is disabled – they are being disabled. (DPOREF5)

Recognising that disability is a social construct empowers our rights, it puts rights front and centre. (DPOREF5)

I’d love if the text [of this updated guidance] retained ‘disabled person/people’. This is the language of the social model. ‘Persons with disabilities’ was not desired [language] by disabled people. (DPOREF2)

Another DPO had mixed views amongst its Steering Committee members. One interviewee stated:

I like either. The news often uses ‘person with a disability’. (DPOREF4)

Another interviewee in the same group said:

I like ‘person with disability’. (DPOREF4)

Another noted:

It’s important to ask people. (DPOREF4)

One DPO interviewee explained that language can act as a barrier to engaging disabled people in consultation, stating:

[People can become] immediately hostile if incorrect language is used. There’s a learning piece that has to be addressed in terms of how Departments address disabled people. (DPOREF2)

This interviewee also pointed out not to assume there is a shared understanding of the term ‘lived experience’.

What does the term ‘lived experience’ mean? It can be social or medical model (DPOREF2)

The ILMI Youth Collective members highlighted their preference for the use of the term ‘disabled person’. The group members made the following comments:

Language is very important and a powerful tool to influence the narrative around disabled people’s lives.

Too often, non-disabled people who read a book decide what language is used – it makes you feel very restricted.

Anyone who has difficulty understanding why we prefer to use the term ‘disabled people’ is usually non-disabled. Disabled people can also be on their own journey with language. I say ‘disabled person’ because it is the social model. It says my body is not at fault – it’s what I come up against outside my four walls that’s at fault. It is the political, social and cultural barriers I face. It’s me saying I’m proud of who I am. It’s also me saying I am not the problem here.

For me, as long as language is acknowledged in the document it’s fine. I prefer ‘disabled people’ but I can accept ‘people with disability’.

Many people that use the term ‘people with disabilities’ see being disabled and other identities as separate – all identities fit into each other and influence each other, like a tapestry. Language cannot be seen as a way to separate identities.

If organisations don’t want to use the term ‘disabled person’ it is a huge red flag.

Another group member shared his experience speaking to a service provider about language, stating:

The language they were using really upset me, it was as if they said my disability imprisons me.

This group member described how using the word ‘disabled’ to describe himself:

Almost feels like coming out (as a proud, disabled person).

#### Language and the Deaf community

A DPO interviewee highlighted the importance of language with regard to the Deaf community.

Deaf people do not see Deafness as a disability, and rather see ourselves as a linguistic minority. Despite this, we are involved in the disability service as we are experiencing barriers, negative attitudes and fighting for access in the same way. (DPOREF3)

The interviewee also raised the lack of understanding of Irish Sign Language as a common issue, stating:

People look at sign language for Deaf people and think it’s for people who need to speak with their hands, but it’s not. It’s the exact same as a spoken language - we have grammar, linguistics, it has its own structure. People think it’s a communication tool and aid and it’s not - it’s a full language. When people are aware of that it becomes a lot clearer. (DPOREF3)

Deaf identity and the linguistic element of the Irish Sign Language Act is so important to us - it always comes back to language. If you are a Deaf woman, you identify as Deaf first before identifying as a woman. Our language is a priority for us. If we are talking about children, it’s about language, if we are talking about babies, it’s about language, if we’re talking about services, it’s about access to language. (DPOREF3)

#### UNCRPD and language

Some DPO interviewees made comments regarding the use of person-centred language (‘persons with disabilities’) in the UNCRPD itself, stating:

It does create confusion and it is a pity. Even the term ‘Disabled Persons Organisation’ - sometimes it’s called ‘Persons with Disabilities’ Organisation’. It doesn’t make sense, it’s clearly a ‘DPO’. (DPOREF2)

Firstly, we decide what language we use because it is our lived experience. Secondly, CRPD is a legal document. We do not use legal language in day to day life. We do not speak in legal language when we're looking to exercise our normal rights. If I go into a shop to buy something, I have rights. I don't have to be quoting the dense language of consumer protection. (DPOREF5)

UNCRPD says that ‘organisations of persons with disabilities’ are at the heart of the Convention. It’s frustrating that this language was used because we have to constantly explain to people that organisations of people with disabilities, equals representative organisations, equals DPOs. We prefer the term DPOs. (DPOREF5)

#### Personal choice and language

In terms of whether or not individuals involved in a consultation should be asked their preference with regard to language, some DPOs shared the following views:

Yes, that’s fine, but there is a danger it reverts back to ‘persons with disabilities’. It would be great to promote social model language. We (DPOs) have a mandate to push the social model terms, including ‘disabled person’. We took a vote about language in 2018.” […] Other people may use different terms but you could set out in this document from the start what language you are using. Using proper language would make a huge difference for us. (DPOREF2)

It cannot depend on what one particular advocate says. It’s through a process of collective agency and deliberation. (DPOREF5)

But the language used can come down to the individual preferences of somebody. So for instance if somebody is trying to explain to me go over there and as you can see the shop there, I avoid telling them I’m visually impaired because they might not understand that, but if I tell them I'm blind, they will. So depending on the context, a person will decide their own language. But in terms of documentation in reports like the Ask Me guidelines, it's the DPOs that need to be reverted to in terms of language. (DPOREF5)

#### Language that should not be used

DPO members also highlighted language which, in their view, should not be used. It is important to note that this is not an exhaustive list, but reflects examples which were shared during the consultation discussions. The following comments were shared:

We need to be careful with terminology. Words like ‘hearing impaired’ for example can be inappropriate. Be mindful of the language being used and get clarification first. Terminology when talking about our identity is important. If we state the words in a certain way, it can end up being translated into something else and we end up with words like ‘hearing impaired’. Within the guidelines we need to be very mindful of terminology and also to have a glossary of the language. (DPOREF3)

I know a lot of people will accept the word ‘hearing impaired’ but that’s about a physical impairment. People may make that distinction for themselves, but for those that are born Deaf, there is no hearing loss. Deaf people don’t feel they have a ‘loss’ of sound as they never had it – it is normal for them. When I was growing up, people would say “you’ve lost your hearing” and I was confused as I never had it. If someone grew up hearing and then had a hearing loss that would be a different story. Deaf people do not “suffer with” a hearing loss so this is about being proud of our own identity and about being positive. (DPOREF3)

This DPO interviewee also noted that the term “deafblind” should be written all in one word. Additionally, the Anne Sullivan Foundation who made a written submission highlighted:

Worldwide, the term “deafblind” is a combined vision and hearing disability and the term is used as an umbrella term which includes people who also may have some residual vision and/or hearing.

Another DPO raised a point regarding the terms ‘blind’ and ‘visually impaired’.

’Blind’ covers everyone who’s partially sighted or totally blind. Equally, ‘visually impaired’ covered everyone who’s blind or partially sighted. For instance, if we were targeting visually impaired people that means totally blind and partially sighted people. We don't agree with the language of ‘blind and visually impaired’ as if they are separate – it’s as if to be blind is to be totally blind but to be visually impaired is to have some sight which is not the case. So what we say in our documents is ‘blind or partially sighted’ which covers everything. ‘Visually impaired’, like ‘blind’ is a generic descriptor. (DPOREF5)

Another DPO highlighted terminology regarding autism.

Language can be a barrier. Many government agencies use ‘Autism Spectrum Disorder’ which is offensive for many in the community who then will not engage. Language is always evolving. It used to be ‘person centred’, however it is argued that your disability isn’t something you can take on or off. Many now prefer to use ‘identity’ language. (DPOREF1)

A member of the ILMI Youth Collective stated in their view, they:

Absolutely cannot use [the terms] ‘additional needs’ or ‘special needs’.

Epilepsy Ireland also highlighted in its submission:

In terms of seeking submissions from persons with a disability – that terminology in itself can be difficult. From an epilepsy perspective, there are many living with the condition who wouldn’t consider epilepsy a disability but rather a long-term illness, invisible condition or invisible disability.

#### Language is evolving

DPO interviewees also highlighted the evolving nature of language, making the following comments:

The appropriate language to use is constantly evolving. Before, people used the word ‘handicapped’ and then it changed to ‘disabled’ and now the term ‘End User with a Disability’ is emerging. To keep up with appropriate language it is important to check in with DPOs. (DPOREF3)

Back in the 30s, or even the 80s, people would have defended the use of the term ‘handicapped’. Disabled people themselves would have defended the word, used of the word ‘handicapped’ because that's all they've known and they've been socialised into it. Language changes and our awareness of disability is changing. It is a social construct just like any other form of discrimination. (DPOREF5)

In ten years we will talk less about “autism” and more about “neurodiversity”. (DPOREF1)

This interviewee highlighted that in the UK, the term “neurodiversity” is already widely used. Neurodiversity includes other differences and disabilities such as ADHD and Dyspraxia, which may present with similar accommodation needs to autism.

### The role and function of DPOs

The UNCRPD outlines a specific definition of a Disabled Persons’ Organisation (DPO) as opposed to a service provider organisation or other civil society organisation. All five DPOs interviewed agreed that the guidelines should outline the definition of a Disabled Persons’ Organisation (DPO) and its role as defined by UNCRPD. Some also recommended that the guidelines explain what is not a DPO to make the distinction clear.

DPO interviewees made the following comments on this:

I was at the Oireachtas Committee and we were talking about the UN Convention along with a discussion on DPOs. I don’t think there is a good understanding in Ireland around what DPOs are and under-supporting of DPOs is a big problem. Trying to educate public bodies is very positive and I think it should come clearly through the guidelines that consulting with the disability community requires direct consultation with DPOs and indeed other disabled people. I think often this gets lost. (DPOREF1)

Service providers do great work but I think it should be quite clear that there is a distinction between these and DPOs. If you are working in a particular government department you might think that by talking to that particular service provider you are speaking to the disability community. I think you need to consult with all of these [organisations] but there should be an understanding of the difference. It would be useful to explain in the guidelines the difference between a DPO and other kinds of organisations such as service providers. (DPOREF1)

Public officials need to consult with Deaf people because they make decisions based on assumptions. Historically, a lot of consultation would have been done on our behalf but it’s important that you go directly to the source. It’s the representation ‘of’ rather than the representation ‘for’. I see more consultation taking place with the Deaf community and as a result of that changes can happen, but if it’s the case that consultation happens without us, then it’s just a case of carrying on with the same issues that we have had in the past. (DPOREF3)

According to the CRPD, DPOs must be prioritised as the only representative organisations of disabled people. DPOs also need to be specifically distinguished from any other consultees and given all necessary supports and facilitations. Involving DPOs on an equal basis with disabled individuals or with service providers etc. does not meet these obligations. (DPOREF5)

Various consultative mechanisms in the State don’t include DPOs. They consult with service providers, not DPOs. […] The service provision aspect is very important. I think it may need to be written into a point that representative organizations cannot be service providers, they can't, it’s a conflict of interest. Unlike any other sector, the legacy of service providers representing the voice of disability is so strong. They get paid massive money from the state, they are very strong on branding, advertising, marketing. (DPOREF5)

The CRPD makes very clear the experts are not the service providers, the experts are the representative organizations. The door is always open to service providers whereas it's always closed to DPOs in our experience. (DPOREF5)

We go to loads of Departmental Committees and we say that individuals don’t have a mandate to speak on behalf of people, to report back to people. Their thinking can be haphazard, they have no accountability for what they say. The most democratic way is for consultation to be in the DPO structure. Often disabled people can be in a token position of sitting on a Board - but they aren’t bringing a mandated collective voice of the disability community. (DPOREF2)

The Government goes to organisations representing disability service providers as ‘disability experts’ – you wouldn’t go to a ‘people of colour expert’ to talk about race. Disability service providers are distinctly different from Disabled Persons’ Organisations. (ILMI Youth Collective)

Some public submissions also highlighted that DPOs should be consulted and prioritised over service providers. Others shared their experience engaging in consultation as individuals with a disability. Some submissions also reiterated the point that Departments and public bodies need to be educated about the definition of a DPO.

### The inclusion of children and young people

UNCRPD Article 7 outlines the right of children with disabilities to:

express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.[[3]](#footnote-3)

General Comment 7 also highlights the role of organisations and initiatives of children and young people with disabilities. The right to participation of children is also protected under the UN Convention on the Rights of the Child (UNCRC).

The ILMI Youth Collective members felt strongly that disabled young people should be consulted on issues that affect them. They made the following comments:

Disabled people are just people. We are the experts in our experience, like any other minority group.

Government should remember that we are all part of the electorate and our votes count.

This is the first time I have been approached directly to take part in a consultation. Being represented authentically is important.

This group member stated that usually organisations approach disability service providers instead.

The group reported that, although they had not previously taken part in a government or public body consultation, ILMI as a DPO has created spaces for consultation to take place with young disabled people. For example in February and March 2021, ILMI conducted 11 consultations on different Articles of the UNCRPD. One included UNCRPD Article 7 which focuses on children and young people. The group states that there needs to be more of this direct involvement of young disabled people in consultation.

From the public submissions, an individual submission (SUBREF20) from a person who works with young people, as an employee of a public body, stated:

Young people and children with disabilities don’t get a chance to participate in policy development. The region I work in are beginning to plan to develop participation groups for these young people. However, I would be fairly certain that few staff would be aware of the UN Convention on the Rights of Persons with Disabilities, this needs to change.

### The role of other stakeholder groups

Some additional points emerging from consultation respondents with regard to the role of other stakeholder groups are presented in this section.

The ILMI Youth Collective group members wanted to specifically speak to the role of parents, and highlight the importance of directly consulting with young disabled people, stating:

Often people speak to parents instead of directly to young people. This does nothing for young people’s confidence.

The group members highlighted that when people speak to parents instead of directly to young people, it can be misconstrued, even if parents have “the best will in the world”. One member stated:

There’s a difference between walking the road and walking the road beside us.

The group also highlighted that parents come from a different generation with different attitudes towards disability. The group highlighted that this is another reason why it’s so important to connect directly with young people, as they may see things differently.

It is vital that communication and consultation is directed towards the person as they are the experts in their own lives. i.e., the young disabled person themselves should be consulted and not a parent or guardian because this will change the dynamic and narrative.

Several public submissions highlighted the role of other stakeholders such as family members, carers and service providers, in consultation processes. Submission respondents made the following comments:

The challenges are that parents do all the fighting and pleading for services. (SUBREF10)

As the grandmother of a non verbal child again the parent is the person who is acutely aware of the needs and would like to have a say in what the future holds for their child and how supports can be extended to allow them to have a totally inclusive family life. (SUBREF10)

To effectively partake in policy development people with impairments, our families/friends and carers must be involved at every stage of the policy development and improvements to achieve full disability equality. (SUBREF6)

We impaired people, our families/friends and/or carers must be allowed assist those responsible for policy development to find the necessary supports for us and to move any policy developments forward, if it is to be meaningful development for us. Policy development must include ways for us to say how we want changes to suit us, our families, carers etc. and we must be involved in it at every juncture. (SUBREF6)

Carers will need to be part of consultation processes in order for us to understand the intricacies of communication with their children. (SUBREF20)

No able-bodied person should be talking on our behalf unless they are a carer who has lived with a person with a disability for a considerable period (Nothing about us without us). (SUBREF13)

The Anne Sullivan Foundation in its submission stated:

For our clients with additional needs, such as cognitive impairment, they are reliant on others to be their voice and advocate for their needs as a person who is deafblind. Family members are often relied upon to be advocates and represent these needs, however policy development may not be skills that they possess.

Inclusion Ireland, in its submission, stated:

You should speak to people directly, not to the staff or their families.

Families often take part in consultations for people with high support needs and it is important that everyone who is involved has a say but that we keep policies person centred.

### Definition of disability and its implications for consultation

One DPO highlighted the definition of disability as an issue with potential implications with regard to participation and consultation, stating:

I think the problem is we don’t have one clear definition of disability. For example if the Department of Education is doing a consultation on disability issues they may look at the definition of disability under ESPEN, which is not the same as the definition under the Equal Status Act or UNCRPD. […] Some of the language that comes directly from the statute could cause a problem. (DPOREF1)

The idea is that it should not be a huge list of categories but it should be about the individual impairment interacting with environment and attitudinal barriers. (DPOREF1)

The same DPO interviewee also highlighted that for adults, there may not be a pathway to diagnosis within the HSE, only private diagnosis which is costly. The interviewee stated that this is something to bear in mind for consultation and ensuring people feel they can still take part without diagnosis.

The definition of disability with regard to consultation was also raised by a member of the ILMI Youth Collective, stating that:

[Within the guidelines] it’s important to break down language so it is accessible – for example ‘psychosocial disabilities’. Not everyone will understand what that means and therefore won’t realise they’re included in the consultation. Use a broad definition of disability so people know they can be involved.

This was also highlighted in relation to invisible disabilities. A DPO interviewee stated:

People with invisible disabilities are often made to feel like they have to prove they have a disability. (DPOREF4)

Epilepsy Ireland in its written submission stated:

In terms of seeking submission from persons with a disability – that terminology in itself can be difficult. From an epilepsy perspective, there are many living with the condition who wouldn’t consider epilepsy a disability but rather a long-term illness, invisible condition or invisible disability. By defining all of these under the term disability, that in itself can deter many from making contributions and we feel this should always be considered if seeking feedback.

The Anne Sullivan Foundation highlighted:

A key barrier is the fact that the condition of deafblindness lacks official legal recognition thus it is often a hidden disability. To meet the complex and varied needs of individuals, the State should recognise deafblindness as a unique disability to deafness and blindness and reflect this recognition in policy and legislation. A recent example being the Department of Justice’s call to comment on the State’s initial report to the UN Committee on the UNCRPD. Despite “deafblindness” being reference under “Article 24” there was absolutely no reference in the State’s report on how it was aiming to ensure equal participation and equal rights for people who are deafblind.

### Barriers to participation

The desk-based research highlighted some common barriers to participation (see Annex 1, part 3). The DPOs interviewed all agreed that these barriers exist and some consultation participants also highlighted additional barriers. The common barriers to participation identified through the literature and from this consultation include:

* Negative attitudes towards people with disabilities;
* Structural barriers (e.g. lower educational attainment, lower employment rates, lack of PA supports, unequal access to internet and technology);
* Intersectional barriers experienced by diverse groups;
* Lack of implementation of laws and policies which include provision for participation;
* Lack of awareness, skills and knowledge among public officials about disability;
* Lack of awareness, skills and knowledge among public officials about designing and delivering participatory processes;
* Non-DPO stakeholders being consulted in place of DPOs;
* Accessibility barriers: Inaccessible buildings, transport, and sensory environment; communication; information; websites;
* Lack of capacity-building support for individuals involved in participation processes;
* Lack of training, support and funding for DPOs;
* Poor planning of time and resources to enable meaningful consultation to take place;
* Consultation fatigue as a result of ineffective participation and consultation processes which result in little or no change;
* Lack of evaluation and learning taking place as part of participation and consultation processes.
* Lack of ongoing engagement with stakeholders beyond consultation through to implementation and monitoring.

### Emerging recommendations from Part 1:

1. The guidelines should be underpinned by UNCRPD and clearly set out the obligations on State Parties with regard to participation and consultation with persons with disabilities through their representative organisations.
2. The guidelines should align with existing laws and policies which include obligations that support the accessible and inclusive participation of persons with disabilities.
3. The guidelines should explain the difference between the social model and medical model of disability.
4. The guidelines should be underpinned by a social model approach to disability which examines environmental barriers to participation and how to remove them.
5. The guidelines should outline the context of different language used with regard to disability.
6. The guidelines should outline language which should not be used.
7. The guidelines should provide an explanation of Irish Sign Language and the cultural and linguistic identity of the Deaf community.
8. The guidelines should acknowledge the evolving nature of language and that DPOs should be consulted regarding appropriate terminology to be used at the collective level (e.g. in reports).
9. With regard to individuals taking part in consultation, the guidelines should recommend that the preferred language of that individual be used when referring to them.
10. The guidelines should explain the definition and role of a DPO under UNCRPD and how it is distinct from other stakeholder groups including service providers.
11. The guidelines should outline that in order to meet obligations under UNCRPD Article 4(3), Government Departments and public bodies must consult with DPOs. Some stakeholders recommended the guidelines state that DPO views with regard to disability must be prioritised over those of non-DPO stakeholders.
12. Departments and public bodies should proactively engage children and young people with disabilities, and their organisations, in participation and consultation processes in line with UNCRPD and UNCRC.
13. The guidelines should acknowledge the supportive role of parents, carers and other stakeholder groups - as acknowledged under UNCRPD and UNCRC - while emphasising that consulting with these groups does not replace direct consultation with DPOs, and children and young people with disabilities, whose views must be prioritised with regard to disability.
14. The guidelines should recommend the use of a broad and inclusive definition of disability based on the social model with regard to participation and consultation processes.
15. The guidelines should advise to never ask someone for a diagnosis in order to be involved in participation and consultation processes.
16. The guidelines should highlight common barriers to participation.

### NDA response to emerging recommendations under Part 1:

Emerging recommendations 1 to 10 and 13 to 16 have been incorporated into the updated guidelines. Recommendations 11 and 12 are partially incorporated. The NDA’s rationale for the partial inclusion of these recommendations is set out as follows.

In relation to emerging recommendation 11, this has been partially incorporated. As recommended by stakeholders, the updated guidelines outline that in order to meet obligations under UNCRPD Article 4(3), government departments and public bodies must consult with DPOs in relation to disability issues, even if they are also consulting with other stakeholders. Some stakeholders also recommended that the guidelines should state that DPO views with regard to disability must be prioritised over those of non-DPO stakeholders, referencing General Comment No. 7.

In response to this, the NDA guidelines acknowledge General Comment No. 7, paragraph 14. However, we note that General Comments on the Convention are not legally binding, and the practicalities of implementation in relation to this recommendation are considered in this context. In relation to the prioritisation of DPOs, the NDA advises in the guidelines that DPOs should be engaged in consultation and participation processes as a matter of priority throughout the process, and from the earliest stages. We advise that where limited spaces are available for a consultation which addresses disability issues, priority should be given to DPOs as representative organisations of disabled people. However, in recognition that public officials need to balance the views of a variety of stakeholders in participation processes, often addressing many intersecting issues, the NDA does not consider that it would be feasible to advise prioritising DPO views in all cases. In addition, the NDA recognises and respects that DPOs, as independent organisations, may hold different views from one another. In this case, a prioritisation of the view of one DPO could mean the deprioritisation of a legitimate view of another DPO and its members.

The NDA guidance therefore states that due regard and consideration should be given to the views of DPOs and that officials should recognise and utilise the valuable input of people’s lived experiences, offered by DPOs through their representative role. The NDA is also clear that when giving due weight to stakeholders’ views in participation processes, promoting and upholding disability rights must take priority over other views, such as resource-based arguments, for example. In addition, we advise in the guidelines that when engaging with organisations which may have business needs that are their first priority, their input should be examined in light of any conflict of interest they may have.

In relation to emerging recommendation 12, the NDA considers this a very important recommendation which requires separate, tailored guidance. The NDA is engaging with the Department of Children, Equality, Disability Integration and Youth on the development of guidelines specifically focused on the participation of children and young people with disabilities in decision making. It is likely that this guidance will be published in 2023. The participation of children and young people with disabilities is highlighted in the “Participation Matters” guidelines, but not examined in detail for this reason.

## Part 2: How to make participation work for people with disabilities – (a) Understanding Attitudes and Embedding a Culture of Participation

This section looks at suggestions from stakeholders about how to remove or reduce the main barriers to participation identified.

### Negative attitudes

The consultation responses highlighted negative attitudes towards persons with disabilities, and their representative organisations (DPOs), as a barrier to participation.

For example, one DPO interviewee stated:

We’re often made to feel like we’re different. (DPOREF4)

The door is always open to service providers whereas it's always closed to DPOs in our experience. (DPOREF5)

The ILMI Youth Collective members highlighted the “infantilisation” of young people with disabilities in which adults may assume they are incapable of forming their own view. They added that disabled young people grow up thinking outside the box which makes them a valuable asset in problem-solving, consultations and employment.

Many public submissions also highlighted negative attitudes as a barrier to participation, including DFI, Inclusion Ireland, and the DPCN. For example, one submission stated:

A change of attitudes is needed to genuinely include people with intellectual disabilities in accessible consultation processes. All people, including those with higher needs have to be included on matters that affect them and at all levels, including leadership roles. (Inclusion Ireland)

### Structural barriers

The consultation responses highlighted some of the structural barriers which affect participation and consultation of people with disabilities.

The public submissions highlighted income, employment and education. For example:

[…] many people with disabilities depend on a small income and face many extra costs due to their disability. (DFI)

CSO shows that 13.5% of the population with a disability and there were 176,445 persons with a disability in the labour force giving a labour force participation rate of 30.2 per cent, compared with a rate of 61.4 per cent for the overall population.

Amongst disabled persons aged 15 to 50 (inclusive), 13.7 per cent, had completed no higher than primary level education, compared with only 4.2 per cent of the general population. People with a disability were less likely to complete third level education, with 37 per cent educated to this level, compared with 53.4 per cent of the general population aged 15 to 50 (inclusive). (SUBREF13)

The ILMI Youth Collective also highlighted Lack of Personal Assistance as a barrier, stating:

Young disabled people (16, 17 years old) who need supports such as Personal Assistance should be engaged in that process at this age or younger. Ultimately when they turn 18 they might use PAs or perhaps other independent living supports. People who require support and are under 18 might miss out on social gatherings etc. because they don’t have the support. E.g. they have an “SNA” in the school environment and nothing outside of that environment to engage socially. This needs to change.

DFI also raised this point in its public submission.

Other issues such as lack of access to Assistive Technology, the digital divide were also highlighted in DPO interviews and submissions. These are discussed in a later section of this report.

### Intersectional barriers

The consultation responses highlighted intersectionality as an important consideration. In particular, an understanding that different groups can face additional barriers to participation due to their gender, age, ethnicity, geographic area, etc. The disability community is heterogenous and it is important to ensure a diversity of views are represented. DPO interviewees made the following comments:

Some people say [intersectionality is] about ‘two or more impairments’, which is a type of medical model intersectionality, but we see the social model informed intersectionality as incorporating class, gender, sexuality, ethnic background, poverty etc…. not ‘impairments’ but identities.” (DPOREF2)

The Deaf community is made up of different cohorts of people – for example, there is the Traveller Community but then the Deaf members of the Traveller Community is different again. It is the same for other minority groups, e.g., Deaf Muslim groups. They might be in the Deaf community but they don’t have resources of information about their other identities in ISL. (DPOREF3)

This interviewee gave an example of how intersectional barriers work in practice, stating:

I was talking to a Deaf member of the Traveller Community and they are not allowed to meet with members of other communities such as the Deaf community. They did not have any Deaf Travellers in their area so were completely isolated - for them if they wanted to socially meet people they couldn’t. (DPOREF3)

Some comments were shared highlighting that some groups are harder to reach. For example:

Some people don’t want to expose themselves to interviews. Sometimes these people are more vulnerable because they experience more barriers then just a Deaf person. (DPOREF3)

We have a problem, even within the disability community, around hearing some of those voices in the other direction. For example, within 7 years of running [DPO name] I can count on one hand how many Traveller families we have heard from. So there would be a very strong perception say within the autism community that the voices you hear are white, male, autistic voices and I think there is a body of work to be done around consulting with disabled people to make sure there is diversity within that group. (DPOREF1)

DPOs shared the following comments regarding their own efforts to address intersectionality:

[DPO name] does have contacts with members, in Deaf women’s group, Deaf youth groups etc. and we have subgroups. (DPOREF3)

We try to promote people from diverse backgrounds – we have members who are homeless. We have a bit of an age problem in that we don't have younger members. We are working on a policy for under 18 year olds. (DPOREF5)

We’ve got Full Spectrum (LGBT), a PA Group, a Women’s Group, Youth Group, Olympic Swimmer Group, Social Inclusion & IT Group, Disabled Direct Provision Women’s Group, and soon will have Disabled Traveller Group. The DPO process and principles can be used to capture voices of everyone. (DPOREF2)

When asked how they target these groups, interviewees responded:

We go through other organisations, the disability sector, local development groups, migrant groups, LGBT groups - they are quite happy to send disabled people our way. We can build up capacity around disabled migrants, disabled Travellers. It’s a long process but it’s organic. (DPOREF2)

As well as the DPOs having to be consulted maybe there is a bit of work the State could do in relation to building with minority groups about disability and hearing state funded groups asking them to be something that they look at. […] There needs to be relationship building before consultations happen with minority groups through their representatives. (DPOREF1)

The ILMI Youth Collective members also highlighted:

It’s important to have diversity within a group you are consulting whether that’s in terms of age, different impairments.

Some public submissions, including those by DPCN, Galway Access to All, and DFI, also raised the importance of recognising intersectionality and the diversity and heterogeneity of experiences across the disability community.

### Embed a culture of participation of persons with disabilities across Government

#### Disability inclusion as a Government priority

Some consultation participants highlighted the importance of disability being a priority at the highest level of Government in order to address barriers to participation.

For example, the ILMI Youth Collective group members highlighted that disability rights should be a higher priority for the Government stating:

[The Group] would like to see the Minister for Disability as a more senior position – not a junior minister.

Points regarding the prioritisation of disability and UNCRPD by the Government were also highlighted by Galway Access for All, the DPCN and individuals (SUBREF5; SUBREF7) in the public consultation.

Galway Access for All and individual submissions (SUBREF5; SUBREF7) also highlighted the need for the Government to enforce laws and policies. Some comments include the following:

The biggest challenge for people with disabilities to effectively participate in policy development is the State’s lack of will to take our concerns seriously and enforce rules and regulations. We are not asking for special compensation; we are demanding equal rights guaranteed by the UN Convention. (Galway Access for All)

Access is a civil right not a guideline. We are so very tired of seeing reports after reports when on the ground if feels like our access is shrinking. […] Our access shouldn’t be a recommendation, it should be ensured. (SUBREF7)

Instead of going forward with the UNCRPD being implemented we are fighting to keep what we have now. (SUBREF5)

#### Coordination and collaboration within and across the Government

The following comments were shared regarding the need for better coordination and collaboration across Government regarding disability inclusion:

Departments don’t work together. (DPOREF4)

There are issues with Government Departments not working together well and not speaking to each other internally. (ILMI Youth Collective)

Public submissions from CCUAM, DFI and an individual (SUBREF5) also highlighted the need for greater collaboration and communication, including at the local level.

#### Representation of people with disabilities in public sector leadership and governance structures

Two DPO interviewees highlighted that better representation of people with disabilities in management or governance structures could improve participation, stating:

Who is in senior management? Who are the decision makers? They are the ones saying we will involve Deaf people or we will involve people with disabilities. Deaf people should also be involved in those levels, as decision makers. Deaf participation can happen - you don’t just have to be on the receiving end of it. It would be good see Deaf people at the top of organisations and at all levels. (DPOREF3)

DPOs should possibly be on the Boards of service providers. Not that they would be accountable to that one DPO, but the DPO could ensure that proper consultations take place. Building it into the structure/governance. (DPOREF5)

#### Access Officers

Access Officers were also highlighted as an important way to ensure proactive engagement with people with disabilities in Departments and public bodies:

Very few departments have access officers. (DPOREF5)

We’ve been pleading for a full-time Access Officer […] there seems to be an expectation to document every violation ourselves before someone with the power to fix it will look at it. (Galway Access for All)

#### Funding for DPOs

Some respondents highlighted the need for funding of DPOs to support their engagement in participation processes. The following comments were shared:

The guidelines could highlight that DPOs are not publically funded or highly funded. (DPOREF1)

While the power structure is exactly what it is we cannot compete, we have zero income from the state, the [service provider] is sucking up our representative space. (DPOREF5)

Ensure finance and supports are available to enable DPOs to participate in consultations. (Galway Access for All)

Resource DPOs and disability organisations to participate, building their capacity to represent their members. (DPCN)

#### Senior leadership support for inclusive participation

The importance of organisational culture and senior management support for the participation of persons with disabilities in the work of Departments and public bodies was also highlighted in the consultation.

From Director/senior management all the way down. [Participation] must be embedded in the culture. There are some great people in the sector, who sign contracts that they have to follow the policies of the organisation. Their principles can often be counter to the culture of the organisation. (DPOREF2)

I think as well as senior managers having these guidelines, I think there is another category that should have them as well and it’s at the clerical level etc. Security, reception, canteen. (DPOREF1)

In terms of how to embed this culture of participation, one DPO interviewee suggested

I think that each [public sector] organisation should have its own a consultation charter, specifically related to disability. That could start off as advisory possibly but it should become mandatory. (DPOREF5)

In the public consultation responses, others highlighted the importance of senior management buy-in to ensure sufficient budget allocation and authority to implement the consultation recommendations. Comments include:

It is crucial that any policy development be guided and informed by available public funding to achieve the aims as set out within the timeframe of the policy. To do otherwise is to set a level of expectation above which those tasked with implementation can achieve, which in turn causes frustration, stress, disappointment, and a sense of failure, even where this is outside the control of the individual or the organisation. (IPPN)

Where consultation on public policy documents – local authority strategies, development plans etc. – is undertaken, there is no authority or commitments from other departments or sections of public bodies to realise and implement the suggestions that are incorporated into the plans. Where local authority staff are allocated to support Disabled People’s Organisations and Public Participation Network members, they have limited scope to effect the change required. (Galway Access for All)

Have a commitment, including financial, to undertake the recommendations made through consultation.  Appoint a team/officer within each Department as a contact person responsible for the incorporation and implementation of policies. (Galway Access for All)

Allocating additional financial and human resources is critically important to facilitating a successful consultation meeting. (Anne Sullivan Foundation)

An individual submission from a person employed by a public body who works with children and young people stated:

The participation of children will need yearly funding for it to become normal practice for staff. When the above is complete perhaps then agencies who have a responsibility to work with children/young people with disabilities will be in a position to help develop policies and as such ‘hear the voice of the disabled child’. (SUBREF20)

#### Training and support for public officials

Training for public officials was highlighted as important by many who took part in the consultation. Suggested training topics included Disability Equality Training, Deaf Awareness, training in running participatory processes, child and youth participation, UNCRPD, inclusive digital methodologies, facilitation training, awareness of Deafblindness.

With regard to disability awareness and equality training, the following comments were shared:

Disability Awareness is not the same as Disability Equality. Awareness is usually by a non-disabled person for non-disabled audience and usually focussed on impairment label information. Equality is about the proper language, history. Colleagues in UK are adamant that they don’t do awareness but equality. (DPOREF2)

It’s important that when it comes to senior management that they have Deaf awareness - you can’t make the assumption that you know everything about Deaf people. It’s about being mindful that there is a Deaf community with its own culture, language, linguistics, history etc. (DPOREF3)

Education is very important. [DPO name] is open to helping Government and society to understand how to embrace us. (DPOREF4)

Another DPO interviewee pointed to the lack of awareness of many public officials regarding DPOs, stating:

I've just been dealing with a report by [a public body] that's going to be released this week or next week which is about service provision for people, including with disabilities, voluntary versus statutory, cooperating better and all the rest of it. Not one DPO was mentioned or contacted by the author of the report. I called them and they said that they had never heard of DPOs. […] They need to be aware of the difference between DPOs and service providers. That's the biggest problem. They see anything with “disability” in its name and they think, “that'll do”. (DPOREF5)

Public submissions from the NCBI, Galway Access for All, DFI, the Anne Sullivan Foundation and the DCPN also highlighted the need for training of public officials, including Disability Awareness training and training in participatory methods.

Improving the skills of public officials in facilitating the inclusion of children and young people with disabilities was another area highlighted by consultation stakeholders. For example, a DPO interviewee stated:

In a meeting with a Department, I raised the issue of young people not being consulted on a policy that directly affected them. In response, the Department officials said that if we consult with children, we don’t really have the skills so what ends up happening is that certain children will be pushed to the front, who have particular points of view, and will be used as a vehicle for those viewpoints. I think that because we are not better at reaching more young people it is nearly sometimes used as an argument against consultation. (DPOREF1)

An individual submission from a person employed by a public body, who works with children and young people, stated:

In order for children and young people to participate it’s my firm belief we have to start with the staff and stakeholders who have little experience of working with this group but have a responsibility to them […] Then we need to reinforce training in participation to emphasise its importance. (SUBREF20)

The ILMI Youth Collective also highlighted that Departments and public bodies should understand that:

Consultation is not just something that is ‘empowering’ for us – when we take part in consultation we improve their policies, budgets which in turn equality proofs them.

### Emerging recommendations from stakeholders under Part 2:

1. Address attitudinal barriers – recognise people with disabilities, and DPOs as representative organisations, as experts and agents.
2. Recognise the structural barriers faced by people with disabilities, and DPOs as representative organisations, in terms of participation.
3. Take an intersectional approach to the design of participation and consultation processes to ensure that they are accessible to all and reflect a diversity of experiences across the disability community.
4. Participation of persons with disabilities must be embedded from the highest, strategic level (including Ministerial and Departmental senior leadership) down to the implementation level by:

* Prioritising disability inclusion across Government;
* Improving coordination and collaboration across Government Departments and agencies regarding participation of persons with disabilities;
* Improving representation of people with disabilities in public sector leadership;
* Appointing Access Officers across the public sector who have responsibility for information and communications in addition to physical accessibility
* Ensuring senior leadership support for participation, including in planning and budgeting processes;
* Increasing awareness, knowledge and skills of public officials at all levels with regard to disability equality, participatory processes and inclusive child and youth participation.

### NDA response to recommendations from stakeholders under Part 2:

The points made in emerging recommendations 17 to 19 are acknowledged in the updated guidelines. In relation to emerging recommendation 20, some of the points, while important, are beyond the scope of these guidelines. However, the guidelines do acknowledge the importance of embedding participation in the culture of a Department, public body or local authority. Senior leadership support for participation of disabled people, including adequate resourcing, is highlighted in the guidelines. The importance of collaboration and sharing learning across the public sector is also highlighted. Disability Equality Training is highlighted as vitally important. A distinction is made in the guidelines between Disability Equality Training (the recommended approach) and Disability Awareness Training, as requested by DPO participants which took part in the consultation.

## Part 3: How to make participation work for people with disabilities – (b) Designing inclusive, accessible and responsive participation processes and mechanisms

### Universal Design

Submissions highlighted that persons with disabilities should have an opportunity to participate in processes dealing with a broad range of policy areas, not just those which are deemed disability-specific.

In interviews with DPO stakeholders it was asked whether a Universal Design approach should be outlined within the guidelines, in order to ensure that Departments and public bodies are advised in such a way that all participation and consultation processes are accessible to persons with disabilities. DPO interviewees shared the following comments:

Universal Design is interpreted by some as “we’ll design for as many as we can”. It’s seen as an aspirational thing and that we can’t design for everybody. So Universal Design, it has to be made clear, it's about access for all. This doesn't mean, for example, access for cyclists. A cyclist is not a thing under law, a cyclist is a form of transport. Whereas a disabled person is something under law. (DPOREF5)

I have an ongoing bug bear that I don’t think that UD guidelines always capture the needs of autistic people. Particularly around sound etc. I just think it’s important that the sensory element is included. (DPOREF1)

UD is fantastic but it does not include Deaf people. For example, if you go into a building, you have fire alarms but a lot of them are not visual, they are all sound-based. If I am stuck in a lift and press the bell someone talks to you which is not accessible for Deaf people. There is no visual way to access info. Intercoms all depend on sound. It is best to have a visual screen through which Deaf people can communicate. For example, there is a lift in the Deaf Village and it is glass so if someone is stuck, they can get another person’s attention easier. This is similar to lifts in shopping centres. (DPOREF3)

[Universal Design] needs to be medical-model and social-model proofed. (DPOREF2)

Public submissions from NCBI and Galway Access for All agreed that persons with disabilities should be consulted on a broad range of issues. NCBI also suggested that the underlying principle for consultative processes should be Universal Design.

### Important elements of participation processes

Some consultation responses highlighted cross-cutting elements that should underpin an effective participation process including transparency, trust and respect, two-way dialogue and ongoing engagement.

#### Transparency

Transparency and clarity surrounding the process was highlighted as an important element of consultation. Some comments from stakeholders include:

It should be explained in an accessible format at the beginning of the meeting how data and information is going to be collected and that information will be anonymised and then the recording will be deleted to allow the disabled person feel fully at ease when sharing their experiences. (ILMI Youth Collective)

Ensuring participants are fully aware of the process, how it will work and what follow up will happen with the information they provide is vital in building trust in the process. (NCBI)

[…] we feel it is always very important to spell out clear timelines, what the goal of contributions are and ensure that contributors are kept informed throughout the process. (Epilepsy Ireland)

Galway Access for All also highlighted the importance of clarity about how the consultation materials will be incorporated and utilised.

#### Trust and Respect

The following comments were shared in relation to trust and respect:

When consulting it is important that an atmosphere of respect, understanding and non-judgment is fostered in the consultation space, by both the participants and facilitators, and that confidentiality and anonymity for each participant are maintained in the process. This will allow all participants to feel sufficiently comfortable in sharing their authentic and honest lived experiences. (ILMI Youth Collective)

Young disabled people should be given the space and time to express their views free from judgment. (ILMI Youth Collective)

Some comments from the public submissions include:

People might be afraid, if I speak up will things change for me. (Inclusion Ireland)

We impaired persons must be treated as equals in any deliberations with the people responsible for policy development. (SUBREF6)

Good communication is based on trust. It is paramount you trust the person you are conversing with to provide the correct information in an easy to understand manner and not lead you astray. (SUBREF6)

Ensuring parity of esteem amongst all those participating is vital to facilitating meaningful engagement in the process. Everyone should have the opportunity to speak, have their voice heard and where there are disagreements, these should be managed respectfully. (NCBI)

#### Two-way Dialogue

Consultation stakeholders raised the importance of consulting bodies understanding consultation processes as a two-way communication, rather than a top-down information sharing approach. One DPO interviewee stated:

[Dialogue is] A two-way exchange of information between two equal bodies rather than a topdown telling people what to do, and then that information and experience not being used. (DPOREF2)

Public submissions from the NCBI and two individual submissions (SUBREF2; SUBREF5) also highlighted this point.

#### Ongoing engagement

Submissions highlighted the importance of ongoing engagement rather than once-off consultation. Some comments include:

Consider and commit to relevant ongoing consultation and engagement [and] considering how those being consulted be able to further participate, even if this is simply being kept up to date with developments. (DFI)

In the context of UNCRPD and the Public Sector Duty requirements, public bodies will need to have ongoing systems to “listen” to disabled persons. Their management information systems need to track feedback on an ongoing basis and this can get us beyond the “once off” nature of consultation. (DFI)

Consultation is not an ‘event’, it is the place where listening takes place and following it the consulting body needs to demonstrate to the participants how their subsequent decisions were informed by that listening. (DFI)

Consultation should be an ongoing process and be constantly monitored internally and externally as there have been problems in the past. There must be accountability on all sides. (SUBREF5)

Elements of ongoing engagement and two-way dialogue are also discussed in more detail later in this report.

### Proactive and early engagement

The DPOs interviewed all agreed that consultation with DPOs should take place as early as possible in the process. Many also highlighted the obligation on Departments and public bodies to proactively engage with DPOs, rather than waiting for a DPO to contact them. The following comments were shared:

It is important to be involved from the beginning. Sometimes when you do get involved, they are already halfway through the process and suddenly they realise they missed something about Deaf people that they will need to change. If we are involved from the start this would not happen. (DPOREF3)

When I get involved in the conversation there had been no consideration for ISL, I tell them that we have ISL material and information for children etc. and they say “oh we didn’t know that” and then they have to go back to the beginning and start from scratch. That shows that if anything is relevant to Deaf people they have to be included from the start. People assume they know, but it’s best to get the facts right from the beginning. (DPOREF3)

I think the Government are very slow [to consult]. I went to a Minister launching a survey about people living in the community […] She said she forgot to include anything about disability. It’s very easy to include disability - ring up Inclusion or the National Platform. (DPOREF4)

The onus should be on the various sectors to seek out the most relevant DPOs to consult with. […] different DPOs have different core areas of concern. (DPOREF5)

They need to contact us, not waiting for us to contact them all the time. It cannot be a passive thing on their part. (DPOREF5)

They have to remember that the obligation is now on the State to engage with us, the DPOs. (DPOREF5)

It should not just be up to disabled people to highlight gaps in law and policy in order to realise their rights, but that the Government should be proactive in ensuring rights are upheld. (ILMI Youth Collective)

Another DPO interviewee pointed to the ad hoc nature of engagement, stating:

It’s very hit and miss and it depends on the agency and the piece of work, timelines and all of those things. (DPOREF1)

Public submissions also highlighted the need for consulting bodies to engage early with persons with disabilities. In order to achieve this, submissions highlighted the need for consulting bodies to raise awareness of consultation processes amongst persons with disabilities and to proactively identify and target them as a key stakeholder group for involvement. Some comments include:

Nothing about us without us. This means at the earliest stage of any design at local level all the way to national level. (SUBREF5)

The timing of consultation is especially important. Consultation must be from the pre-planning stages, not just a tick box exercise of what the public body has decided will be approved. (Galway Access for All)

Some public submissions highlighted as a challenge a lack of awareness or understanding of decision making and consultative processes and how they can input into them as a key barrier. Some comments include:

How do you participate in policy development when it is difficult to find out what the policies are? (SUBREF10)

I think there needs to be a lot more communication or awareness surrounding important topics and things that are going to affect these people. (SUBREF18)

There is no clear pathway of how to be heard by people that make the decisions. (Inclusion Ireland Self Advocate)

Communication around the opening of policy development procedures across all available channels is key to ensuring people engage. (Epilepsy Ireland)

The improvements that could be made in relation to the challenges for people with disabilities to effectively participate in policy development are around language awareness, how policies interact with their daily lives and how they get a say. (CCUAM)

Cairde, in its submission, reported that people it engages feel they are not asked to input into policy development processes, and often don’t understand what information is required or what decisions are being made at a local/national level.

Submissions by NCBI, Epilepsy Ireland, and the Anne Sullivan Foundation also highlighted the need for persons with disabilities to be specifically targetedfor engagement early in a process. Some comments include:

It is vital the people with disabilities are included from the beginning of any process so they can participate fully and influence the changes that will be made in a meaningful way. (NCBI)

[…] even prior to the accommodations outlined above our clients need to be invited to such meetings which they often are not. A key factor is the lack of recognition and awareness of deafblindness as a unique disability in its own right. (Anne Sullivan Foundation)

Proactively include people who are deafblind in all consultation processes” and “Proactively include organisation who support people who are deafblind in consultation processes. (Anne Sullivan Foundation)

### How to raise awareness and target stakeholders

DPOs, as representative organisations, have networks and methods to reach persons with disabilities for consultation. For example, DPOs interviewed reported having within their networks persons with disabilities throughout the country, including people with various intersectional identities such as LGBTQI+, women, young people, those with experience of Direct Provision, those from the Traveller Community, those with experience of homelessness. (See Section ‘Intersectionality’ in this report).

In terms of other methods, one DPO interviewee (DPOREF1) noted that for them, Facebook is very important and social media in general. However they also noted that there are many people who are not IT literate and there’s a danger they won’t be reached this way. This interviewee suggested using various methods to reach people stating:

It’s such a broad spectrum that you should reach out to DPOs, organised groups, universities, service providers, online etc. (DPOREF1)

Public submissions also highlighted some suggestions with regard to raising awareness of consultation processes and targeting persons with disabilities. Comments include:

Recognising the different platforms that are most used by different age cohorts, it may be suitable to use these platforms to reach people that may otherwise be hard to reach e.g. younger people. (NCBI)

Local Government needs to create strategies to connect with citizens as there appears to be a lack of thinking between public bodies and citizens. This could be done by partnering with DPOs to make sure they take centre stage with Strategic Policy Committees (SPCs) and the Local Community Development Committees (LCDCs). (CCUAM)

Epilepsy Ireland also recommended the use of both traditional media and social media. Submissions from DFI, CCUAM and two individuals (SUBREF11; SUBREF18) highlighted that persons with disabilities can be reached through organisations which have existing relationships with them. Organisations highlighted include DPOs, voluntary organisations, schools, the HSE, youth organisations and clubs.

### Accessibility

Accessibility barriers including language, information, communication, the physical environment, technology, were highlighted consistently among consultation respondents. These are highlighted in more detail in the sections below.

More generally, the point was raised that accessibility must be ensured and reasonable accommodation provided proactively, rather than putting the onus on the person with a disability to always request it.

It’s important to ask people how they can take part BUT don’t put all the heavy lifting on them either. Just provide the information from the outset – e.g. telling people upfront what supports are available, there will be accessible bathrooms, there will be ISL etc. It takes the burden off disabled people to always have to be asking about it. Supports need to be linked from Government Department to Government Department and public body to public body so young disabled people can participate and be truly represented. (ILMI Youth Collective member)

The DPCN also agreed with this point.

Others highlighted that accessibility is not a ‘one-size-fits-all’ approach, stating:

A key challenge is that the extent and type of support needed differs depending on individual needs. People who are deafblind are a heterogenous group within which there is a wide spectrum of need and ability. (Anne Sullivan Foundation)

#### Accessibility of the physical environment

Physical accessibility of in-person consultation activities was highlighted as a barrier by all DPOs interviewed. Some provided specific comments to highlight certain issues. These are not an exhaustive reflection of all the considerations needed to ensure an accessible physical environment but reflect points raised in the consultation. Comments include:

The design of signs can be tough even on people who can read and write sometimes.” (DPOREF4)

People are rushing by you, not thinking about the person walking slowly, you’re in their way.” (DPOREF4)

Another DPO interviewee (DPOREF1) highlighted the sensory element to physical accessibility. They advised that their DPO has a Sensory checklist which can be used for guidance. Sensory elements could include the choice of room, for example. The interviewee provided an example of a room within one Government Department in which there is a persistent buzzing noise, which many people might not notice but which some may find very distracting.

Some public submissions also highlighted physical accessibility as a barrier. For example, DFI and the NCBI.

NCBI also raised that understanding of physical accessibility must go beyond wheelchair access stating:

The Draft State report on the UNCRPD focuses on wheelchair accessibility of transport links and the built environment ignoring other issues related to the built environment and transport issues e.g., lack of eye-level or large print departure boards and signage, assigned seating signage, lack of/inconsistent audible announcements, shared paths, eye-level signage in buildings.

#### Accessible transport

The issue of **transport** to meetings was also highlighted as a barrier. Many DPOs reported that since moving meetings online due to COVID-19 restrictions, the barrier of inaccessible transport has been removed (see section ‘Online meetings’ for further comments on this).

In the public submissions, inaccessible transport was highlighted as an issue by Inclusion Ireland, NCBI and the Anne Sullivan Foundation. One submission stated:

70% of participants who took part in NCBI’s 2016 Out of Sight Report use public transport, highlighting that accessibility of transport links for service users is a significant issue. (NCBI)

The ILMI Youth Collective also highlighted that having to give advanced notice to access public transport affects young people’s ability to be spontaneous and has implications for access to in-person consultation activities.

#### Accessible information

Lack of accessible information is a key barrier highlighted in the consultation. Consultation responses highlighted that this can include inaccessible language, inaccessible format of information, and lack of time and support to understand and process information.

#### Accessible language

The following comments were shared regarding accessible language:

It is important that all policies, legality, terminology and any information that is used is translated in plain English and also into Irish Sign Language (ISL). ISL is the preferred language of the Deaf community, English is the second language, but written English is not always accessible. DPOREF3

The majority of people with disabilities have access to the same language as that of the nation but not the Deaf community. […] Deaf identity and the linguistic element of the Irish Sign Language Act is so important to us - it always comes back to language. (DPOREF3)

In the public submissions, DFI and the Anne Sullivan Foundation also raised the need for ISL interpretation.

With regard to plain language, the following points were raised in the public submissions:

Language can be deliberately difficult, it can be challenging to understand so people won't question what's happening, this goes against making things easy to access and understand. (DPCN)

Policy-making should not commence with pre-set assumptions and barrier-making language or concepts. (SUBREF2)

Our experience in relation to the participation of adults with disabilities in policy development is that the language used can be above their heads. (CCUAM)

The word consultation can be difficult to understand and even the word policy can be hard to understand so background information and an understanding of what people are getting involved in is really important. (Inclusion Ireland Self Advocate)

Just make it easy to understand language in materials like posters or videos. Don’t use the doctor language! (Inclusion Ireland Self Advocate)

Never use trade language and if required give the more normally used wording with it. (SUBREF5)

#### Information in accessible formats

A lack of **information in accessible formats** was also highlighted as a barrier.

For example, a DPO interviewee highlighted the widespread issue of inaccessible documents for visually impaired people, stating:

PDFs are the norm for instance […] so immediately, that's the first barrier - we have to convert that. I mean that's not searchable unless you have an expensive professional Acrobat Reader to work with screen reading technology, and that's just not accessible. It’s against the Web Accessibility Directive 2016. It's just completely endemic this thing and it is absolutely shocking. (DPOREF5)

People are expected to do work-arounds. For example, converting a PDF into Word. This takes extra time to do and you’re not guaranteed it’s going to work. You have to make screenreader accessible document, that’s .doc versions and all images have to be described. (DPOREF5)

Often their [Government Department and public body] websites are not accessible so we don’t find out about a consultation. (DPOREF5)

Another DPO interviewee stated that they prefer to receive information in easy-to-read format with plenty of time beforehand to read it, stating:

There is not much information for us. (DPOREF4)

Easy Read is good for everyone, not just people with ID. (DPOREF4)

Accessible information was also highlighted in the public submissions by Inclusion Ireland, the NCBI, Cairde, the Anne Sullivan Foundation, DFI and the DCPN.

Ensuring the EU Web Accessibility Directive is implemented will ensure that the information provided in outline platforms is accessible. (NCBI)

“[…] the information required for meaningful engagement must be fully accessible. This means that all materials must be available in different formats and compatible with assistive technology (AT). AT is a vital tool for people who are blind and vision impaired in accessing information and without it, it is extremely difficult to meaningfully engage in any consultation process.” (NCBI)

Inclusion Ireland also highlighted the importance of information in easy-to-read format and using video as well as written information. This point was also made by Cairde.

The Anne Sullivan Foundation highlighted that the deafblind community is heterogeneous and different formats are required for different people. Some examples of accessible formats for deafblind people include Braille, large print and swell symbols (tactile raised lettering or pictures).

#### Timely provision of accessible information

A DPO interviewee (DPOREF1) raised the issue of having sufficient time to process information. This interviewee suggested sending questions in advance and allowing time after the meeting to reflect and come back with comments. Similarly, the ILMI Youth Collective also highlighted this point stating:

Some disabled people need time to process information and collect their thoughts so it is important for accessibility purposes where possible to give an outline or structure of the meeting or consultation. E.g. include structure, timing, and questions to be asked. (ILMI Youth Collective)

The submissions from DPCN and DFI also highlighted the need to provide information in advance of consultations so people come fully informed and prepared.

A member of the Inclusion Ireland Self Advocates Group shared an example of how support can be provided effectively to facilitate participation:

I’m on the Board of Inclusion Ireland, and we get help from Christine, she does the papers in easy to read and all that. We meet with Christine the day before the Board meeting and we go through the agenda of the Board meeting, what’s coming up. We give our own self-advocate’s report to the board. The day after the meeting, Christine would do a debrief, and we talk about how the meeting went, and how we felt about it. And you’re getting your opinion across and people are listening. You know, things change slowly, they won’t change overnight, but they change, slowly. (Inclusion Ireland Self Advocate)

#### Accessible communication

Consultation respondents highlighted that persons with disabilities may communicate in different ways and that consulting bodies should communicate in a way that best suits the person who is participating.

One DPO interviewee highlighted that there can be hierarchies of communication within groups of participants with different disability types and that it is important to be aware of this in order to ensure discussions are inclusive of everyone. They suggested:

Decide on the pace of the discussion depending on the individuals there […] Recognise that a non-verbal person might have lots to say, so design the discussion around that. (DPOREF2)

Another DPO interviewee raised the importance of facilitating a persons’ communication preference, stating:

There are Deaf people that prefer to write and others that prefer to sign but the essential thing is that it is accessible to all. (DPOREF3)

Subtitles are handy but again, are only appropriate for some people. Similarly, many hard of hearing people don’t use ISL and only rely on subtitles. (DPOREF3)

Public submissions also highlighted the various ways different persons with disabilities communicate and that consulting bodies should use different methods to communicate depending on what is required. Comments include:

We should have more meetings with government so they take our voices seriously, they should communicate in a way that suits disabled people. (Inclusion Ireland Self Advocate)

[…] use different methods to communicate with diverse groups and people. ISL for example is needed for Deaf people but is very hard on people who are non-neurotypical. (SUBREF5)

[There is] a lack of consideration of the different ways that people with disabilities might communicate. For example, many 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. (DFI)

Give people the opportunity to have a “buddy” or support person with them. (DFI)

For the people we support who are deafblind, communication is the biggest barrier to their participation in policy development. There is limited access and availability of trained communication guides and funding for ISL interpreting can also present barriers. There is a dearth in the availability and skillsets in trained tactile sign language, stenography, guides, PA support, etc. (Anne Sullivan Foundation)

The Anne Sullivan Foundation highlighted that 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/Hand-over-hand/ tactile sign language /finger-spelling, Lámh, Objects of reference/symbols, Picture Exchange Communication System (PECS) symbols or pictures, and Gestures.

#### Access to internet and technology, including assistive technology

Comments were shared in relation to access to internet and technology, including assistive technology.

Access to internet and technology is a big one for us – it takes a while to become competent in it, or for people over a certain age, but it affects everyone. (DPOREF5)

People can’t always access consultations because they don’t have the technology to access. (Inclusion Ireland Self Advocate)

People need access to a computer phone, technology and the support. (Inclusion Ireland)

Whether the meeting is taking place online or face to face, additional barriers can include access to technology and if the person does have access to the technology, the platforms or software used to facilitate engagement may not be compatible with assistive technologies which are essential for many people with sight loss. (NCBI)

Despite the significance of assistive technology for people who are blind or vision impaired, funding for assistive technology in Ireland is fragmented. Currently, there is no standardisation of assessment or funding of assistive technology applications across the country. Many people are unable to afford the upfront costs of essential assistive technology and must go without. While the HSE do provide the Technical Aids Grant in some areas, those aged 65 and over are not eligible for the grant. There is also very little information available to those wishing to apply for the grant, and smartphones are not available under the Technical Aids Grant. NCBI recommends standardisation of funding and assessment practices across the country, with eligibility extended to those over 65 and inclusion of smartphones under Technical Aid Grants funding to support access and engagement with policy discussions and decision-making structures. (NCBI)

Lack of access to assistive technology was also highlighted by DFI in its submission.

#### Inclusive Timeframes

Submissions highlighted that consultation processes with short timeframes make engagement difficult.

Oftentimes, there will be limited resources within the organisation and a number of projects will be ongoing so the more notice that is given to disseminate, the more of a chance that considerable feedback can be obtained. (Epilepsy Ireland)

In order to allow genuine input it is necessary to give a longer lead in time for consultation. (NCBI)

Facilitating extra time for responding to consultations, avoid having consultation sessions during (summer) months when organisations and individuals are operating at a reduced level. (Galway Access for All)

#### Capacity-building for participants

Submissions also highlighted the importance of capacity-building support for people with disabilities to meaningfully participate in a consultation process or mechanism.

A DPO interviewee highlighted the importance of support for those taking part, stating:

One thing that I think is important is sometimes there might be early stage consultation, be it a survey or focus group or something, and then maybe an ongoing consultation and then when it goes to very intense consultation there is not enough support. Sometimes people e.g. parents, autistic people themselves get lost in it. It can be very intimidating for some people and support is needed. It can leave people very vulnerable and exposed. It should never be one person it should always be at least two. People need to have the support to engage. (DPOREF1)

A number of public submissions also highlighted the importance of training and capacity-building with the following comments:

Capacity building can be the difference between isolation and exclusion from all aspects of life for people with disabilities on the one hand, and becoming change agents on the other. (CCUAM)

People with disabilities need to have a seat at the table but also need to know the processes for engagement and feel empowered and confident in being able to participate. This training should be age-appropriate and should also include self-advocacy training. Facilitators need to undergo appropriate training to ensure everyone can participate fully. (NCBI)

They [Cairde service users] like to understand what they are deciding and how it will affect them on a day to day / practical level. (Cairde)

[A challenge is] People not supported to fully participate in consultations - prior to consultations to ensure they understand issues, form own opinions etc. particularly regarding people with intellectual disabilities and those with high support needs. (DPCN)

The DCPN suggested holding preparatory sessions to help people prepare, particularly for people with intellectual disabilities. They provided the following example:

A good example of this was demonstrated at a recent DPCN consultation on Gender-Based Violence. A Centre Manager at a disability service played a key role in holding 3 workshops prior to the consultation where disabled people were given opportunities to fully understand the issues, talk in a safe space of their own experiences, using role play and accessible materials and rehearse what they wished to feedback at the public consultation; this provided key insights into the complexity of the issues being discussed. (DPCN)

The DPCN also suggested peer training for disabled people to build their capacity to consult and engage with their own representative groups. In addition, the DPCN highlighted the need for capacity building for disabled people to use technology and online tools as consultations are now likely to continue online.

#### Payment for participant expenses and time

Payment is another issue that was highlighted in the consultation. Reimbursement for costs of participation (e.g. travel to meetings, food costs etc.) was highlighted as a means to reduce barriers to participation. In addition, some respondents also raised the issue of payment for time. The following comments were shared:

Disabled people have a feeling of being ‘researched out’ and also taking people’s time and not paying for them. (DPOREF2)

A bone of contention with many people in our community would be that they are asked to travel to events and speak at different events but maybe their expenses aren’t covered or maybe they cannot afford to be there to give their opinion. So making sure that when you are doing consultations you have the budget for things like time, travel expenses, etc. (DPOREF1)

Payment for time is something that would be really important. It’s about valuing expertise as per effective participation. (ILMI Youth Collective)

Another DPO interviewee raised the issue of how funding is allocated without regard for the extra cost of disability. They provided the following hypothetical example:

Senior management makes a decision that they are going to instigate a consultation project and €10,000 is handed over to the organisations. Now let us say the [service provider organisation] for example want it. Our funding is automatically reduced by having to pay for interpreters so our situation differs greatly to the [service provider] because we would be looking at say €3,000 on interpreter costs, €7,000 towards the project. The preference would be that the funding organisation takes on board that these costs should be an addition and getting that awareness across that €10,000 for the [service provider] is not the same as €10,000 for a Deaf-led organisation. We require people with knowledge and understanding that when they hand out funding it has to be done differently. Senior management will always say the interpreter costs are included in the funding. Other organisations are getting the full value of the funding but we are not. Funding needs to be separate from interpreter costs. (DPOREF3)

Public submissions also highlighted the issue of payment for time and/or expenses. Comments include:

It is usually unpaid time and work from the disabled community to offer their expertise.  It should be valued like other public service consultations and remunerated accordingly. (Galway Access for All)

[…] we have often been asked for our input about wheelchair accessibility on outdoor trails/urban design and have been approached by numerous county councils, local orgs, students etc. While we welcome being acknowledged and love to help, it also feels like we’re working for free. […] It’s extremely time consuming and we are advising people who are already getting paid in this line of work. So there must be a structural flaw. […] We recognise that input from the disability community is key but it feels like we’re working for free. (SUBREF7)

DFI also highlighted the importance of covering costs (e.g. transport) and compensating people for their time and expertise.

### Provide Feedback

In terms of receiving feedback on their inputs into consultation processes, all DPOs interviewed reported that they rarely received any feedback, or received insufficient feedback. Some comments include:

In our experience, feedback is minimal. Very often when we say we want to be involved in a consultation we don’t get any feedback. It’s disheartening and disillusioning for our members. (DPOREF5)

It often feels like we feed into policy and it gets put in a file and forgotten about until the next election. (DPOREF4)

[Consulting bodies are] Very slow to come back, if they come back at all for feedback on consultations. (DPOREF4)

It’s important to keep people in the loop and let them know how their input was used. Usually you take part in something and then never hear about it again. (ILMI Youth Collective)

Feedback was also highlighted as important in the public submissions by Epilepsy Ireland, the NCBI and DFI. The following individual comments were also shared:

Follow up immediately after the meeting, with thank you for attending and the promise to get back to the participants. Keep your promise. I have left meeting thinking we had made a difference and they changed nothing. Keep the participants up to date after the meetings. (SUBREF5)

[Organisations] don’t ‘do’ feedback very well, in most cases they are too busy to give impaired people feedback in relation to the difficulties and challenges we encounter. (SUBREF6)

#### How to provide feedback effectively

A DPO interviewee highlighted how, as a DPO, they share feedback when carrying out consultation activities, stating:

We’ve tried to incorporate feedback, we do zoom polls, capture on screenshot, instant feedback. Live chat on Zoom - I’ve come up with exercises in my workshops where people can put answers in live chat etc. People’s comments get typed up. You can see immediately that people’s comments are going up, they have ownership and engagement in the discussion, it’s transparent, people can respond. (DPOREF2)

The following comments were also made by DPOs regarding feedback:

Feedback should be accessible (DPOREF1)

You have to make sure that an [ISL] interpreter is present for feedback. It’s very difficult to do written feedback when literacy levels in the Deaf community are so low. (DPOREF3)

Feedback can be done by getting involved in meetings, ISL report on video and providing choice is important too. (DPOREF3)

I would really welcome consultation reports from the point of view of transparency. (DPOREF)

In the public submissions, the NCBI suggested ensuring audio descriptions are available for Oireachtas committees and government debates.

### Analysis of consultation findings

Some consultation respondents highlighted issues that arise during analysis of consultation inputs. For example, a DPO interviewee raised an issue regarding how consultation findings are aggregated in a way that prioritises a popular view over views which are raised by a smaller minority but which represent rights which must be protected or upheld, stating:

An issue to highlight is the problem of aggregating responses – for example, stating that a 93% positive response was received during a public consultation, but not highlighting that the proposed changes will prevent access for disabled people. (DPOREF5)

No way should these things be put to a popular votes. Rights are not subservient to popularity. (DPOREF5)

The same DPO interviewee raised that amalgamation of feedback can lead to issues raised by a particular group getting lost, stating:

In the feedback, we prefer to have visually impaired separated and for us to be dealing on a one to one with visual impairment and not to have everything jumbled up. (DPOREF5)

Another DPO interviewee similarly stated that they have experienced this in terms of Deaf issues not being explicitly included and being told it is ‘implied’ in the findings instead. They stated:

An evaluation will be written differently if there are multiple groups attending. I have often brought the issue of ISL up and have been told, well it’s implied but it’s not implied. (DPOREF3)

Another DPO interviewee highlighted how inputs can be used in a way they hadn’t intended, stating:

Sometimes you are asked questions and you don’t know in what context the question is being asked and then you sometimes find in the final report that your reply has been taken out of context. Some questions can be quite leading and again if we want to be as inclusive as possible in consultations you need to realise that you are not necessarily dealing with someone who goes to these things every day. (DPOREF1)

The same interviewee highlighted potential problems that arise during analysis of consultation inputs, stating:

I sometimes think that the research can be sloppy, particularly on the difference between qualitative and quantitative. If we want to be as inclusive as possible there needs to be a distinction in the reporting between what was said etc. (For example, taking a quote from one respondent and emphasising that point of view in a report, whereas quantitatively it was only one person’s view). (DPOREF1)

Similarly, the ILMI Youth Collective stated:

The disabled person’s views should not be altered to fit a narrative.

### Listen and take action

DPOs, young people and public submissions highlighted experiences of consultation in which their impression was that they were invited in order to ‘tick a box’ rather than for their inputs to be heard and actioned. Respondents reported that issues contribute to consultation fatigue and lack of trust in the process and consulting bodies.

A DPO interviewee highlighted that apathy can arise when no action is taken as a result of consultation, stating:

We are talking about lack of implementation and that can make people feel, “why will I bother because nothing will happen”. (DPOREF1)

Another DPO interviewee highlighted a lack of trust in public consultation processes. In relation to the consultations carried out by the relevant Government Department with regard to the UNCRPD State Party Report, they stated:

Are they going to abide by it, or forget about it until the next Election? (DPOREF4)

Another DPO commented:

We're not told anything. Clearly what the priority is to tick a box and so we generally don't know about things until they are signed, sealed, delivered, which is not much good is it? (DPOREF5)

The ILMI Youth Collective members also highlighted that each of them had several experiences of tokenism when engaging with organisations, with one member stating they have “too many to relay”.

This issue was also highlighted in the public submissions. Comments include:

Having been involved in consultations where the organising was primarily carried out by non-disabled persons, I have found that the needs of the organisation to be seen to be ‘doing the right thing’ appeared to be greater than ensuring the ‘right thing’ was actually done. […] In reality, involving disabled persons in policy-making seems to be an exercise only, based on the necessity of appearing inclusive. (SUBREF2)

The problem lies in the government departments and councils across the country. Disability access, inclusion and equality is a box ticking exercise to them. They believe they know more about Persons With Disabilities than we do. (SUBREF5)

We need to be able to say no and be heard not the way it is at present. We force them to talk to us, they hold a consultation, we explain to them why their plan is terrible and how to make it work. They used to argue back, now they listen take notes and gleefully ignore everything we have said, and the NDA have said. […] So again, they tick the disability inclusion box. (SUBREF5)

When participating, they [Inclusion Ireland members] are sometimes not listened to and the “inclusive” consultation feels tokenistic. (Inclusion Ireland)

Sometimes when people ask for my opinion, I feel like I am brushed off. So policy makers say they want to hear from people with disabilities themselves but then they don’t really listen. (Inclusion Ireland Self Advocate)

Submissions from the DPCN, Galway Access for All, DFI, and Epilepsy Ireland highlighted experiences of consultation which they describe as ‘box-ticking exercises’.

Others highlighted that the result of a high frequency of consultations, often with the same groups involved, and little resulting progress leads to consultation fatigue, frustration, and lower quality policies. Some comments include:

There can be endless consultations around disability issues, yet very little widespread progress including accessibility issues of those consultation processes for persons who are non-verbal, and with sight and hearing impairments. (DPCN)

[Government] does not recognise the frustration expressed by participants about being on consultative committees but having little impact or influence on decision-making processes. (DPCN)

There are frequent opportunities to contribute to consultations, this is time consuming and there is an element of fatigue as the same individuals and groups are required to coordinate this. (Galway Access for All)

Submissions also highlighted the importance of consulting bodies listening to inputs. Comments include:

[…] communication is pointless if you do not listen and attempt to understand the replies you get with regards to your message. (SUBREF6)

The most practical point for running an all-inclusive consultation process with impaired persons, our families/loved ones, carers etc. is to LISTEN to our needs. Listening is the number one form of communication. (SUBREF6)

People who make decisions for those with disabilities are totally out of touch with the real world. People with disabilities are not being heard at all. (SUBREF11)

Government departments are not listening to impacts which are multi-layered in terms of impacts at both physical, emotional, psychological levels in term of not getting to work, not socialising etc. This causes a lot of stress and anxiety, making people feel more vulnerable. (DPCN)

### Evaluation and Learning

None of the DPOs interviewed reported that they had ever been included in an evaluation of a consultation process.

In response to this question, one DPO interviewee stated:

I don't mean to be flippant but no, that would be like, in 100 years’ time maybe something like that would happen. I have some distant memory of somebody asking me to do a survey on what I thought [of a consultation] but the survey was inaccessible! (DPOREF5)

Another DPO interviewee stated:

[Officials are] very slow to come back, if they come back at all for feedback on consultations. The Government doesn’t think of people with disabilities. (DPOREF4)

On whether they would welcome the opportunity to be involved in an evaluation of a consultation process, one DPO interviewee shared the following comment:

I would really only want to be involved in an evaluation if I was really happy and wanted to say something nice or if I was unhappy about something. There is a risk of results being disproportionate as a result. It would be important for any evaluation to be succinct. (DPOREF1)

The same interviewee suggested:

Could there be a checklist? Where it is encouraged and stated how you follow these steps [for meaningful participation] because I think that with UNCRPD reporting it would be really useful for us to see these guidelines published and available to public bodies and what % are actually using them. (DPOREF1)

Other comments shared included the following:

They need to come back with us and ask, ‘How was it for you in terms of a visually impaired issues? Did you feel you were listened to?’ The substantive issues have to be responded to. (DPOREF5)

As part of an organisations’ consultation charter or strategy they could include KPIs, ask ‘did we do it OK?’ (DPOREF5)

Evaluation should be ‘effective’. This goes back to dialogue, so that people can actually see they are changing the programme, having an impact. (DPOREF2)

Public submissions from the NCBI, the DPCN and an individual (SUBREF5) also highlighted the importance of evaluating how well consultation processes and mechanisms are working.

### Monitoring

With regard to what happens after a policy has been developed, the following comments were shared.

Monitoring is important as well - staying involved. (DPOREF2)

Rehabcare also highlighted the importance of monitoring how well various policies and strategies are working.

### Practical considerations for running participatory processes

Consultation respondents shared some practical tips for running effective participation and consultation processes. These are outlined below. It is important to note that this is not an exhaustive list but reflects the points which were highlighted in the consultation responses.

#### Planning

The Anne Sullivan Foundation highlighted the importance of planning in advance, stating:

Key learnings for the ASF in facilitating such meetings include the importance of detailed planning in advance, booking communication guides/interpreters well in advance, arranging transport if necessary, understanding each members communication requirements (for example some member will require tactile signers, others one on one ISL interpreters and others might need assistive technology).

#### Choosing your approach

Many consultation responses highlighted the importance of using a variety of approaches, being flexible and creative and ensuring that approaches chosen are age-appropriate. Suggestions range from one-to-one meetings, group meetings, suggestion boxes, written submissions, video/audio submissions, surveys, phone calls, Zoom.

DPO interviewees shared the following suggestions:

[Include] an opportunity to attend in person, written submission, video submission. (DPOREF1)

It sounds like common sense, but being flexible and listening. Because there's no way [DPO name] can say that every blind or partially sighted person needs X, Y or Z or make that call. Even among our representatives it's all about flexibility. People may not have exactly the same degree of impairment or may have a different way of handling it. (DPOREF5)

Another DPO interviewee gave an example of how using creative methods elicited a wider response in a consultation they ran, stating:

We needed 100 cases for our [DPO name] project - we’re using photography, creative workshops, films - all these different methods to evaluate a programme. We’d never get 100 case studies if we asked everyone to write a review. The outcome is a case study but you get much richer lived experience and lots more of it. (DPOREF2)

The ILMI Youth Collective stated that consultation should include:

Alternative methods of consultations: zoom, telephone, video, hardcopy etc.

Public submissions from DFI, NCBI, DPCN, Epilepsy Ireland, Cairde and CCUAM also highlighted the importance of being flexible and using a variety of methods.

Some suggestions included:

In-person and online focus groups, written submissions, allowing video/audio files, combination of surveys and phone call interviews etc. (DFI)

Use of modern technology within the local community to gather information and feedback from all local people all the time on a variety of topics has great potential. This would be a live engagement and would allow for ongoing feedback to public agencies. (DFI)

It is important to recognise that individuals are different and may wish to engage in consultation processes in diverse ways so using a variety of methods for consultation is recommended. These can be surveys, focus groups, town hall style meetings etc. (NCBI)

Having fun helps people to engage and relax. Energisers really help to get people going. (Inclusion Ireland)

A suggestion box located in an easily accessible place where ideas could be submitted. (CCUAM)

Use technology to communicate and facilitate an audio perspective. (CCUAM)

More creative and innovative ways are required, using assistive technology in consultation processes. (DPCN)

The submission from NCBI also highlights the importance of age-appropriate approaches, stating:

If the consultation is open to people of all ages, it should be tailored to different age cohorts. The setting, language and schedule used for adults will need to be different for younger children to understand and engage with. The use of imagery, colour and play can facilitate engagement with children in a different way than you would engage with adults. (NCBI)

With regard to whether consultation activities take place online or in-person, again there is no one-size-fits-all approach and the submissions highlight that it depends on the stakeholders preferences. Comments include:

They like face to face contact, they prefer if someone else uses technology on their behalf to submit views. They trust those around them to submit their views and not to alter the view when submitting it. (Cairde)

We believe that a consultation process which involves both online and in person practices would be the best option for many to contribute to the policy development process. (Epilepsy Ireland)

Use a mixture of online, Zoom and in person methods. (SUBREF11)

#### Partnership approach

Some submissions highlighted that a partnership approach, in which persons with disabilities are involved in organising and leading the consultation process, can be effective.

For some people with disabilities when there is a consultation that is solely being run by non-disabled people, there can be a sense of “Can I really trust that?” Everyone is there with the best of intentions but still in reality it’s a group of non-disabled people talking about disabled people. (DPOREF1)

When asked what the solution might be, the interviewee responded:

There is something about consultation in partnership with DPOs. I think it’s about maybe more willingness to engage with DPOs and having disabled people involved in the management of the consultation process. (DPOREF1)

The following comments were shared in the public submissions:

Having people with disabilities leading and facilitating consultations helps people feel like they can be involved and it also shows people that their voice is important. (Inclusion Ireland)

It is important to have people with disabilities running and facilitating consultation because a lot of the time the consultation is about us, people listen more and learn more, it is good to have the lived experience. Staff can support people with disabilities to lead. (Inclusion Ireland Self Advocate)

We are more than capable of organising our own consultations, chairing them, actively participating in them and reporting back to Government etc. regarding our requirements. (SUBREF6)

#### Pace and breaks

Comments were shared regarding the importance of being mindful of the pace of meetings. For example:

If the meeting is going too fast, the [ISL] interpreter might ask you to slow down just for the ease of interpretation or to give the information correctly. They don’t want to be catching up the entire time. (DPOREF3)

Interpreters obviously need breaks but it’s not only the interpreter who needs it - we do need breaks too! It’s very tiring because you have to be looking at the interpreter at all times. We can’t passively listen like hearing people – we actively follow the interpretation. (DPOREF3)

Decide on the pace of the discussion depending on the individuals there […] Recognise that a non-verbal person might have lots to say, so design the discussion around that. (DPOREF2)

Meetings need breaks - and longer breaks. (DPOREF4)

Time is very important. People need to get the information and questions in time so they can get ready and get support if they need it. (Inclusion Ireland)

Do not try and rush it” […] “Plenty of time is needed as people can tire easily in new surroundings and when feeling stressed.” (SUBREF5)

They don’t like been rushed into a decision or be given too many options. (Cairde)

The Anne Sullivan Foundation in its submission also highlighted the need for set breaks throughout the meeting and an understanding that the pace of the meeting must be slow to facilitate the inclusion of deafblind participants.

#### Inclusion tips for meetings and events

DPO interviewees shared some practical tips for inclusive meetings and events.

One DPO interviewee (DPOREF1) described an approach it used to facilitate the inclusion of autistic participants. At the DPO conference, everyone at the conference was given stickers in red, amber or green. The stickers indicated whether the person was comfortable with someone speaking to them during the breaks. Green meant “talk to me”, amber meant “talk to me if you know me already”, and red meant “don’t talk to me”. Participants could change their dots any time giving them control over the interactions. It’s important that these stickers are given to everyone and not just autistic participants.

The same DPO (DPOREF1) also developed an ‘Autism-friendly clap’ for its conference. Some autistic people reported that they find applause uncomfortable because it is sudden and its duration is not predictable. The autism-friendly clap involves providing a visual signal to say that applause will begin in 5 seconds, giving people time to put in earplugs if needed, after which there is a countdown of 5 seconds of clapping.

This DPO also suggested sending out a picture of the facilitator in advance along with the programme or agenda.

Even if accommodations are not used during the event, it’s still important that they’re there. People reported that it gave them a sense of confidence and made them think the organisers were thinking of them. (DPOREF1)

Regarding ISL interpretation at meetings and events, one DPO interviewee stated the following:

I often think that the interpreter should be there from the minute you walk in the door because a person would speak to you but then would think that you are rude because you did not respond and if an interpreter was there beside you could respond. Also at events, Deaf people who require the interpreter should sit in the first few rows so as not to have any distractions. If the interpreter is on stage, then the person can sit anywhere and be able to see them. When it comes to break times I do not have an opportunity to network because the interpreter is on their break. (DPOREF3)

Others suggested giving participants guidance. For example, the DPCN suggested guidance on effectively representing your group and feeding back. A member of the ILMI Youth Collective stated that when being asked to join a panel, it is good to give guidance about what you want a panellist to talk about.

The ILMI Youth Collective also advised that it can be helpful for the individual(s) responsible for running the consultation to share their contact details with the participants at the end of the consultation. This means that if any other contributions occur to the participants in the aftermath of the meeting, these can be formally recorded and included in the notes of the meeting.

The submission from Inclusion Ireland also highlighted the need for clear practical information about in-person meetings, stating,

For in person consultations be clear about the date, time, directions and that the agenda is clear.

The NCBI further highlights the importance of:

Ensuring a solutions focused approach during any consultation or committee structure etc. This would help to create a constructive environment for discussion.

Some comments highlighted that people with disabilities should be invited to consultations in order to analyse the issues, and not just to share their personal stories:

There is a perspective that consultations with disabled people is on their ‘lived experience’ only, not any analysis of the issues. (DPCN)

It is important not to always put it on disabled people to share their personal stories – it’s like if you don’t share your story, we won’t change anything. Disabled people’s stories are none of your business. (ILMI Youth Collective)

Anne Sullivan Foundation highlighted the importance of good facilitation in order to ensure only one person talks at a time. This submission also recommended to provide sandwiches for 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.

A member of the ILMI Youth Collective raised the issue of privacy when taking part in a consultation. For example, if service providers are in the room, disabled people may not feel comfortable speaking up in case it affects their services. In addition, they highlighted that a disabled person may travel to an in-person meeting with a PA, or in the absence of a PA, with a family member. It can be difficult to maintain privacy in that situation. They highlight that providing an option to join online can remove this issue as they can join without a PA or family member present.

#### Submissions

With regard to inviting submissions as part of a consultation process, DPOs shared the following comments:

If Deaf people are sending in an ISL submission just to make sure people actually receive the video, sometimes they are limited in the size they can make, they can often feel they are limited in the length. Just to make sure that they have a method for long videos to be accepted. Or give people a time limit for their videos, e.g. 2 minutes. Be prepared if you receive a video and you don’t know what it says to get it translated. (DPOREF3)

If it’s an open ended consultation I think it’s a good idea to give people a little bit of guidance. Some guideline questions that you might like to address in a submission and a suggested word limit. (DPOREF1)

#### Focus groups

When running focus groups, one DPO interviewee stated:

I believe in terms of focus groups that it needs to be Deaf-only rather than competing with others. At the same time, it’s good to hear from others and learn about their experience. (DPOREF3)

Looking at the diversity of the community – it is not homogeneous so you can’t have one generic set of information. (DPOREF3)

The ILMI Youth Collective stated that they feel it is important not to break people into impairment groups for consultation.

#### Surveys

The following comments were shared in relation to survey accessibility:

People want to share the surveys with Deaf people but then there is the issue of the English, it should be translated into ISL. For example, the DPO/UNCRPD survey went out and there was a high response from the Deaf community because there was a version in ISL. When there’s no ISL, Deaf people do not bother as it takes a lot of effort for them. (DPOREF3)

Surveys regarding policy development and existing policy effectiveness could be presented for people with disabilities in an easy read format. (Rehabcare)

### Online meetings

DPOs highlighted that there are many benefits to delivering consultations online including opportunities for improved accessibility of meetings, reaching more people, opportunities for more frequent and continuous engagement, cost saving benefits. A number of challenges were also highlighted including lack of high quality internet access in rural areas, accessibility challenges arising from poor planning and facilitation.

#### Benefits of online meetings

The DPO interviewees shared the following comments on the benefits of online meetings:

I think it fantastic to have Zoom because I have asked for that kind of service before and was always refused but now since COVID came along I am getting it. It’s now possible to have more accessible meetings online. (DPOREF3)

Some people can’t attend social events for a variety of reasons – they find it exhausting, they have care responsibilities etc. Therefore, it’s good to also stream online.” They advised to “Make the same accommodations online as in person, also prepare participants that technology can fail. (DPOREF1)

I feel we are reaching people now that we did not reach before. I think it would be a shame now if we lost access to that tech. […] We moved everything to Zoom in March 2020. In terms of dialogue with members, the AGM every year was once a year, people coming together, could get a bit messy because some members sometimes saw it was the only chance to raise their individual access issues on a social model platform. But the AGM last year on Zoom, there wasn’t one issue, it went so smoothly because we had created so many opportunities to engage with the organisation - so many platforms for people to bring their issues to. By creating so many accessible spaces for people to talk, dialogue isn’t a once-off thing that has to be compressed into an hour or two. (DPOREF2)

My participation in the various consultations has been made so much more convenient. And for other representatives, some of our local ones it is very useful. Even with you here today, we probably would have arranged a meeting, and it would have been a lot of hassle for me to find out where you were. And then it would have been real nuisance. It's just a stressful thing if I have to travel. So this [the Covid lockdown] has hopefully made people more aware of it. Even ourselves you know, it's made our representatives’ jobs much easier [...] Travel creates a lot of hassle and stress. You can’t rely on it and also then it can be messy trying to haggle for taxi fares be paid by the council etc. (DPOREF5)

It's really fantastic because before all this came along we were finding it very difficult because we're nationwide and it was very difficult with meetings, impossible I would say, and then we certainly couldn't afford rooms or anything to meet. (DPOREF5)

The ILMI Youth Collective highlighted the issue of transport, stating:

[Meeting online] takes away the worry about getting from A to B. Transport can be a big problem – e.g. you have to book a taxi a week in advance if using a wheelchair.

#### Challenges of online meetings

In terms of the challenges with online participation, DPO interviewees highlighted shared the following points:

It can be hard in Zoom. Some people are in Units and there were loads of people in the Unit and there was so much noise around if people don’t mute their microphone. (DPOREF4)

Zoom is boring, and often too long. (DPOREF4)

Zoom is important but there is a need to go back and understand how the interpreter can be used within Zoom in terms of spotlighting. If it’s a webinar or a meeting it needs the interpreter to be pinned on the screen at all times. There are those elements that are not quite understood as yet. […] When you are in a large meeting the boxes on the screen move around but the Deaf person ends up having to find out where the interpreter is gone. […] I think there is value in having guidelines on the use of Zoom. (DPOREF3)

There is a need to be mindful of hard-of-hearing people too and need to be guided by the interpreter. A lot of people do not know how to use or work with an interpreter. For example, when I am in a meeting and people are speaking all at the same time. (DPOREF3)

Captions again do have a value but you have to pay extra. There needs to be access to make it equitable. (DPOREF3)

One DPO interviewee offered guidance in terms of managing the use of the chat function for participants with a visual impairment taking part in an online meeting, stating:

There are some problems with Zoom in that if my screen reader is reading that message [in the chat box function] then I can't hear what somebody saying. So there needs to be an awareness of some of the issues around remote conferencing. Also, I can't raise my hand for instance. Again, I’d have to use my screen reader, and then stop what anybody else is saying. So, you know, there has to be a plan around raising hands and things like that on video conferencing. (DPOREF5)

I don't think it'd be fair to ask everybody not to use it because that inhibits their communication with the facilitators. People just need to be aware. We would encourage representatives to raise these issues in advance. But again it comes back to facilitators listening and being flexible. (DPOREF5)

The same DPO interviewee also highlighted that it isn’t everyone’s preference to take part online and that internet connectivity can pose a problem for some, stating:

Some of our members would still prefer to be there in person. Which is great you know if that is what they want. We need to look at it from the needs of those with the least ability [to use the technology] or the most impaired or from the most marginalized point of view. And there’s the fact that internet access is not what it should be down the country as well. And that needs to be bought up to scratch but once that is the case, people should be able to use remote [conferencing] whenever they want. The cost of any supports provided should be provided by the people doing the consultation. (DPOREF5)

The ILMI Youth Collective offered guidance around ensuring there is a point of contact on hand to solve any technical challenges, stating:

For larger consultations taking place on-line, it can be useful 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, or on the day of the meeting, they will be able to receive the assistance that they require. (ILMI Youth Collective)

### Emerging recommendations from stakeholders under Part 3:

1. The guidelines should highlight that persons with disabilities should be engaged in a broad range of policy consultation and participation processes, not just those deemed ‘disability-specific’.
2. The guidelines should highlight that a universal design approach to consultation design which addresses barriers to participation can be effective if it is understood and applied properly and implemented in consultation with DPOs and other relevant stakeholders.
3. The guidelines should highlight that effective participation processes should be underpinned by transparency, trust and respect, two-way dialogue and ongoing engagement.
4. The guidelines should highlight the importance of engaging proactively and early with DPOs in participation and consultation processes.
5. The guidelines should recommend identifying the most relevant DPO(s) to engage with based on the subject matter.
6. The guidelines should recommend raising awareness of consultation and participation processes among DPOs and other relevant stakeholders, ensuring intersectional groups are targeted.
7. The guidelines should recommend reaching relevant stakeholders through DPOs in the first instance. Stakeholders may also be reached through other organisations, service providers, social media, or other methods if necessary. Engagement with individuals and other stakeholder groups does not replace the need to engage with DPOs.
8. The guidelines should recommend that the consulting body should proactively ensure accessibility and provision of reasonable accommodation in participation and consultation processes
9. The guidelines should recommend that the consulting body should proactively inform stakeholders of accessibility and reasonable accommodation provision, taking the onus off participants to request supports, in addition to asking participants if anything additional is needed to ensure their access.
10. The guidelines should recommend that the consulting body should recognise the heterogeneity of persons with disabilities and their accessibility requirements.
11. The guidelines should highlight the importance of ensuring accessibility of the physical environment used for consultation, for all persons with disabilities.
12. The guidelines should highlight that physical accessibility includes a broad range of elements including building access, signage, audio announcements, the sensory environment and more.

The guidelines should highlight barriers caused by inaccessible transport. This could include, for example, providing an accessible taxi to a meeting, offering an option to join online, giving sufficient advance notice of in-person activities to allow the participant to make transport arrangements, or any other accommodation identified by stakeholders with disabilities.

1. The guidelines should highlight barriers caused by inaccessible information:

* Translate all relevant consultation information into Irish Sign Language;
* Provide Irish Sign Language interpretation for consultation activities;
* Use plain language in consultation documents;
* Produce information in accessible formats and ensure compatibility with assistive technology;
* Ensure accessibility of information on websites in line with the EU Web Accessibility Directive;
* Provide information in a timely manner.

1. The guidelines should highlight barriers caused by inaccessible communication:

* Recognise the diversity of communication methods used by persons with disabilities;
* Use different methods to communicate with and accept communications from diverse groups and facilitate communication based on the choice of the participants;
* Set the pace of the discussion in a way which facilitates the inclusion of all participant’s communication styles;
* Provide communication support where necessary;

1. The guidelines should highlight barriers caused by lack of access to internet and technology, including assistive technology
2. The guidelines should highlight that timeframes should be long enough to facilitate inclusive participation and consultation.
3. The guidelines should highlight the importance of providing capacity-building support for consultation participants. This could include preparation days, self-advocacy training, peer training on consultation with representative groups, and support before, during and after consultation.
4. The guidelines should highlight barriers caused by the cost of engaging in participation and consultation processes and recommend consulting bodies reimburse expenses incurred. Some stakeholders also suggest the guidelines should recommend paymentfor participant’s time and expertise.
5. The guidelines should highlight the importance of providing timely feedbackto stakeholders, in accessible formats, throughout the process and at the end of the process, including:

* Updates on the process;
* Information regarding how consultation inputs were used;
* Arationale for any consultation recommendations not taken on board;

1. The guidelines should highlight various considerations for analysis of consultation findings including the following:

* When aggregating consultation findings, upholding rights must not be undermined by majority opinion or budgetary concerns.
* Do not take consultation inputs out of context or alter inputs to fit a prescribed narrative;
* Care should be taken when amalgamating feedback into themes to ensure that specific issues although perhaps only relevant to a minority receive due attention.

1. The guidelines should highlight that listening and taking action is an important step to ensure participation and consultation processes are meaningful.

* Departments and public bodies undertaking consultations should commit to listening and taking action on consultation findings including allocating sufficient time, resources, and personnel to implement recommendations.
* Departments and public bodies should provide a clear rationale for anything which cannot be implemented.

1. The guidelines should highlight ways of evaluating participation and consultation processes and mechanisms with DPOs, and other relevant stakeholders, and applying the learning to future processes.
2. The guidelines should recommend engagement with DPOs and relevant stakeholders in monitoring the implementation of policies after they have been developed.
3. The guidelines should include practical tips for inclusive participation and consultation activities as highlighted by DPOs and other stakeholders.
4. The guidelines should recommend ensuring detailed planning of all logistical and accessibility requirements, e.g. booking interpreters, organising transport, etc.
5. The guidelines should recommend public officials consider a partnership approach in which DPOs and other relevant consultation stakeholders lead or co-facilitate the consultation process.
6. The guidelines should recommend choosing a variety of flexible, creative and age-appropriate participation and consultation approaches
7. The guidelines should recommend that officials ensure an inclusive meeting pace and sufficient break times.
8. The guidelines should include information about running an inclusive submissions process including:

* Submissions information should be available in accessible formats, including Word, easy-to-read and ISL.
* Accept submissions through a range of methods makes it more inclusive (e.g. post, email, video, audio);
* Provide guiding questions, word limits, video length limit.

1. The guidelines should include information about running an inclusive focus group:

* Some prefer to be split into a separate group based on disability type, while some prefer not to split groups by disability type. It depends on the context and the preferences of the stakeholders involved.
* Ensure focus group participants reflect the diversity of the community.

1. The guidelines should include guidance around creating accessible surveys.
2. The guidelines should include information about running inclusive and accessible online meetings.

### NDA response to emerging recommendations from stakeholders under Part 3:

All the emerging recommendations in this section are incorporated in the guidelines, with the exception of emerging recommendation 39, which was partially incorporated. As suggested by stakeholders, the guidelines highlight barriers caused by the cost of engaging in participation and consultation processes and recommend reimbursing expenses incurred. The guidelines recommend that in addition to reimbursing for travel and subsistence expenses, public bodies should reimburse other categories of expenses, such as Personal Assistance hours, childcare, or other caring costs, for example. Some stakeholders also suggested the guidelines should recommend paymentfor participant’s time and expertise. The NDA acknowledges that this is an important issue for many individuals who give their time to participate in consultation processes. We also recognise, based on our focus groups with public officials, that there are administrative barriers in many cases which would prevent public officials from paying individuals who take part in public consultation processes. The NDA highlights the importance of 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.

## Part 4: Additional points

### Title of the updated guidelines

The following comments were shared regarding the title of the updated guidelines.

’Ask Me Guidelines’ may have been appropriate twenty years ago when bodies were not obliged to consult with disabled people through their DPOs as an established part of Human Rights law. So, back then, the cuddly title was designed to entice - and clearly has generally not been effective. However, nowadays, in this new phase of Human Rights law (including the Websites Accessibility Act, the EU Accessibility Act, Public Sector Equality Duty, and especially, the Convention on the Rights of People with Disabilities), such consultation is to the front and centre of all operations of statutory bodies. As such, given the new legal weight, we suggest that the informal-sounding "Ask Me Guidelines" title be replaced with "Consultation Obligations". (DPOREF5)

The name of the guidelines is very important as it sets the narrative for the whole conversation. ‘Ask Me guidelines’ does not specify who the guidelines refer to. It is a bit “light” or “weak” especially now since ratification of the UNCRPD. Keep it simple but meaningful e.g. ‘Guidelines for effective consultation with young disabled people’. (ILMI Youth Collective)

Young disabled people don’t want the guidelines to be an ‘excuse’ to not consult us properly so the name should reflect that. The name of these guidelines needs to be direct, self-explanatory, it must be social model language [Disabled people]. (ILMI Youth Collective)

### Format of the guidelines

Some comments were shared regarding the format of the updated guidelines.

The guidelines must be in an accessible format e.g. proper colour contrast accessible for screen readers etc. It is important to realise disability and being inclusive does not only exist for a wheelchair users. Impairments among disabled people are vast and wide ranging so when developing guidelines it must be cross impairment focused. (ILMI Youth Collective)

[On having an ISL version of the Guidelines] I would love that, it would be wonderful because there are occasions when you can look at a report and misinterpret some of the wording. The ISL version would be preferred but you could have the written version and then compare to the ISL version. If you take for example our AGM report, we always have ISL version and written. We used to do it with DVD but now we have YouTube etc. so it’s giving the choice of both. It’s extra work and extra effort, but it is ensuring language access. For a hearing organisation that would not be a consideration to have two types of report but for us it’s essential. (DPOREF3)

### Emerging recommendations from stakeholders under Part 4:

1. The title of the updated guidelines should be updated to reflect UNCRPD participation and consultation obligations.
2. The updated guidelines should be made available in various accessible formats.

### NDA response to emerging recommendations from stakeholders under Part 4:

Emerging recommendations 54 and 55 were accepted. In relation to emerging recommendation 54, the new title of the guidelines is “Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making.”

In relation to recommendation 55, the guidelines will be available in accessible PDF, accessible word, easy-to-read summary, and Irish Sign Language video summary. The NDA will produce other accessible formats upon request as required.

# Section 2: Feedback from public officials on the stakeholder recommendations

## Focus groups with public officials

Public officials from Departments, public bodies and local authorities were invited to take part in focus group meetings in which the emerging recommendations from stakeholders outlined in Section 1 of this report were shared. Officials were invited to comment on the opportunities and challenges presented by these emerging recommendations from an implementation perspective. A summary of the feedback received from public officials is presented in this section.

Twenty-six officials from six Departments, one public body and four local authorities took part in the focus groups which took place in January 2022. The questions which guided the discussion are listed in the Annex 3. A list of Departments, public bodies and local authorities represented in these focus groups is outlined in Annex 4.

### Suggested points from public officials under Part 1: Understanding Disability

1. Include guidance on language and disability in the updated “Ask Me” guidelines.
2. Include an explanation of the Social Model of Disability in the updated guidelines.
3. The guidelines should include the definition of a Disabled Person’s Organisation (DPO).
4. The guidelines should outline the role of DPOs in consultation processes and explain why they must be consulted with.
5. The guidelines should outline the role of other non-DPO stakeholders in consultation processes.
6. The guidelines should outline how to contact DPOs.
7. The guidelines should outline the role of the Disability Participation and Consultation Network (DPCN).

### NDA response to suggestions from public officials under Part 1:

Suggestions 1 to 6 from public officials have been incorporated into the updated guidelines. However, in relation to recommendation 7, it was decided not to outline the role of the DPCN, or other consultation or monitoring mechanisms currently in operation, within these guidelines as the role and membership of these groups may change over time, particularly as Ireland develops its UNCRPD implementation strategy. Instead, the disability stakeholder landscape will be addressed through shorter NDA advice papers which can be more easily updated as the landscape evolves.

### Suggestions from public officials under Part 2: Embedding a culture of participation

1. The guidelines should outline the importance of organisational culture and senior management buy-in for participation of disabled people.
2. The guidelines should outline the importance of support for participation of disabled people translating into resources such as budget, dedicated staff, adequate time allocated during policy/strategy discussions.
3. The guidelines should outline the importance of both general and tailored Disability Awareness Training.
4. It was suggested that structural changes are needed across Departments/roles in order to embed disability inclusion.
5. The guidelines should outline the importance of sharing learning and knowledge across the public sector in relation to the participation of disabled people in decision making.
6. It was suggested that the NDA host a centralised webpage which could be a ‘one-stop-shop’ on engagement with DPOs, people with disabilities.

### NDA response to suggestions from public officials under Part 2:

Many of the points raised under Part 2 are important, but quite broad and beyond the scope of these guidelines to achieve. Suggestions 8 and 9 have been included in the guidelines. Suggestion 10 has been partially included, but the guidelines emphasise Disability Equality Training, rather than Disability Awareness Training, as this was recommended by DPOs which took part in the consultation. The point in relation to the need for tailored training in certain cases was also included in the guidelines. Suggestion 11 is considered by the NDA to be beyond the scope of these guidelines. Suggestion 12 has been included in the guidelines. Suggestion 13 is considered to be beyond the scope of these guidelines and remit of the NDA. The NDA does not hold a register of DPOs and would not consider that a hosting a centralised webpage is possible or desirable in terms of consultation and participation due to the ever evolving DPO landscape and the independence of DPOs, and indeed the NDA.

### Suggestions from public officials under Part 3: Designing accessible, inclusive and responsive processes

1. Include more guidance on how to reach the right people. For example, a list of DPOs and information about who they are representing.
2. A register of DPOs would be helpful to alleviate concerns about knowing which organisations are authentic.
3. Include guidance on what to do when there is a local level consultations which requires local views in which participants would not necessarily be part of a DPO.
4. Include a point about setting expectations with stakeholders of what a consultation will achieve because not all views can or will be incorporated as a result of consultation.
5. Include a point in relation to the importance of public officials providing feedback to consultation stakeholders on the process and outcome of the consultation.
6. Acknowledge that some consultations receive responses in the thousands and it will not always be possible to respond to everyone individually.
7. Include information about different ways to deliver feedback.
8. Include checklists which officials can use to support their planning. It was also recognised that it will not always be a simple step-by-step process, but that checklists would still be helpful.
9. Include a point to say it’s important to make consultations accessible for all people who want to take part in them.
10. Acknowledge in the guidelines that taking part in consultation activities requires taking time off work, rearranging parenting and caring responsibilities, paying for petrol, and other barriers. Recommend that travel and subsistence expenses should be paid in order to reduce these barriers.
11. It was acknowledged that payment of consultation stakeholders for their time would likely make people feel more valued. However, concerns were raised that setting up criteria across the public sector for this kind of payment would be difficult. Administrative barriers may prevent this. For example, it’s likely not possible for local authorities given the structure of their funding streams.
12. Officials requested practical guidance on accessibility, including details of accessible document formats, Irish Sign Language, captions and so on.
13. Include guidance on adequate timeframes for consultation, while acknowledging that in practice there may be short timeframes, sometimes because of political decisions.
14. Acknowledge that consultation needs to be a balanced with moving work forward. The point of consultation is to get something done at the end of it. It was suggested that the guidelines note that expectations should be set with stakeholders regarding scope and timelines at the start.
15. Recommend that officials consider holding consultation meetings outside of office hours to facilitate greater participation.
16. Recommend that when analysing consultation feedback, outlier points must also be adequately reflected. It was suggested that these points should be named also and to say why it cannot be acted on if this is the case.

### NDA response to suggestions from public officials under Part 3:

In relation to suggestions 14 and 15, a list of the DPOs which took part in the consultation are included in the guidelines along with their contact information. However, the NDA does not hold a register of DPOs or information about their membership. Furthermore, the DPO landscape is likely to continue to evolve in the coming years. These are important points, but not one that these guidelines can address. The remaining suggestions from public officials under Part 3 have been incorporated in the guidelines.

# Annex 1. DPO interview themes and questions

Below is a summary of the themes which emerged from the desk-based research and the guiding questions used for discussions with DPO stakeholders as part of this consultation processes.

## Emerging findings: Law and policy

* The findings suggest that the guidelines should explain what the UNCRPD and General Comment 7 says about the participation of disabled people.
* The findings suggest that the guidelines should explain what is a Disabled Person’s Organisation (DPO). It should explain that DPOs are the representative organisations of disabled people.
* The findings suggest that the guidelines should also explain other relevant laws and policies. For example, the Irish Sign Language Act, Public Sector Duty, and the National Disability Inclusion Strategy.

### Questions:

* Do you agree or disagree with these points?
* Is there anything else you think should be added to this section regarding relevant laws and policies?

## Emerging findings: Models of disability and language

* The findings suggest that the guidelines should explain the difference between the social model of disability and the medical model of disability, and that the medical model is not consistent with UNCRPD.
* The findings suggest that the guidelines should explain the different language used to talk about disability. For example, the difference between using identity-first language (e.g. disabled person) and person-centred language (e.g. person with disability). The findings suggest that DPOs in Ireland have a preference for identity-first language.
* The findings suggest that the guidelines should provide information regarding the culture and linguistic identity of the Deaf community.
* The findings suggest that the guidelines should advise to ask people involved in a consultation which language they prefer to use themselves.

### Questions:

* Do you agree or disagree with these points?
* What language do you prefer to use to talk about disability?
* Should the guidelines include words **not** to use?

## Emerging findings: Barriers

* The findings suggest that the guidelines should explain that disabled people face barriers to participation and that these barriers must be removed so that disabled people can participate.
* Common barriers include:
* Inaccessible buildings, transport, and sensory environment;
* Inaccessible communication;
* Inaccessible information;
* Negative attitudes towards disabled people;
* Lack of awareness, skills and knowledge among public officials about disability;
* Lack of implementation of laws and policies which include participation;
* Lack of training and support for DPOs;
* Poor planning – e.g. not enough time for proper consultation, lack of resources;
* Taking part in consultations but not seeing any change as a result;
* Unequal access to internet and technology.
* The findings suggest that the guidelines should explain that some disabled people face extra barriers which must be considered. For example, disabled women, migrants, LGBTQI+, children and young people, and others.

### Question:

* In your experience, are the above barriers to participation accurate? Are there other barriers you wish to highlight?
* Do you have any advice for including people who face extra barriers?

## Emerging findings: When to consult

* The findings suggest that the guidelines should recommend consulting with DPOs as early as possible in the process.
* The findings suggest that DPOs should be told how their feedback was used.

### Questions:

* At what stage do you prefer to be consulted? At what stage are DPOs usually consulted?
* How do you prefer to receive feedback on your contribution to a consultation process (e.g. report, meeting, video etc.)?

## Emerging findings: Planning inclusive participation

* The findings suggest that the guidelines should explain that participation is an on-going process, not a once-off event. This means that the whole organisation needs to embed a culture of participation from senior management to project delivery level.
* The findings suggest that the guidelines should have a section for senior managers which explains why participation of DPOs is an obligation under UNCRPD, the benefits of inclusive participation, and practical measures regarding planning, budgeting and staff training.
* The findings suggest that the guidelines should have a section aimed at staff who deliver projects. This section would provide practical information about how to plan and deliver an inclusive participation process both offline and online, how to embed feedback throughout the process and how to carry out an evaluation.

### Questions:

* Do you think the guidelines need to be pitched at both senior management and project staff level? Are there any other levels to consider?
* Do you have any suggestions about what information should be included for senior management or for project staff in addition to the above?

## Emerging findings: Universal Design

* The findings suggest that the guidelines should outline the concept of universal design. This suggests the guidelines should provide practical advice on designing inclusive processes by removing barriers to participation and being flexible to adapt processes wherever necessary.

### Questions:

* Do you think universal design is an appropriate approach to recommend in terms of designing inclusive consultations?

## Emerging findings: Practical tools for running offline or online consultations

* The findings suggest that the guidelines should explain in practical terms how to deliver an inclusive in-person or online consultation.
* The findings suggest that the guidelines should also explain how to do a ‘blended’ consultation where some people join online and some people join offline.

### Questions:

* Do you have any practical tips or tools to share from your experience of running inclusive consultations either in-person, online or a mixture of both?

## Emerging findings: Evaluation

* The findings suggest that the guidelines should explain how to carry out an evaluation of the consultation process with DPOs. The learning from the evaluation process should be used to inform the design of future consultation processes.

### Questions:

* Has your DPO ever been included in an evaluation of a consultation process? If yes, what worked well or didn’t work well? If no, how would you like to be included in future?

## Additional points to consider

* Is there anything you would like to add that has not been covered in the emerging findings outlined above?

## Public consultation methods

The NDA will also have a public consultation on these guidelines so more people can share their views. People can contact us in the following ways:

* Write to us by email or post
* Send us a video
* Phone us

### Question:

* Do you have any other suggestions for how people can share their opinion with us?

We will also develop related guidance with practical advice on consulting with children and young people with disabilities.

### Question:

* Do you have any experience of including children and young people with disabilities in consultation?
* Does your DPO have a youth network? If yes, would they be interested in taking part in a consultation?

# Annex 2: Public submissions questions

## Question 1

What is your experience, positive or negative, in relation to the participation of people with disabilities, including children and young people with disabilities, in policy development?

For example, this could include taking part in a consultation on a national, local or organisational policy or service; monitoring how well a national, local or organisational policy or service is working; being a member of an Advisory Group, Public Participation Network, Self Advocacy Group or other consultation group, etc. Please highlight if your response relates to adults, children and young people or both (suggested word limit 500 words)

## Question 2

What are the challenges for people with disabilities, including children and young people with disabilities, to effectively participate in policy development? What improvements would you suggest?

Please highlight if your response relates to adults, children and young people or both (Suggested word limit 500 words)

## Question 3

Do you have any practical tips for running an inclusive consultation process with people with disabilities, including children and young people with disabilities?

This could include a consultation in-person, online, or a mixture of both.

Please highlight if your response relates to adults, children and young people or both (suggested word limit 500 words)

## Question 4

Please add anything here that you didn’t get to share in the questions above.

(Suggested word limit 500 words)

# Annex 3: Focus group questions for public officials

## Guiding questions for discussion

Please keep these questions in mind as you read the draft recommendations.[[4]](#footnote-4)

1. Do you think all the important areas regarding the participation of persons with disabilities in consultation processes have been covered? Is there anything missing or anything which needs particular attention?
2. What is needed to support the implementation of these recommendations in your area of work? Is there anything which would be particularly challenging to implement?
3. Is there anything below which is already being implemented in your area of work? Is it working well?

# Annex 4: Stakeholder information

## Participation of Disabled Persons’ Organisations

The following Disabled Persons’ Organisations took part in interviews:

* As I Am
* Independent Living Movement Ireland
* Irish Deaf Society
* National Platform of Self Advocates
* Voice of Vision Impairment

Youth focus groups took place with members of Independent Living Movement Ireland’s Youth Collective.

Comments on the draft guidelines were also received from several of the above named DPOs and two additional DPOs, Physical Impairment Ireland and Disabled Women Ireland.

## Participation in the public submissions process

The following organisations made public submissions:

* Cairde
* County Carlow Universal Access Movement
* County Kildare Access Network
* Disability Federation Ireland
* Disability Participation and Consultation Network
* Epilepsy Ireland
* Galway Access for All
* Inclusion Ireland
* Irish Primary Principal’s Network
* National Council for the Blind Ireland
* RehabCare

Nine submissions were also received from individuals.

## Participation of public officials

Public officials from the following Departments, public bodies and local authorities took part in focus groups:

* Department of Children, Equality, Disability, Integration and Youth
* Department of Education
* Department of the 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

1. The NDA is the independent statutory body that provides information and advice to the Government on policy and practice relevant to the lives of persons with disabilities.  [↑](#footnote-ref-1)
2. SUBREF6 [↑](#footnote-ref-2)
3. UNCRPD Article 7 Children with Disabilities [↑](#footnote-ref-3)
4. This refers to the recommendations from stakeholders outlined in Section 1 of this report. [↑](#footnote-ref-4)