

A GUIDE ON

EFFECTIVE PUBLIC CONSULTATION PROCESSES

for People with Psychosocial Disabilities



Mental Health Reform and the Disability Participation and Consultation Network (DPCN)

Mental Health Reform (MHR) is a funded member of the Disability Participation and Consultation Network (DPCN). The DPCN is funded by Government to ensure that people with disabilities are involved in the development of policy and legislation. It exists to realise the spirit of Article 4 (3) of the UNCRPD where Government are obliged to actively engage and consult with people with disabilities through their representative organisations. The members of the DPCN steering group are Disability Federation of Ireland, AsIAM, Mental Health Reform, Inclusion Ireland, Independent Living Movement Ireland, Irish Deaf Society and the DPO Network.

About Mental Health Reform



Mental Health Reform (MHR) is Ireland's leading national coalition on mental health. Our vision is of an Ireland where everyone can access the support they need in their community, to achieve their best possible mental health. In line with this vision, we drive the progressive reform of mental health services and supports, through coordination and policy development, research and innovation, accountability and collective advocacy. With 80 member organisations and thousands of individual supporters, MHR provides a unified voice to Government, its agencies, the Oireachtas and the general public on mental health issues.



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Department of Children, Equality,
Disability, Integration and Youth



DPCN

THE DISABILITY
PARTICIPATION AND
CONSULTATION NETWORK

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Introduction

What is the UNCRPD and why the views of people with psychosocial disabilities matter

The Irish Government ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. This means that Ireland has undertaken to protect the rights of people with disabilities, facilitate their inclusion in society, eliminate discrimination against them and ensure their equality under the law. Article 4.3 of the convention says that countries which sign up to the UNCRPD are obliged to actively engage and consult with people with lived experience of disabilities when developing legislation and policy.



People who have long-term mental health difficulties have rights under the UNCRPD. The term used by the United Nations to describe people living with long-standing mental health difficulties is “psychosocial disabilities”. This is not about a diagnosis; it is about the interaction between someone with a mental health difficulty and their social environment.

Psychosocial disability refers to the functional impact or barriers that those living with mental health difficulties experience every day.

While progress is being made to improve engagement with persons with disabilities, people with psychosocial disabilities continue to be socially excluded, experiencing prejudice and discrimination in many areas of daily life including health, employment, housing and protection under the law.



Background

The guide is a blend of good practice and evidence-based advice. MHR conducted two online focus group consultations with 15 people with lived experience of mental health difficulties who generously contributed their insights and experiences to inform this guide.

What this guide does

Mental Health Reform (MHR) has developed this guide to provide advice and information on how to consult effectively and inclusively with people with psychosocial disabilities. It is written to ensure that consultation processes by public services are as accessible and inclusive as possible for people who have lived experience of psychosocial disabilities. We are mindful that public services may also have employees with psychosocial disabilities.

By incorporating the tips and recommendations in this guide, organisations are signalling their intent to deliver more authentic public consultation processes which acknowledge the needs of people with psychosocial disabilities.

Who is this guide for?

This guide is aimed at government departments, statutory agencies and organisations in the public sector who conduct consultations. This includes organisations delivering services in health, education, defence conservation, economics and policing as well as local authorities.

This guide covers:



What a culture of participation looks like



Tips on the different phases of a public consultation process - planning, design, implementing, follow up and evaluation



Tasks and processes for effective and inclusive public consultations

What a culture of participation looks like for people with psychosocial disabilities



Departments and statutory agencies committed to facilitating the participation of people with psychosocial disabilities have a visible and tangible culture of participation. It can look like this:

- ★ The UNCRPD is clearly signposted and promoted in all their policies, publications, and organisational ethos. As much as possible, their buildings reflect the commitment to accessibility for people with psychosocial disabilities.
- ★ The organisational strategy references the UNCRPD and shows what steps it is taking to be as inclusive as possible as both an employer and as a service provider.
- ★ All staff are informed and trained on the social model and human rights models of disability¹.
- ★ The organisation shows that it understands, in practical ways, how societal and environmental barriers impact on people with psychosocial disabilities and their ability to access services.
- ★ Staff receive ongoing Disability Equality Training from a human-rights based perspective with specific modules on psychosocial disabilities.
- ★ Person-first language is used in all of the organisation's publications and processes and tokenism is understood and actively avoided.



¹ The social model of disability looks at environmental barriers to participation and seeks to remove them while the human rights model recognises that people with disabilities are equal to others and, as such, are entitled to equal rights and equal opportunities to participate in society.

- ★ Senior leadership demonstrates their support for the National Disability Authority's *Participation Matters Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making*². (More information is available in the Appendix on page 20)
- ★ Facilitating access and participation of people with psychosocial disabilities is named as a strategic and unit objective, as appropriate, and is a metric in performance reviews as appropriate.
- ★ Resources are allocated to support active participation and engagement of people with psychosocial disabilities in how services are designed and in all public consultation processes.
- ★ Organisational culture welcomes, rewards, celebrates and shares innovations which improve inclusion and participation of people with psychosocial disabilities.
- ★ Learning from ongoing evaluation and monitoring progress on inclusion and participation is proactively shared across all functions to improve outcomes and decision making.
- ★ Use of the *Customer Communications Toolkit for the Public Service - A Universal Design Approach*³ is promoted and encouraged³.



² National Disability Authority, "*Participation Matters: Guidelines on Implementing the Obligation to Meaningfully Engage with Disabled People in Public Decision Making*" (Dublin, Ireland: National Disability Authority, September 2022), <https://nda.ie/publications/participation-matters-guidelines-on-implementing-the-obligation-to-meaningfully-engage-with-disabled-people-in-public-decision-making>.

³ Centre for Excellence in Universal Design, "*Customer Communications Toolkit for the Public Service - A Universal Design Approach*" (Dublin, Ireland: National Disability Authority, December 2019), <https://universaldesign.ie/products-services/customer-communications-toolkit-for-the-public-service-a-universal-design-approach/>.

Planning a consultation process for people with psychosocial disabilities



Organisations committed to facilitating people with psychosocial disabilities to participate in consultations should endeavour to implement as many of the following measures as possible. Please note this list is not exhaustive.

Consultation should be done directly with people with lived experience when possible and processes should be adapted to their needs. Clarify the what, why, timeline and the how of the consultation process they are planning.

They think through what method is most suitable for their consultation - whether face to face or online consultation(s), a call for submissions, a survey, focus groups, one to one meetings, working groups with terms of reference or facilitated engagement through creative approaches.



Find ways to ensure that the family, friends, carers and supporters of people with psychosocial disabilities are engaged with and invited to be involved from the earliest stages of the consultation.



Involve the families, friends, carers and supporters - they take care of them, they know all the triggers” – Focus Group Participant



Have a comms system set up so that people can input into it. The people, the families, friends, the support workers have all the knowledge so they need to be involved from the start too.” – Focus Group Participant



Ensure that the specific needs of people with psychosocial disabilities are identified and planned for in advance and are appropriately provided for when required in face to face and online events. This minimises discomfort and helps to generate a relaxed atmosphere.



Use experienced facilitators who skilfully attend to both the task and process of engaging with people with psychosocial disabilities.



Use facilitators with lived experience or disabled facilitators where possible.



Allow enough time between a call for submissions and the closing date for submissions to ensure adequate time to engage.



Hold in person or online events in the evenings, during lunch times and at weekends to facilitate people with psychosocial disabilities who work as much as practical.



If you want to contribute it's easier between 6pm to 11pm so that people with jobs can go and participate. – Focus Group Participant



Designing a consultation process for people with psychosocial disabilities



Departments and agencies that prioritise the inclusion of people with psychosocial disabilities should do the following when they design a consultation:



Select the right method to achieve effective inclusion from the consultation.



Consider the language used carefully, using person-centred or preferred terms.



Avoid any jargon and communicate in plain English about the consultation process.



Avoid stereotyping, patronising and negative language, including terms such as ‘sufferers’ ‘victims’ ‘disorder’ and verbs such as ‘battling’ and ‘overcoming’. Pay close attention to using the most appropriate social media platforms when publicising the consultation process and work with relevant organisations to maximise awareness. Be sure to signal the venue’s suitability for people with psychosocial disabilities in all communication prior to the event.



If the consultation is in person, visit the venue in advance to ensure accessibility and check its suitability for people with psychosocial disabilities. Provide a nearby quiet space for participants so people can have breaks away from the event.



For online consultations, be mindful that not all participants will have access to a laptop or computer. In this instance, you should offer an appropriate room or an office space for the participant to take part in the consultation where they can access a computer.



If the participant does not have access to a personal computer device for online consultations and a consent form must be signed in advance, you should offer to sign the consent form on behalf of the participant and appropriately record the giving of consent.



“If there are echoey rooms this is very distressing and I get very drained.”

– Focus Group Participant



If material is being sent out in advance, check the language and tone and keep it brief. Make sure to send it out at least a week before the event.



Provide a trigger warning in advance which contains accurate information on relevant supports and services in the event that participants become upset during the event.

Holding a consultation for people with psychosocial disabilities



Departments and statutory agencies that prioritise the inclusion of people with psychosocial disabilities should do the following when they design a consultation:



Ensure that a welcoming atmosphere is evident from the beginning of the event.



When you're talking about tough stuff a nice setting is very important."

– Focus Group Participant



Take time at the start of the event to explain the housekeeping information and in particular to make sure that the agenda is understood.



The agenda is explained thoroughly ... it shouldn't be too long with too much content."

– Focus Group Participant



From the outset, the facilitator should show in their speech and behaviour that they are respectful to people with psychosocial disabilities.



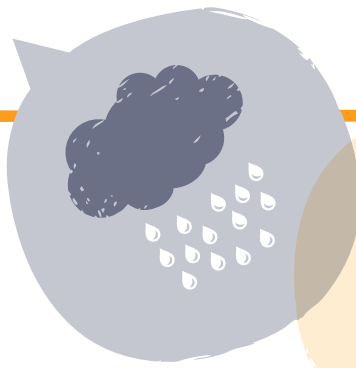
Treat me as an equal I may know as much about the mental health services as they do."

– Focus Group Participant



I often feel infantilised or that they think I don't know what I'm talking about."

– Focus Group Participant



Careful thought goes into the language used throughout the event. The facilitator does not use patronising or complicated terms.



They are not dumbing it down but they're not excluding people - that takes experience. – Focus Group Participant



They should use plain language. There shouldn't be shame about that - just communicate clearly and plainly.
– Focus Group Participant



The facilitator allows participants as much time as they need to contribute. Be sensitive to the individual preferences of participants.



I struggle to make eye contact or if I'm asked a question that I can't answer immediately I have to take my time.
– Focus Group Participant



It would help if there could be an option for writing things down and the facilitator could read it out. – Focus Group Participant

What a suitable venue looks like:

- * Welcoming warm space
- * No distractions, no background noise, no echoes, no harsh lighting
- * The room fits the people neither too big or too small
- * No glass doors to protect privacy

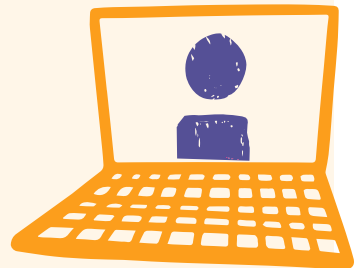


People with psychosocial disabilities describing a successful consultation with them said:

- * If it's working people are at ease and having fun.
- * If it was going well there would be laughter!
- * The facilitator is passionate and not just ticking a box. This is conveyed and people pick this up.
- * They (the facilitator) empathises with me and puts themselves in my shoes.
- * I don't want your sympathy but empathy would be nice.
- * I wouldn't be judged - I could say anything.
- * They create bonds of friendship and mutual trust - this is important for proper understanding.
- * Everyone feels that they can contribute.
- * Being able to write things down and share them that way.

What makes an online consultation successful?

- ★ Use an accessible online conferencing platform
- ★ Have a moderator who offers clear technical instructions at the start and who provides help if participants have technical issues
- ★ Make sure that everyone is comfortable that the event is being recorded and that their permission was sought in advance
- ★ Ask participants to mute when they are not speaking to reduce background noise
- ★ Be sensitive about the Webchat and Questions and Answers functions. Some people like the Webchat enabled and prefer not to have to ask for it to be switched on. Others find it distracting. Provide clear instructions on how to disable the Webchat at the start of the session. Include the comments as they are written as the event unfolds.
- ★ Ensure that the Question and Answers function is on as this allows people to ask questions without speaking.
- ★ Harness the content from the Webchat and Questions & Answers.
- ★ Keep shared presentations to a minimum, use images when possible.
- ★ Allow adequate time for people to 'raise a hand' and contribute.
- ★ Ensure that short breaks are factored in to provide a pause for participants and time off screen.
- ★ Keep online events short and no longer than 90 minutes



Following up and evaluating consultations for people with psychosocial disabilities



Providing people with psychosocial disabilities with follow up and follow through after a consultation event or process is an important way of building trust and respect. In the absence of this there is the risk that participants can feel dismissed and question whether their involvement in the process was respected and valued.

Departments and agencies which value the engagement of people with psychosocial disabilities in their consultation process do the following:

- ★ Ensure that all participants are updated and aware of how the consultation is proceeding and signal what will happen when it ends.
- ★ Inform all participants how their contributions were used to inform the process and thank them for their engagement.
- ★ Outline clearly what the results of the consultation process are when it has ended.
- ★ Choose the most appropriate method to feedback to participants - a report, a meeting, a webpage and use all appropriate channels to ensure that people with psychosocial disabilities access the information.
- ★ Consider an evaluation of the participation process itself to capture good practice and to learn more from those who participated. There are checklists available to use which can be used to improve both the level and point of engagement of people with psychosocial disabilities in the process.

What do people with psychosocial disabilities want from a consultation?



When we asked people with psychosocial disabilities what they want in a consultation process they told us that being listened to was their top priority. This was closely followed by the need to use skilled and experienced facilitators. We grouped the skills they identified as essential into two categories: tasks and processes.

Facilitator Tasks	Facilitator Processes
<p>They have carefully thought through the agenda and are clear on what the goal of the session is. They have checked all technical equipment and are briefed on the sound and lighting systems.</p>	<p>They are experienced in all aspects of psychosocial disability and know how to encourage people to relax and contribute.</p>
<p>They make sure that the room is appropriately set up, that it meets the specific needs of people with psychosocial disabilities.</p>	<p>They have a light touch, are non-threatening, show empathy and use humour to create a safe, comfortable atmosphere.</p>
<p>They can make an informed judgement on what will work best seating wise, if flexibility is possible, at the outset of a meeting/consultation.</p>	<p>They are respectful and listen very attentively. They summarise input back to participants, taking their time to ensure that they have understood what they have been told.</p>

They clearly explain the agenda, running order and ensure flexibility, they explain the housekeeping information in a way that everyone is comfortable with and understands.

They are skilled in identifying bias and prejudice and can address these attitudes comfortably and effectively.

They are welcoming of people standing, sitting, moving in and out of the room.

They are never coercive - they do not force a conversation to a conclusion, push the agenda forward or override what is being shared by participants.

They are welcoming of any and all physical behaviours people with psychosocial behaviours may manifest / demonstrate.

They are welcoming of family, friends, carers and supporters and welcome their participation, while always checking for the consent of the person with lived experience and ensuring that they want this extended participation.

They welcome the different ways that people can participate and encourage people to use these.

They are empathetic, respectful and show dignity, compassion and unconditional positive regard to all participants.

They see that the agenda gets covered without being rigid. They ensure that the pace is appropriate, relaxed and that the content used in presentations is appropriate, using images where they can.

They put people at their ease. They do not pre-judge participants or engage in stereotyping. They accept and meet people where they are.

They can make a sound judgement on when to have breaks and use creative ways to ensure that people are supported during these breaks and not forced into stressful conversations with strangers. They explain and promote this approach throughout the process⁴.

They ensure as much as possible that everyone has the opportunity to contribute and deal gently but effectively with participants who might want to talk a lot more than others.



4 An effective system to reduce unwanted interaction at breaks is to ask people, as they register to select if they want to engage with others during breaks or not. Their choice is indicated by a coloured dot added to their nametag.

We wanted to give the people with psychosocial disabilities whom we consulted for this guide the last word. We asked them what they were feeling when a consultation they were participating in was going well. This is what they said:

When it's going right I feel:

Hope
Understood
Relief
Heard
Appreciated
Relaxed
Comfortable

Useful Resources

National Disability Authority. (2022). *Participation Matters Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making.* https://nda.ie/uploads/publications/NDA-Participation-Matters-Web-PDF_092022.pdf

Department of Public Expenditure and Reform. (2017). *Customer Communications Toolkit for the Public Service - A Universal Design Approach* <https://universaldesign.ie/products-services/customer-communications-toolkit-for-the-public-service-a-universal-design-approach/customer-communications-toolkit-for-the-public-services-a-universal-design-approach.pdf>

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United Nations. (2021). *UN Disability Inclusion Strategy - Guidelines on Consulting Persons with Disabilities* https://www.un.org/sites/un2.un.org/files/un_disability-inclusive_consultation_guidelines.pdf

Appendix

The National Disability Authority published *Participation Matters Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making in 2022*. The principles of meaningful participation from this guide are replicated below:

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

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

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

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

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Special thanks to the staff at MHR who supported the research and development of this guide.



Thank
you!

About the Author

Audry Deane combines her management development consultancy work (MBA, lecturer in creativity and innovation) with her 25 years as a policy and advocacy expert in the community and voluntary sector to secure improved outcomes for marginalised groups.

Her 2020 report *Giving-Health-Inequality-a-Voice-Final.pdf* (eapn.ie) for the European Anti Poverty Network on health inequalities was one of the contributing voices which prompted the development of the Sláintecare Healthy Communities Programme which focuses on addressing the ‘causes of the causes’ of health inequalities. Audry worked with the Department of Health’s Healthy Communities team for a year in its start-up phase as Project Mentor.

She is a member of the Residential Tenancies Board, Legal Services Regulatory Authority and Medical Council Ethics Committee. Her passion is for equitable public services and she gets up in the morning to work for quality accessible public services which meet the needs of the most vulnerable. She is chair of the Dun Laoghaire Rathdown Drug and Alcohol Task Force.





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