

**March 2023**

NDA Submission on the draft Patient Voice Partner Policy for the Irish Public Health System[[1]](#footnote-1)

# Introduction

The National Disability Authority (NDA) is the independent statutory body with a duty to provide information and advice to the Government on policy and practice relevant to the lives of persons with disabilities, and to promote Universal Design. The NDA welcomes the opportunity to make a submission on the draft Patient Voice Partner (PVP) Policy for the Irish Public Health System, which will have significant relevance to disabled people.

Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in March 2018. The UNCRPD provides the framework to promote, protect and ensure the rights of all persons with disabilities and promotes equal rights in all areas of life. It also outlines specific obligations on the State which are of relevance to the draft PVP Policy.

The NDA advises that the Department of Health engages with the Department of Children, Equality, Disability, Integration and Youth (DCEDIY), as the focal point of UNCRPD coordination, in order to ensure that there is harmonisation between the PVP policy and the requirements of the State under UNCRPD particularly with regard to the participation of Disabled Persons’ Organisations (DPOs) in policy development and the provision of funding to these organisations. The submission below addresses areas in which harmonisation between the two strategies are of particular significance.

# Model for engagement with PVPs

The NDA welcomes the aim of this policy to embed the participation of patient representatives in the development of health services and health policy and to streamline the selection and recruitment processes across the Department of Health, the HSE and HIQA.

The NDA wishes to highlight obligations set out under the UNCRPD which have implications for the proposed model of engagement. Article 4(3) of the UNCRPD obliges States Parties to closely consult with and actively involve disabled people in decision making processes through their representative organisations.

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”[[2]](#footnote-2)

The UNCRPD Committee in its General Comment No. 7[[3]](#footnote-3) states that Disabled Persons’ Organisations (DPOs) are the representative organisations of disabled people. DPOs are a type of civil society organisation which are led, directed and governed by disabled people. These are distinct from organisations ‘for’ disabled people which advocate on their behalf or which provide services to disabled people.

The categories of engagement set out in the draft PVP policy make reference to participation of Patient Voice Partners (PVPs) in committees and working groups, inputting into priority programmes, and in making strategic recommendations around health service delivery or reform. These are all areas in which the State is obliged to consult with and engage DPOs, when the issues under discussion are of relevance to disabled people. Therefore, in order to ensure harmonisation of this policy with UNCRPD obligations, it is necessary to consider how DPOs fit into this model of engagement. For example, making particular efforts to target DPOs when sharing a recruitment notice for a PVP role and prioritising their selection to these roles when they relate to disability services or policy.

The NDA wishes to highlight its ‘[Participation Matters: Guidelines on Implementing the Obligation to Meaningfully Engage with Disabled People in Public Decision Making’](https://nda.ie/publications/participation-matters-guidelines-on-implementing-the-obligation-to-meaningfully-engage-with-disabled-people-in-public-decision-making) as a useful resource in this regard and we are happy to advise further. These guidelines were developed following substantial consultation with DPOs, public officials and other relevant stakeholders.

# Payment of PVPs

Payment for a participants’ time and expertise in processes of engagement is an issue that is often highlighted by stakeholders. [[4]](#footnote-4) The NDA has included advice regarding payment in our ‘Participation Matters’ guidelines which has been shared widely across the public sector and therefore should be considered within the draft PVP Policy.

With regard to the payment of expenses, the NDA ‘Participation Matters’ guidelines advise that this is necessary in order to reduce barriers to participation. Travel and subsistence expenses are commonly paid across the public sector for engagement in consultation and we note that this is included in the draft PVP Policy. However, in addition to travel and subsistence expenses, the NDA advises that additional expense categories be considered for payment in order to facilitate the equal participation of disabled people. For example, some disabled people may require their personal assistant to attend a meeting with them, whose costs should also be covered. We have also advised covering expenses such as Personal Assistance hours, childcare, and other caring responsibilities where necessary for a participant to engage.

In addition to expenses, the NDA has also advised that core institutional funding is required from the State for DPOs in order to meet UNCRPD requirements. The UNCRPD Committee outlines in its General Comment No. 7 that State Parties are obliged to provide funding to DPOs in order to build their capacity to engage in all phases of policy-making. At present, there is no routine State funding mechanism for DPOs, but this may change in future.

We note the criteria for payment of category three PVPs within the draft policy. The NDA advises that coordination with DCEDIY is necessary in order to ensure alignment of the PVP policy with UNCRPD requirements regarding the funding of DPOs. In order to future-proof the draft PVP Policy we recommend considering how the policy will approach payment of participants who are being paid by their organisation to attend such meetings, in order to avoid duplication of funding streams.

We also wish to highlight that if DPOs are not included in a consultation on a particular policy or service through the PVP structure under category three, but are engaged through another parallel process, this could result in a hierarchy of engagement in which patient representatives are paid for their time while DPOs, which the State is obliged to fund and consult in these processes, are not paid. In this scenario the State would not be meeting its obligations under UNCRPD. Again, we advise that engagement with DCEDIY on this issue is necessary in order to consider various scenarios which could arise.

We advise that it would be important to consider the wider implications of this funding model in the context of the State’s obligations under UNCRPD. The PVP Policy is likely to set a precedent for other Departments and agencies in terms of payment of consultation participants, beyond the health sector.

# Language considerations

The NDA has some concern about the language employed in the draft document and in particular in relation to the use of the word “patient” in the draft Patient Voice Partners policy document.

The NDA produced an Advice Paper on Disability Language and Terminology in 2022[[5]](#footnote-5). The Advice Paper highlights that as conceptions of disability have changed (in particular the shift from the medical model to the social model) so too has the language and terminology related to disability. Debates about the appropriateness of disability terminology and language continue so while there is no universally agreed consensus on which terminology to use in relation to disability the NDA Advice Paper highlights the following principles which can inform considerations around disability language and terminology

* Consider the context
* Ask people about their preferences
* Avoid medicalised language
* Avoid stereotypes
* Avoid euphemisms
* Avoid negative language

Disability is not a health condition. Therefore, unless in a relevant setting or context, medical language should not be used to refer to a person with disability. People with disabilities should not be described as “patients” except in the context of discussing their medical care.

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

If it is intended the Patient Voice Partners model outlined in the draft would include scenarios where people with disabilities would participate on committees which would discuss social care (rather than medical care) then using the term “patient” would be inappropriate and would be likely to cause offence. The NDA therefore advises that the scope of the Patient Voice Partners model and the language need to be jointly considered.

# Supports

The NDA welcomes the inclusion of a section on “Induction, Training and Support” in the draft Patient Voice Partners policy document. Sections of the ‘Participation Matters’ guidelines would also be relevant in this regard. It may be worth referring to this document in the final draft as it contains a lot of practical considerations in relation to including people with disabilities in consultation meetings and events (much of while would be applicable to PVP meetings).

While the current text in the draft Patient Voice Partners policy document is reasonably comprehensive we would advise that there could be more emphasis on the need to talk to the PVP on a regular basis about their accessibility and support requirements rather than listing possible supports. So for example suggesting that PVP Committees consider a “wheelchair accessible meeting room” is important it may not be sufficient as many venues with wheelchair accessible meeting rooms don’t have toilet facilities accessible to people who use modern power wheelchairs and may not be adjacent to or accessible from public transport. Therefore, the best way to ensure that someone with a disability will be able to access and participate in a meeting is to discuss their support requirements with them and regularly review how those supports or accommodations are working.

The current text on supports in the draft Patient Voice Partners policy document could be enhanced in relation to the needs of people with sensory issues, such as people with autism (in relation to environmental considerations) and in relation to supports prior to and during meetings and how meetings are structured and chaired in relation to people with autism and people with intellectual disabilities.

The NDA advises that the ‘Participation Matters’ guidelines be referenced as a resource to PVP Committee chairs in the document. We are also willing to discuss and provide you with further information on organising accessible meetings as you draft Patient Voice Partners policy document.

# Conclusion

The NDA welcomes the consultation on the draft PVP Policy. We advise that the Department of Health engages as a matter of priority with the Department of Children, Equality, Disability, Integration and Youth in order to ensure that there is harmonisation between the PVP policy and the State’s requirements under UNCRPD as outlined above. We are happy to advise further on any of the issues raised in this submission.

1. <https://www.gov.ie/en/consultation/29a5e-public-consultation-on-a-draft-policy-for-patient-voice-partner-in-the-irish-health-and-social-care/> [↑](#footnote-ref-1)
2. [UNCRPD Article 4(3)](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html) [↑](#footnote-ref-2)
3. [UNCRPD Committee (2018) General Comment No. 7 on the participation of persons with disabilities](https://digitallibrary.un.org/record/3899396). [↑](#footnote-ref-3)
4. See: [NDA (2022) Participation Matters Consultation report](https://nda.ie/publications/participation-matters-guidelines-on-implementing-the-obligation-to-meaningfully-engage-with-disabled-people-in-public-decision-making) pages 56 – 57. [↑](#footnote-ref-4)
5. NDA (2022) [Advice paper on Disability Language and Terminology](https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology) [↑](#footnote-ref-5)