PPI IGNITE NETWORK

RESPONSE TO THE GREEN PAPER ON DISABILITY REFORM PUBLIC CONSULTATION.

PPI: The involvement of service users and members of the public and patients as equal partners contributing their lived experience to research and/or partnerships with public service organisations.

Our Perspective

“That people who are likely to be using new treatments are directly involved in, and shape, the decisions made to produce the new treatments.”

Trish O’Donovan, PPI contributor, Primary Care, University of Galway.

The voice of people in receipt of disability payments, prominent users of our health services, is essential to shape research and health service design. Their lived experience means that they are often best placed to support the design and evaluation of initiatives aimed at improving health and social care. Already a marginalised group, the revised disability payment system should reduce, not increase, the barriers to their involvement.

The PPI Ignite Network promotes excellence and inspires innovation in public and patient involvement (PPI) in health and social care research in Ireland. Our response to the Green Paper is focused on limiting barriers to involvement for people in receipt of disability payments.

Facilitating PPI is increasingly a focus for the Department of Health, the Health Service Executive (HSE), and research funders, reflecting Ireland’s research and innovation strategy, which specifically highlights the need to *“Strengthen the citizen’s voice in the R&I [Research and Innovation] process”.*

It is important to recognise that people with lived experience contribute time, skills, experience, and expertise through their PPI activities. This should be recognised, valued and rewarded.

Our work is underpinned by our Values and Principles Framework*.* Drawing on the values of respect, equality, and inclusion in particular, we believe and advocate that members of the public and patients who get involved in research, should receive financial recognition in acknowledgement of their time and their unique expertise.

Summary of Recommendations

- Ensure that those on Personal Support Payment can undertake PPI activities without risk to their tier placement or to any additional social welfare benefits they receive.
- Implement an earnings disregard on monetary payments for PPI activities up to an agreed limit.
- Address inconsistencies in permission status and limitations for people with disabilities looking to engage in Personal Support Payments.
- Facilitate a streamlined system to resume Personal Support Payments and move along tier categories for those with episodic conditions.
- Explain fully, and make publicly available, the assessment criteria of Tier placement on the Personal Support Payments

Additionally, we encourage the Department of Social Protection to

- Organise and facilitate a public consultation of young people with disabilities.
- Initiate the process to develop a long-term, cross-department strategy for the employment of persons with disabilities.
- Appropriately set disability payments in line with the increased cost of living for people with disabilities across all payment tiers.

What is the PPI Ignite Network?

The PPI Ignite Network is comprised of seven Universities, ten National Partners and over fifty local partners[1]. PPI is a pathway to more impactful research, where those who are most affected by research results have a say in what research is done and in using the research evidence to change policy. The Network aims to improve patient outcomes by supporting PPI and changing the research culture in Ireland. The Network builds capacity for involvement across stakeholder groups by embedding PPI in higher level education, offering training in PPI approaches, developing resources to help researchers practice PPI, and promoting excellence in PPI activities.

The PPI Ignite Network welcomes the opportunity to submit a response to the Department of Social Protection's Green Paper on Disability Reform. We commend the Department's commitment to its obligations as defined in the UNCRPD to consult people with lived experience in the creation of policy that will impact their lives through a wide public consultation. Barriers to employment continue to be a key factor separating people with disability from economic independence, social inclusion, and personal fulfilment (Government of Ireland, *Comprehensive Employment Strategy*, 2015). We appreciate the government's recognition that change is needed to ensure better equality and employment outcomes for all.

Currently, people on social welfare benefits do not get involved in PPI, or only in a voluntary capacity, due to the potential risk of losing some, or all, of their benefits. This inequality means that the voice of an already marginalised group of society, who are prominent users of our healthcare facilities have been sidelined and silenced as they cannot afford the associated risk of taking on PPI activities.

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[1] This response reflects the views of the PPI Ignite Network and may not reflect the views of the individual organisations within the Network.

“People living with a disability have a valuable contribution to make, bringing their lived experience to help shape health and social care services. We should not design services for them without them. The proposed new approach to disability allowances provides a unique opportunity to remove the barriers currently preventing the voice of people with disabilities from being heard.”

Prof Sean Dinneen, National Lead, PPI Ignite Network

Public policy is now being driven by involvement of people with lived experience.

"Involvement of service users and their carers should be a feature of every aspect of service development and delivery" (Department of Health and Children, A Vision for Change, 2006)

> "[The Healthy Ireland Framework] proposes a necessary shift towards a broader, more inclusive approach to governance for health, moving beyond the health service, across national and local authorities, involving all sectors of society, and the people themselves." (Department of Health, Healthy Ireland Framework, 2014)

"Patients must be at the heart of any health system, and we need to facilitate and encourage greater public and patient involvement (PPI) in research…By putting the patient at the centre of the priority setting we will also be able to achieve greater impact" (Health Service Executive, HSE Action Plan for Health Research 2019-2029)

> "Strengthen the citizen's voice in the R&I [Research and Innovation] process" (DFHERIS, Impact 2030: Ireland's research and innovation strategy, 2022).

"… the need to better embed research within the health-care system in Ireland, and central to that was the patient voice, with the need for public and patient participation and engagement in health research expressed." (Government of Ireland, Creating Our Future, 2022)

> "Engaging with disabled people in decision making…makes government more responsive to the rights of people with disabilities and makes laws, policies and services more effective by taking account of the lived experience of those affected." (National Disability Authority, Participation Matters, 2022)

Basis of our recommendations

Recommendation 1: *Ensure that those on Personal Support Payment can undertake PPI activities without risk to their tier placement or to any additional social welfare benefits they receive.*

Currently people on invalidity pension must apply for Partial Capacity Benefit to take part in PPI activities, risking a reduction in weekly payments and potentially the loss of additional social welfare benefits, such as carers allowance. Our concern is that people on the new Personal Support Payments taking part in PPI activities may be deemed to have a ‘capacity to work’ and be moved into a different tier or lose valuable additional benefits. We therefore recommend that the Department ensures that those on Personal Support Payments can undertake PPI activities without risk to their tier placement or to any additional social welfare benefits they receive.

Recommendation 2: *Implement an earnings disregard on monetary payments for PPI activities up to an agreed limit.*

Those who are availing of disability benefits are uniquely disadvantaged should they accept compensation for the contribution of their time. While it is impossible to generalise, individuals involved in PPI activities may spend between 30 and 100 hours per annum in these endeavours. In the current system, income support is reduced on receipt of an occasional remuneration for PPI activity. This issue will be particularly relevant for working people with a disability assigned to tier 3 where they will be discouraged from getting involved in research if they will lose the remainder of their income support.

Additionally, as their weekly benefit will decrease in line with a remuneration received, working people with a disability will not be meaningfully recognised for their contribution to research.

Therefore, we propose that the Department implement an earnings disregard on monetary payments for PPI activities up to an agreed limit. Such a system will ensure that getting involved in research remains viable for working people with a disability and that they can be recognised for their contribution in a worthwhile fashion. We believe that the public good and societal benefit of involvement justifies introducing a *lived-experience* disregard for all disability related allowances. The value of this disregard should be agreed in consultation with relevant stakeholders and people with lived experience.

Recommendation 3: *Address inconsistencies in permission status and limitations for people with disabilities looking to engage in Personal Support Payments.*

At present, different rules govern whether a person in receipt of disability payments requires permission to get involved in PPI, and how many hours they are restricted to. These are:

Social Welfare Scheme	Permission Status	Criteria/Limitations
Disability Allowance	Permission must be sought before voluntary activity.	No restrictions.
Invalidity Pension	Must apply for Partial Capacity Benefit for permission	19.5 hours (max) of voluntary activity per week.
Blind Pension	No prior permissions are required.	No restrictions.

Carer's Allowance	Permission must be sought before voluntary activity.	18.5 hours (max) of voluntary activity per week.

This is a key inconsistency which the Green Paper fails to address. The current disorganisation of permission statuses disincentivises people with disabilities from participating in their communities. We call on the Department to address the inconsistencies in permission status and limitations for people with disabilities looking to engage in voluntary activities.

Recommendation 4: *Facilitate a streamlined system to resume Personal Support Payments and move along tier categories for those with episodic conditions.*

The three-tier system does not consider those with episodic conditions. While they may be capable of part-time or full-time work periodically, their condition could quickly deteriorate and require further assistance. This difficulty is compounded by the several agencies and schemes one must contact to restore their disability benefits if employment does not work out (Department of Social Protection, *Make Work Pay*, 2017). We ask that the Department facilitate a streamlined system to resume Personal Support Payments and move along tier categories for people with episodic conditions.

Recommendation 5: *Explain fully, and make publicly available, the assessment criteria of Tier placement on the Personal Support Payments*

We are concerned that the assessment criteria for people with disabilities are not sufficiently transparent. The Green Paper remains unclear and imprecise on how assessments will be conducted in new tier categories. This has led to understandable worry amongst people with disabilities, uncertain of where they will be categorised and what impacts this change will have on them. We ask that the Department explain fully, and make publicly available, the assessment criteria of tier placements on the Personal Support Payments.

Additional recommendations for your consideration.

Organise and facilitate a public consultation of young people with disabilities.

We are concerned that there has been no action taken by the Department to consult with young people about this change. In failure to sufficiently advertise to and consult with people under the age of eighteen, they are in breach of the State's obligations to have youth voices heard as is underlined in Article 12 of the UN Convention on the Rights of the Child and Article 7 of the UNCRPD (United Nations, 2009). We recommend that the Department organises and facilitates a public consultation of young people with disabilities.

Initiate the process to develop a long-term, cross-department strategy for the employment of persons with disabilities.

The current state of disability employment strategy is siloed and disorganised. We recognise that the Department of Social Protection is not, and cannot be, responsible for the broad range of policies which would need to be implemented to effectively break down attitudinal, policy and access barriers to involvement in our communities and workplaces. However, there is currently no plans for a long-term, cross-departmental strategy for employment of persons with disabilities. We recommend that the department initiate this process.

Appropriately set disability payments in line with the increased cost of living for people with disabilities across all payment tiers.

Disability payments should offer a liveable subsidy for recipients. Currently, the flat rate disability payment ‘is not sufficient to prevent poverty among people with a limited capacity to earn additional income’ (Department of Social Protection, 2023). Considering this admission, it is puzzling to see the flat rate disability payment unchanged in the Tier 3 bracket. Individuals placed in Tier 3 will be corralled into employment which may be unfit for their needs to avoid poverty. The Department must appropriately set disability payments in line with the increased cost of living for people with disabilities across all payment tiers.

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Health Service Executive, 2019, *HSE Action Plan for Health Research 2019-2029*, https://hseresearch.ie/wp-content/uploads/2019/12/10-Year-Action-Plan.pdf

National Disability Authority, 2022, *Participation Matters: Guidelines on implementing the obligation to meaningfully engage with disabled people in public decision making*.

We appreciate you taking the time to read our response. We are always open to questions, and welcome engagement, please do not hesitate to get in touch. Our contact details are listed below.