

Cumann Síceolaithe Éireann

# The Psychological Society of Ireland's Submission to the Green Paper on Disability Reform: A Public Consultation to Reform Disability Payments in Ireland

### **Background and Context**

On Wednesday 20 September 2023, the Department of Social Protection published the Green Paper on Disability Reform – A Public Consultation to Reform Disability Payments in Ireland<sup>1</sup>, representing the current Government's proposal on how to reform the existing system of social protection payments that are made to people with disabilities and their carers. This paper is part of a public consultation process, which seeks to invite feedback and responses to the proposals from individuals and stakeholder organisations, particularly people with disabilities, their representative organisations, or indeed professional bodies, including the Psychological Society of Ireland (PSI), that work with and advocate for those affected by a range of different disabilities.

#### Why is this important?

The Central Statistics Office (CSO) Census 2022 data suggests that approximately 22% of the Irish population identifies as disabled, which the latest census defined as "having at least one long-lasting condition or difficulty, to any, some or a great extent". This appears to reflect an increase in the prevalence of disability relative to the previous census, though direct comparisons are challenging as the way disability is defined is not the same across time. It does appear to be mirrored by the number of individuals in receipt of Disability Allowance payments, which reflects a 55% increase in recipient numbers from 2012-2022 (IGEES, 2023). CSO data also shows that about 20% of individuals in this category are nine times more likely to experience 'consistent poverty' compared to those who do not receive Disability Allowance payments.

<sup>&</sup>lt;sup>1</sup> From this point onward, the Green Paper on Disability Reform – A Public Consultation to Reform Disability Payments in Ireland will be referred to as the Green Paper.

Furthermore, when viewed in the international context, Ireland compares less favourably than our European Union (EU) and Organisation for Economic Co-operation and Development (OECD) counterparts with the employment rate and societal engagement of disabled people. Whilst Ireland's overall employment rate is among the highest in the EU, the disability employment gap in Ireland has been the largest in the EU, at 38.6%. These statistics highlight the need for review and reform of Ireland's social protection system. Some of those reforms are likely to reside within the social protection payments themselves. Other reforms may reside within the supports offered and provided to individuals capable of working or earning in different ways. Perhaps the need for reform to also occur at the level of society itself and the barriers society may inadvertently place in the way of disabled individuals and their rights of access to State services, education, training, and employment.

#### The Psychological Society of Ireland's Overarching Position

It is important to state that the PSI broadly welcomes this consultative process, which is likely to benefit greatly from the views of those most affected by these proposals and associated policies. We note the multiple acknowledgements by the Government of the Green Paper document not being the best solution, or being in any way finalised at this point, but rather, it is framed as a stepping stone and that this consultative process is seen as moving towards a fair, equitable, person-centred model of social protection and income support.

The PSI supports Irish disability legislation that is aligned and congruent with the social model of disability as set out by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), which the Irish Government signed in 2007 and ratified in 2018. As per the UN CRPD, the PSI fully supports disabled persons as having equal rights with their fellow citizens and supports disabled persons' rights to be fully included and to effectively participate in all aspects of society. For this aspiration to be meaningfully achieved, the PSI feels it is essential for the State to honour its mandate to closely consult with and actively involve disabled persons (and their representative organisations) in issues which concern them, particularly relating to reform of the social protection system seeking to support them. This is supported by Article 4.3 of the UN CRPD.

# **Information Gathering Process**

The PSI sought to gather as much pertinent information as possible to help inform its response to the Government's Green Paper. It did this largely by way of the following methods:

- In October 2023, the PSI established a Disability Reform Working Group, comprising two PSI Council members with extensive experience working in the disability sector, as well as the PSI Chief Executive Officer, and the Policy and Research Officer.
- By late October 2023, the Working Group contacted the following divisions and special interest groups (SIGs), which were identified as representing PSI members most likely to be working in, studying, or advocating on behalf of those in the disability sector, to inform them that the PSI would be drafting a response to Government on the Green Paper publication. These included the Divisions of Neuropsychology, Division of Clinical Psychology, Division of Forensic Psychology, Division of Health Psychology, and Division of Behaviour Analysis, and the SIGs in Intellectual Disabilities, Autism, and Human Rights and Psychology. The PSI's Working Group invited the views of these subgroups so that this feedback could be incorporated into the PSI's response.
- In early November 2023, a conference call between representatives of the PSI Working Group and the Chairperson of the Disabled Persons' Organisation (DPO) Network, Ms Jacqui Browne, was confirmed. This was scheduled to facilitate a discussion of the Green Paper on Disability Reform and it was of utmost importance to the PSI that the views of DPOs, representing individuals and children living with disabilities, would help to shape and inform the PSI's response.
- In December 2023, while the PSI's Working Group was finalising its submission to the Government's Green Paper, the deadline for submissions was extended by three months. This allowed further consultation between the PSI's Working Group and its divisions and SIGs, and the DPO Network, with regard to its response. Given the complexity and scale of this process, the reforms that are required to adequately address the difficulties inherent in such a complex undertaking, and the opportunity that the Government has to overhaul and improve Irish society's attitudes towards and treatment of disabled persons, this three-month extension was helpful.

At all times during the PSI Working Group on Disability Reform's scope of work, many documents were used as primary source materials. The (non-exhaustive) list of documents can be found in References on page 9.

# **Main Findings**

- The Government is proposing the need to standardise conditions that determine qualification for the scheme. Simplifying access to social protection payments appears to be in the interests of all individuals and carers who may be claiming payments.
- 2. Instead of three different social protection payment schemes, it is proposed that there will be a unified payment scheme, referred to as the 'Personal Support Payment'. It is suggested that this will address anomalies and disparities across the existing schemes and address the complexity, confusion, and associated administrative burden of the existing schemes. It is the PSI's view that this proposal has received a relatively positive response from those across the disability sector and appears to represent a progressive step.
- 3. The Green Paper also proposes to introduce a three-tier system of payment, categorising individuals with disability into three tiers of disability, which would ultimately be linked to individual support needs. The Green Paper uses the terms "severity" of disability or "capacity to work" to differentiate the tiers from one another. Based on the PSI's information gathering process via its membership and in liaison with DPOs, this proposal has not been welcomed for myriad reasons, including but not limited to: risk of increasing stigma; creating avoidable adversarial dynamics during assessment and Intreo engagement processes, particularly if deemed mandatory; and, despite assurances from the Department of Social Protection that it is not an attempt to introduce a United Kingdom (UK) welfare system by stealth, which has been judged in the main as a budgetary saving measure. The tiered model set out in the Green Paper does have structural similarities to the UK model.
- 4. Within the island of Ireland, a great deal of assessment of individuals diagnosed with disabilities are conducted solely within a biomedical framework. The PSI considers firstly that the both assessment processes whereby those whose needs are being determined by an assessment process, as well as impacted by this current consultative process, would reflect a social model of disability with more health and social care professions (HSCP) involvement. As noted, a great deal of the biomedical model of assessment is incongruent with the United Nations (UN) Charter for Human Rights. There are a vast array of disabled individuals whose needs may not be recognised or supported by medical models but for whom will nevertheless require disability support. Subsequently, much of the nomenclature in official policy and documentation is disrespectful of the individual rights of disabled persons should the Government continue to use solely the current more widely used biomedical framework. While a biopsychosocial approach is mentioned in the proposal, assessment is defined as being medical without any HSCP input.
- 5. The PSI does not see assurances in the documentation around assessments that those administering assessments will adequately and sensitively understand the needs whether these assessments are psychological or medical or involving other relevant disciplines of

disabled people where they are required. Furthermore, it appears that the onus will be placed on disabled people and/or their carers to provide sufficient evidence that the correct assessments have been conducted. Many disabled individuals may not know how to access relevant healthcare professionals or how best to represent their needs. The wellestablished lack of access to services in the following areas will compound this: physical and sensory disability, neurorehabilitation, intellectual disability, mental health, primary care. Our concern is that the system will emphasise or accept only one type of assessment and that a disabled individual will be expected to know exactly how to access the assessment they need and where to access it.

Furthermore, a disabled person may need to access additional medical reports and provide this information to third parties when this may be an onerous process for them already. This may not be recognising that one person may in fact be experiencing multiple different types of disability and may not be aware of where and how to access the types of assessment or support or even reports needed to access a disability payment in the first instance. The reality of living with a disability frequently includes so-called invisible signs such as fatigue, pain, bladder and bowel difficulties, communication and cognitive impairment, dizziness, and mental health difficulties. Some of these symptoms may be fluctuant but long-term and in themselves disabling nonetheless. This is particularly the case among people with certain neurological conditions (e.g., acquired brain injury, multiple sclerosis, etc.). The medical assessments must adequately tap into such issues in all their complexity as they impact quality of life, ability to apply oneself to training and occupation, and the psychological resources each individual requires to meaningfully engage in training and work. Failing to allow for the broad and deep complexities of disabilities and even how a disability might vary across time, will be extremely limiting and cannot be accounted for strictly with one model of assessment at one discrete point in time by only one professional at only one service.

6. The Department of Social Protection intends to allow disabled people who are 18 years old or over eligibility to access the Personal Support Payment, to ensure that there are consistent rules that cover who would be entitled to access social protection payments across the board. This is different to how some social protection payments, such as Disability Allowance are presently paid, which happens from when a disabled person turns 16 years old onwards, but this brings Disability Allowance into line with other disability payments. To account for this change, the Department would continue to pay Domiciliary Care Allowance until the disabled child turns 18 years old. This appears to be a positive suggestion as it supports and incentivises the retention of disabled individuals in education or training, whilst ensuring that families are supported and compensated for the extra costs associated with their disability. It would be very important that the proposal clearly outlines the need to standardise the conditions that determine qualifications for the scheme. Simplifying access to social protection payments is in the interests of all those that need to claim payments. It is acknowledged that the current process for accessing the current

Domiciliary Care Allowance and Disability Payment is extremely onerous for those who have to complete the process. It would be very important that any changes to a process do not make it more onerous on disabled persons or their carers.

7. The Green Paper discusses the work and training opportunities available to disabled people and the need to increase these. We strongly agree with the statement that such opportunities should be available. Many barriers prevent disabled people from training and working and these must be addressed. These include the discrimination and exclusion experienced by disabled people. This cannot be overcome by mandating training/work and by making vital payments contingent upon this. Discrimination, inequality, and exclusion must be tackled for the proposals to make meaningful change. It is our view that the proposals could place some disabled people in even more financially precarious situations by increasing the demands placed on them, such as to attend work or training which can bring with it many hidden costs for disabled people. The implication that more disabled people should be in training or employment does not take account of the range of support that many disabled people require in such circumstances. This includes transport/travel, health, assistive technologies, disability friendly workplaces and training settings, job coaches and practical/formal work-based supports, augmentative communication resources and more. The Green Paper reassuringly suggests that those currently in receipt of payments would be transitioned to the new system on a no-loss basis to the new system.

# Recommendations

- 1. The suggestion for categorisation of disabled individuals into three tiers of disability or three tiers of capacity to work appears overly reductive and lacking in the sensitivity or nuance that this may require. While we recognise the need for categorisation, we recommend that this piece should have significant reconsideration to avoid further stigmatisation of vulnerable individuals. The current suggestions in the existing document also run the risk of inadvertently creating a system whereby pressure is exerted on agencies or disciplines to provide diagnoses if doing so might place a person in a different tier of disability, which thereby might yield a higher disability payment, but which may not actually reflect the individual's support needs. It is important to create support systems that are adequate to the human's level of need, that are empowering, enabling, and not pathologising, and that is genuinely providing support where needed and not inadvertently placing additional barriers and stigma in the way of already marginalised and vulnerable members of society. This is why focusing on support needs rather than levels of disability is important.
- 2. Assessments indicating eligibility for disability payments should include psychological and other allied health multidisciplinary assessments in a transparent way and should take into account the social model of disability as espoused by the UN Charter for Human Rights and UN CRPD.
- 3. Assurances will need to be made to those impacted by any changes to the current system that neither the onus for further assessment nor provision of documentary evidence of further assessment will be placed on them to complete such paperwork arising from changes to the current system. In other words, there will need to be a system in place that enables a smooth manner in which disabled persons can transition from the older system to the newer system with as few bureaucratic barriers as possible. It would be important to clarify whether this is an indefinite or a time-limited guarantee and/or if persons need to seek extensions to their payments over time.
- 4. Assurances should be made for individuals who may have varying support needs at different times that, should they be in a position to work more hours in a given week or month, they will not lose access to their current "tier" or level of disability if this will financially disadvantage them to do so. Punishing disabled individuals for "well" days will disincentivise them from engaging in other activities (including the world of work or education) that may otherwise be helpful, sustaining, or contributing to their overall health, wellbeing, or thriving. This is not in line with the science of human behaviour and would not be in line with long term societal wellbeing. Indeed, putting a system in place that does not allow humans to have "well days" where they can work without losing benefit means that these persons will never leave a "benefit system".

- 5. Consideration should be given for not just assuming that a person should be returning to work, but under what types of conditions and supports a person might need to access in order to make this a possibility. Disabled individuals face epistemic injustices in school, health care and larger society that need to be considered at a macro-level before assuming that after a period of time, a person can and will return to education or work.
- 6. Consideration of the types of support that an individual might need to enable them to not just return to work, but also to thrive, needs to focus not just on the transition period between when a young person transitions from the ages of 16-18 and into adulthood. Rather, a disabled person with support needs, *and their carers* will need support and consideration in a more global way as a person moves along their developmental trajectories. In order for this to be effective, taking note not just of one diagnostic medical assessment, but rather the multi-systemic barriers for a disabled person to succeed throughout education and later in occupation needs to be addressed early on such that a person has higher chances of accessing the world of work to begin with.
- 7. Consideration should be given to the lack of availability of a wide variety of practical supports for disabled persons to return to work prior to assumptions being made that a disabled person's goal should be to be in employment.
- 8. Consideration should be given to access to provision for a disabled person's wide ranging occupational, mental health, physical health, social, communication, sensory, intellectual, motor coordination, emotional, behavioural, and educational needs before making assumptions that a person must return to work within certain time frames.
- Consideration should be given to those on long waiting lists for assessments or for those who cannot fill out the paperwork necessary to access disability payments once they have had assessments conducted. Consideration should be given to whose responsibility this is.
- 10. It is noteworthy to our Working Group that many disabled persons and their carers have informed us of how challenging it is to access assessments for certain types of disabilities to seek these payments in the first instance, how difficult it is to complete the paperwork for these allowances, how they are often rejected several times before an application is approved, perhaps reflecting the inherent flaws and limitations of the current biomedical assessment modality. This is a cause of significant concern as it suggests that many vulnerable individuals might not access these payment supports unless they have the task persistence to endure these lengthy processes and overcome these systemic barriers. The PSI is advocating for a social model approach to evaluating disabled persons characterised by multi-disciplinary assessment and guidance, to avoid and minimise the potential iatrogenic harm caused by systemic barriers.

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