



## ***Green Paper on Disability Reform:***

### **Submission to the Department of Social Protection on the Reform of Disability Payments in Ireland.**

Family Carers Ireland

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## Introduction

Family Carers Ireland welcomes the opportunity to submit our views to the Department of Social Protection on the Green Paper for the Reform of Disability Payments. Representatives from Family Carers Ireland attended a number of the consultation events hosted by the Department during Autumn 2023 where we set out our views regarding the Green Paper. This submission provides an additional written summation of Family Carers Ireland's position on these proposals.

We acknowledge that the Green Paper is not an agreed policy, but rather is a proposal by the Department to encourage creative thinking and focused discussion on how disability payments could be changed to better meet the needs of disabled people and is designed to instigate discussion and debate. We note the Department's confirmation that their proposals may not be the best or only way forward and that no decision has been made on how to proceed. The future direction of disability payments will ultimately be informed by the outcome of the consultation.

Family Carers Ireland is a national charity dedicated to improving support and recognition for Ireland's 500,000 family carers who provide regular, unpaid care to a friend or family member with a long-term illness, health problem or disability, including problems related to old age. We endorse the principles of the UNCRPD and the rights of disabled people to have freedom, choice and control over all aspects of their lives and to directly inform the decisions that impact them.

## Summary of Key Points

### *Overall Comments:*

- (i) Family Carers Ireland acknowledges the aspirations of the Green Paper and its ambition to tackle the poverty and low rates of employment experienced by disabled people. While the Green Paper is a signal that government acknowledges the need for change, if taken alone the reforms proposed risk putting even more pressure on disabled people by failing to address the structural barriers to employment or involving other actors who have a responsibility in this area. While the income and employment support offered by the Department of Social Protection is critical, these supports alone form only part of the policy response required. Broader reforms are needed across other Government Departments, agencies and employers before it will be possible to consider the changes proposed in the Green Paper.
- (ii) We welcome the Green Paper as a lens through which to appraise the current system of disability payments and identify opportunities for change. While we do not support some of the proposals contained in the Green Paper, we accept the key assertions on which the proposals are grounded and the need for reform. Namely, the acknowledgement that:
  - There is an **increasing prevalence of disability** in Ireland, in part linked to our ageing population, which places an urgency on policymakers to address the root causes of the social exclusion of disabled people and to progressively narrow these gaps.<sup>1</sup>
  - People with a disability are at a much **greater risk of poverty** than non-disabled people and this risk is strongly correlated to the difficulties they face securing and holding down employment.

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<sup>1</sup> The number of Disability Allowance recipients increased by 55% in the decade to 2022. In Census 2022 1,109,557 people reported experiencing at least one long-lasting condition or difficulty, accounting for 22% of the population.

- **Ireland has the largest disability employment gap in the EU**, at 38.6%. The employment rate of people with disabilities across the EU was 50% in 2020. Less than one-third of people with disabilities in Ireland were employed in 2019.<sup>2</sup>
- **People with disabilities and family carers incur additional costs** that people and households without a disability do not face. The Indecon Cost of Disability study estimates these costs to range between €11,579 and €16,284 per annum (€223 / €313 per week) depending on the level of disability.<sup>3</sup> A similar study published by the Vincentian Partnership for Social Justice in 2022, estimates that households where high-level care is provided incur additional costs of up to €12,688 per year (€244 per week).<sup>4</sup>
- The additional costs of disability and caring arise, in part, as people are **forced to pay privately** for services that should be publicly available (i.e. transport, respite, assessments etc).
- The range of disability payments currently available can overlap and there is an **opportunity to simplify the payment structures by introducing a single scheme** to replace the Disability Allowance, Blind Pension and Invalidity pension.

(iii) For many years Family Carers Ireland has expressed concern that Disability Allowance – an adult payment for those *substantially restricted from doing work* – is paid to children aged 16 to 18 years. We support the proposal to extend the age of payment of Domiciliary Care Allowance (DCA) from 16 to 18 years contingent on the assurance that young adults aged 16 to 18 years and their families are not financially penalised as a result. We note the Department's commitment to undertake further consultation concerning a transitional support payment to offset any potential loss of income and emphasise the need to ensure this payment is in place before the qualifying age for Disability Allowance is extended to age 18.<sup>5</sup>

*Principles that should underpin disability payment reform (DSP specifically)*

(iv) The Irish social welfare system is complex, having been developed and shaped in response to the lobbying efforts of representative groups over many years. This has created a system in which scheme eligibility varies, with different degrees of incapacity, income and work levels determining qualification. While efforts have been made over the years to simplify the welfare system including consideration of a Single Social Assistance Payment for People of Working Age proposed in 2010<sup>6</sup>, the system remains confusing and difficult to navigate for many people. While the Green Paper proposals are an attempt to modernise disability payments to better support employment and enhance financial security, the Green Paper proposals could lead to further complexity and confusion unless the following criteria are in place:

- **Any assessment of capacity should not rely on a medicalised model but include an appropriate balance of bio-psycho-social factors:** We note the Department's intention to continue to use the current capacity assessment, which includes bio-psycho-social factors. Any new system of disability assessment must use a social rather than medical model of disability and not rely

<sup>2</sup> European Commission Country Report for Ireland 2022.

<sup>3</sup> [Cost of Disability](#), Indecon, 2021.

<sup>4</sup> MacMahon B, Bovlan, H, Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. The additional costs of a Minimum Essential Standard of Living for a household caring for an adolescent with a profound intellectual disability. Dublin: The Vincentian Partnership for Social Justice & Family Carers Ireland.

<sup>5</sup> Family Carers Ireland has written to the Minister for Housing to express our concern that under the existing Differential Rent Scheme the rent of households where a child is awarded Disability Allowance at age 16 will increase due to the child's receipt of Disability Allowance.

<sup>6</sup> Report on the Desirability and Feasibility of Introducing a Single Social Assistance Payment for People of Working Age, Department of Social Protection, 2010.

primarily on medical reports. Furthermore, the introduction of a tiered Personal Support Payment could cause more hardship if the onus is on applicants to 'prove' their degree of incapacity along a three-tier spectrum. This would inevitably lead to increased pressure on GPs and medical professionals who will be expected to provide more granular reports. With the current shortage of GPs and the immense pressure practices are under this is unlikely to be well received by GPs.

- **Must not impose a financial cost on applicants:** Applying for any social welfare payment should not place a financial cost on applicants. However, in recent years, the need to pay privately for medical reports to support an application has become common practice. The granularity of a three-tiered system is likely to ameliorate this if not managed appropriately through the use of a more balanced assessment model.
- **Should not be administratively burdensome or lead to an increase in reviews/appeals:** A three-tiered system could overburden Department staff who administer disability schemes and lead to an increase in requests for reviews and appeals if applicants feel they have been assigned to the incorrect tier. Under the tiered Personal Support Payment, it is proposed that people who have been assessed as having a permanent incapacity (tier 1) will not be subject to review and their entitlement will be assumed to be permanent. In the case of tiers 2 and 3 the payment will be awarded for a specific period – no less than two years. Before this period expires, recipients will be asked to either submit evidence of a continuing entitlement or transfer to another payment. While Family Carers Ireland acknowledges the importance of periodic reviews, if reviews are overly frequent or onerous it will not only frustrate claimants and their families but also the medical professionals expected to provide ongoing supporting evidence. To avoid this, it is important to provide transparency in the review process, informing carers from the outset, when and how frequently they will be reviewed. There is also an onus on the Department to facilitate electronic applications and reviews, allowing claimants to upload necessary reports and information online allowing real-time decision-making.

#### ***Broader structural barriers that must be addressed (outside DSP)***

- (v) The UNCRPD is the cornerstone of disability policy reform and any proposed reform efforts should be rooted in the UNCRPD, in particular Articles 28 (adequate standard of living), 27 (work and employment) and 19 (independent living). It is disappointing that the Green Paper does not make any reference to the UNCRPD or the ratification of the Optional Protocol.
- (vi) As noted, Family Carers Ireland's fundamental concern with the Green Paper is its failure to acknowledge the structural barriers that prevent disabled people from accessing employment and the perceived assumption that incentivising them to work alone will address these barriers. Exhaustive research has shown that disabled people are denied access to employment through multiple barriers including a lack of transport, inaccessible workplaces, negative societal attitudes, a lack of employment opportunities and a failure to provide the support needed to access employment including Personal Assistance Services. Without addressing these structural barriers, welfare reform alone will exacerbate the challenges faced by disabled people, create unnecessary complexities and could be counterproductive. Specifically, the following reforms, external to the Department of Social Protection are needed before the Green Paper proposals could be considered:
  - **Address transport barriers for disabled people:** Disabled people and their families have waited for 11 years for the long-promised Transport Support Scheme to replace the Mobility Allowance (MA) and Motorised Transport Grant (MTG) both withdrawn in 2013 on the grounds of age discrimination. Both schemes were critical in supporting disabled people to access essential

services and employment. The failure to replace the MA and MTG has led to an illogical situation whereby those who received a MA prior to 2013 have been allowed to keep it while others now equally in need are locked out. It also means that the only transport scheme available is the Disabled Drivers and Disabled Passengers Scheme, which is only available to those with a *severe physical disability*, with absolutely no support for those with an intellectual disability or cognitive impairment. This prioritises the transport needs of people with physical disabilities over those with an intellectual/cognitive disability which we believe could be subject to legal challenge. Family Carers Ireland is also calling for the eligibility for the Primary Medical Certificate and the Disabled Drivers and Disabled Passengers Scheme to be extended to include people with a non-physical disability.

- **Assistive Technology Fund to address digital inequality:** Equitable access to technology is an important factor in reducing barriers to employment. Many disabled people are excluded from digital participation due to prohibitive costs of specialised devices and software. Both the Indecon cost of disability study and research undertaken by the Vincentian Partnership for Social Justice show that the additional costs of disability/care are often due to expenses relating to assistive technologies. Family Carers Ireland supports the call from some DPOs for a dedicated fund to provide access to equipment, technology and other essential assistive aids and appliances for disabled people and their families.
- **Personal Assistance Services (PAS):** A PAS is for any disabled person who feels that they need support to do the things that they want to do, inside and outside the home. Personal assistance support includes assistance in getting to your place of work, education and training and for some disabled people makes the difference between being able to take up employment or not. Currently, in Ireland, there is no legal right to a PAS and there is no national system to standardise how PAs are provided, funded, assessed and supported. We join with DPOs in calling for legislation and greater investment in PA services that will give disabled people the right to personal assistance and give them choice and control over their lives and the opportunity to work.<sup>7</sup>
- **Address systemic barriers:** People with disabilities face numerous barriers across the employee lifecycle – from getting an interview to overcoming biases in the recruitment process, securing reasonable accommodation, transport etc. However, as noted the Green Paper fails to address the systemic barriers that disabled people face in finding and retaining work. Government and employers must do more to create a genuinely supportive workplace culture and establish robust protection and policies for accommodation. This includes sanctions for employers who do not comply.
- **Minimum Statutory Employment Target:** The minimum statutory employment target for persons with disabilities to be employed in the public sector is currently at 3%. This will increase from 3% to 6% by 2025 as outlined in the Assisted Decision-Making (Capacity) (Amendment) Act 2022. Public sector bodies are consistently advised that the 3% is a minimum compliance target. We highlight that it's important for them to focus on exceeding this target and progressing towards reaching the new minimum of 6%. Family Carers Ireland supports the NDA's call to introduce a similar employment target within the private sector, however we acknowledge that such a measure would have constitutional challenges as a result of previous Supreme Court jurisprudence.

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<sup>7</sup> [Independent Living Movement of Ireland 'Not in the Driving Seat' \(2023\).](#)

## Alternatives to the Green Paper proposals pending broader reforms (specific to DSP)

Family Carers Ireland recognises the challenges faced by the Department in their efforts to create a modern, fair and progressive disability payment scheme. We acknowledge the achievements to date and re-state the importance of a whole of government response to meeting the employment, income and support needs of people with disabilities and their families. If a substantive cross-departmental strategy to help support labour market engagement alongside activation measures cannot be put in place it might be fairer to focus on measures to better target differentiated income support for people with disabilities having regard to some or all of the following measures.

- **Benchmark disability payments to ensure income adequacy:** Concern has long been raised about the inadequacy of the present ad-hoc system for setting social welfare rates, and how annual flat-rate Budget increases do not address the needs of recipients. To meaningfully bridge the gap between what households receive and what they need to live above the poverty line and afford essential goods and services, social welfare rates should be benchmarked to a minimum essential standard of living. This is in line with the recommendations of the Oireachtas Committee for Budgetary Oversight which notes the need for higher levels of Government spending on universal basic services such as affordable childcare, housing and public transport in tandem with a system of indexation for social welfare rates to ensure income adequacy.
- **Increase the income disregard and allowable deductions for Disability Allowance:** Because the Disability Allowance means test is applied to gross rather than net income and does not take into account normal household expenses such as rent, mortgage repayments, dependent children, college fees, Fair Deal contributions, medical costs etc., the assessment does not reflect the reality faced by many disabled people and their families. These households may appear relatively financially comfortable based on their gross income but are struggling to make ends meet when living expenses and the cost of disability are deducted. Instead, the means test should be applied to net, not gross income (similar to the assessment applied to Carer's Benefit) and the list of allowable deductions be extended to include more costs incurred by disabled people and their carers. For example, the financial assessment for an Under 70s Medical Card allows for a host of deductions including mortgage repayments, childcare costs, home insurance, nursing home costs, education expenses, travel and parking costs. The scheme also gives an allowance ranging from €38 to €78 for each dependent child living in the household and older children attending third level education. A similar model could be applied to Disability Allowance.
- **Cost of Disability Payment:** Family Carers Ireland notes the findings of the Indecon study on the cost of disability and subsequent calls for the introduction of a cost of disability payment. While we support this, a stand-alone cost of disability payment may not be necessary if the means test for Disability Allowance was extended to include a range of allowance deductions and the rate of the Allowance significantly increased to a level where the extra costs of having a disability would be covered.
- **Individualisation – assessing only the income of the disabled person:** The inclusion of a spouse/partner's income in the means tests for the Disability Allowance and Blind Pension is problematic for a number of reasons. Firstly, it assumes that the working/higher earning partner is willing to share their income/assets with the financially dependent carer – which is not always the case and can place disabled people in a financially vulnerable position. Secondly, it can act as a barrier to employment for disabled people as they risk losing their Disability Allowance/ Blind Pension if they work and their income exceeds the means allowed. Family Carers Ireland believes that assessing only the income of the disabled person on an individualised basis would address issues of financial vulnerability and support disabled persons to take up employment.