Cost of Disability Payment:

Submission to the Department of Social Protection on the development of a Cost of Disability Payment

Family Carers Ireland

March 2026

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Towards a Cost of Disability Payment

Family Carers Ireland welcomes the opportunity to submit our views to the Department of Social Protection on the development of a Cost of Disability Payment and to express our strong support for the introduction of such a payment.

For many years, Family Carers Ireland has advocated for recognition of the cost of caring, highlighting the financial, social and personal impacts experienced by family carers who provide essential unpaid care. While the concept of the cost of caring is closely related to the broader cost of disability, we recognise that there are important differences between the two. The cost of disability focuses on the additional expenses incurred by individuals as a result of disability, while the cost of caring reflects the costs borne by those who provide ongoing care and support.

The introduction of a Cost of Disability Payment represents an important step toward recognising the real and often significant additional costs associated with disability, while also acknowledging the vital role that family carers play in supporting people with a disability to live with dignity and independence within their homes and communities.

Who Cares?

Across Ireland, approximately 624,190 people provide regular unpaid care to children and adults with additional needs, physical or intellectual disabilities, frail older people, those with palliative care needs or those living with chronic illnesses, mental health challenges or addiction.[1] Many people take on new caring responsibilities every day. Caring can happen unexpectedly, or increase gradually over time, however most people will provide care or receive care at some point in our lives.

Over the past decade, there has been a significant rise in both the number of family carers and the volume of unpaid care they provide. Since 2016, Census data show a 53% increase in the number of people who provide care, while the number of those caring for more than 43 hours per week has more than doubled. The estimated value of this unpaid care is more than €20bn annually - close to the annual budget of the HSE. Recent statistics on caring shows:

- 14% of respondents to the Healthy Ireland Survey 2025 state they provide regular care. If extrapolated to the national population aged over 15, that's 624,190 family carers.
- Family carers provide an average of 51.4 hours of care each week.[2]
- 10.1% of children aged 10-17 years provide care – that is 61,559 young carers in this age cohort.[3]

This submission, which follows the template suggested by the department, sets out Family Carers Ireland's experience of supporting carers across Ireland, many of whom provide care for people with disabilities. It highlights the financial pressures associated with disability and caring and emphasises the importance of ensuring that the Cost of Disability Payment developed by the department recognises the extent of these additional costs and is set at an appropriate rate to meet them - consistent with the right of persons with disabilities to live independently and be included in the community, as set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

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[1] Healthy Ireland Survey 2025 which shows that 14% of respondents provide regular, unpaid care.

[2] Central Statistics Office (CSO) Census of Population 2022.

[3] WHO Health Behaviour in School-Aged Children Survey 2022.

1. Purpose of the Cost of Disability Payment.

Family Carers Ireland welcomes Government's acknowledgement of the additional costs faced by people with disabilities and their commitment to introduce a Cost of Disability Payment. The concept of the Cost of Disability is not just about economics – it's about human rights. People with disabilities have the right to live independently, participate fully in society and access the supports they need, as enshrined in the UNCRPD. Failing to provide adequate financial support for the additional costs associated with disability effectively limits access to these rights, forcing many to compromise on basic needs, education, employment or social participation. The introduction of a Cost of Disability Payment is critical given that:

- **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. According to the most recent Central Statistics Office (CSO) *Survey on Income and Living Conditions (SILC)*, about 11.7 % of the overall Irish population were at risk of poverty in 2024. By contrast, CSO and advocacy analyses show that people who are unable to work due to a long-standing health problem (commonly used as a proxy for disability) have a much higher risk – around 32.5 % were at risk of poverty in 2024, roughly three times the national average**.**

- **Ireland has the largest disability employment gap in the EU, at 32.6%.** With the EU average employment rate for people with disabilities at 51% in 2023, fewer than one-third of people with disabilities in Ireland are in work – a stark indication of the barriers to employment faced by people with a disability.

- An ESRI and IHREC report published in March 2025 found that households with a disabled member in Ireland **spend 52 - 59% of their disposable income on disability-related costs**, rising to 93% for households where the person has a complex disability. The weekly cost ranges from €488 to €555, with disabled households at a much higher risk of poverty when these costs are factored in. The report found that disabled people face a double economic penalty by having lower average disposable incomes and higher average expenditure needs.[4]

- The current **cost of living crisis has a disproportionately severe impact on people with disabilities** and family carers. Households that include a person with a disability often face extra, unavoidable costs for essentials such as heating, transport, medical supplies, personal care and essential medical equipment that requires continuous power. Even modest increases in energy prices hit these households harder, because their energy usage is unavoidable and a larger proportion of their income is already committed to meeting disability-related needs.

- The Indecon Cost of Disability Report (2021) found that disabled individuals face significant extra annual costs, estimated between €9,482 and €11,734, varying by age, severity and disability type.[5] Adjusted for inflation, these costs are now **€11,342 - €14,046 annually**.[6]

- Research by the Vincentian Partnership for Social Justice on behalf of Family Carers Ireland in 2022 found that households caring for a child with a profound disability faced significant financial strain,

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[4] Doorley, K., Kakoulidou, T. and Simon, A. (2025). Adjusting estimates of poverty for the cost of disability, Jointly-published Reports 8, Dublin: ESRI and Irish Human Rights and Equality Commission (IHREC), https://doi.org/10.26504/jr8

[5] Indecon International Research Economists (2021). The Cost of Disability in Ireland, Department of Social Protection at https://www.gov.ie/en/department-of-social-protection/publications/the-cost-of-disability-in-ireland-research-report/

[6] Indecon International Research Economists (2021). The Cost of Disability in Ireland, Department of Social Protection at https://www.gov.ie/en/department-of-social-protection/publications/the-cost-of-disability-in-ireland-research-report/

with additional weekly costs averaging €244 (adjusted for inflation, these costs are now €270) - a figure closely aligned to the Indecon Cost of Disability findings.[7]

Family Carers Ireland highlights several key issues that the department should consider in the development of a Cost of Disability Payment:

- **Paying privately for 'public' services:** A key finding of the Vincentian Partnership's research was that the financial vulnerability of family carers and people with a disability is compounded by the burden of paying out of pocket for essential services and supplies that should be publicly provided. These expenses can include assessments, medical equipment, communication devices, mobility aids, incontinence products, home modifications, transport, respite and personal care items - all of which are either inadequately funded, subject to lengthy waiting lists or are simply not available when or where needed.

- **Families 'cushioning' the cost of disability:** The high cost of living means that many adults reliant on a Disability Allowance of €254 per week cannot afford to live independently and are forced to remain living with parents or other family members. Consequently, families often play a critical role in cushioning the real costs of disability by providing housing, food, transport, heating, medicines, laundry and waste collection. The Cost of Disability Payment must be designed to reflect the actual costs a person is likely to incur when living independently – without family support – in line with their right to do so.

- **Personalised budgets:** The Programme for Government commits to *'continue to support the roll-out of personalised budgets nationally'* with responsibility falling to the Department of Children, Disability and Equality and the HSE. A personalised budget is a tailored amount of funding allocated to an eligible person with a disability to enable them to make their own arrangements to meet their specific support needs. A key strength of the personalised budget model is the enhanced autonomy and flexibility it offers. Individuals can select services that are most relevant and meaningful to them, defining the quality, scope and delivery of their supports. Despite the establishment of a Personalised Budget Demonstrator Pilot in 2019, on foot of a recommendation of the Task Force on Personalised Budgets, to assess what is required for introduction of a personalised budget approach, the evaluation of the pilot, undertaken by the National Disability Authority, has yet to be published. The learnings from this evaluation will be crucial to informing aspects of the introduction of a Cost of Disability Payment.

- **Extension of Domiciliary Care Allowance to age 18:** For many years, Family Carers Ireland has expressed concern that Disability Allowance, an adult payment for those substantially restricted from work, is paid to children aged 16 to 18 years. We support the extension of 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.

2. Who should qualify for a Cost of Disability payment?

A Cost of Disability Payment should be designed to reach people who face additional and unavoidable costs directly associated with their disability. Based on policy principles, research and aligned to the UNCRPD, recipients should include:

- Both adults and children with a long-term physical, sensory, intellectual, developmental or psychosocial disability that creates additional living expenses.
- People living independently or with family, as well as those living in the community in residential settings.

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[7] MacMahon B., Boylan, H., Thornton R. (2022) Care at Home: Costs of Care Arising from Disability. Dublin: The Vincentian Partnership for Social Justice and Family Carers Ireland.

- Be paid to people regardless of their employment status.

Considerations for targeting

- The assessment of a person's disability should be based on a functional assessment and not solely on a medical diagnosis.
- Family Carers Ireland recognises the sensitive nature of means-testing, however, we acknowledge the complex decisions involved in delivering a Cost of Disability Payment and understand that prioritising those on lower incomes unable to meet additional costs may be necessary. If this is being considered by the department, we emphasise the need for income and capital disregards to be set at a level significantly generous to enable people who are in work or have savings to qualify.
- Consideration could be given to assessing actual costs to ensure the support provided reflects the additional expenses incurred, rather than relying on blanket payments that may under or over-compensate recipients. However, this must be balanced against the administrative burden such assessments could create, which may make a cost-based approach overly complex to implement.
- The department provides six primary social welfare payments for people with a disability or long-term illness including Disability Allowance, Domiciliary Care Allowance, Invalidity Pension, Blind Pension, Partial Capacity Benefit and Illness Benefit, supplemented by grants from the HSE and specific tax credits and reliefs from Revenue. Careful consideration should be given to the eligibility criteria attached to each of these schemes and whether it meets the threshold for a Cost of Disability Payment.

3. How should the amount of the Cost of Disability Payment be decided?

Family Carers Ireland acknowledges that the resources available to fund the Cost of Disability Payment are finite and difficult decisions regarding eligibility and the rate of payment will need to be made. A Cost of Disability Payment should be designed around clear, rights-based and practical principles to ensure it genuinely addresses the extra costs associated with disability. Based on international best practice, research and the UNCRPD, the following principles should be applied:

- The payment should reflect the real, additional costs of disability, including housing modifications, assistive technology, transport, care, medicines, and other day-to-day expenses.
- It should be sufficient for independent living rather than tokenistic or symbolic.
- All people with disabilities should be considered, including those with physical, intellectual, sensory, developmental or psychosocial disabilities.
- Eligibility should not discriminate based on age, diagnosis or income alone. The functional impact and cost burden of the disability should be the focus.
- Avoids creating two-tier systems, where some groups are left without support (e.g. people with non-physical disabilities).
- Supports the right to live independently and be included in the community (UNCRPD Article 19).
- Recognises the role of family carers while ensuring the person with a disability can make choices about their own life.
- The payment should be transparent, with clear criteria for eligibility, assessment and payment level.
- The payment should be regular and predictable so households can budget and plan effectively.
- The application process should be simple, accessible and minimally bureaucratic.
- The payment should supplement, not replace, other social supports such as Disability Allowance, carer supports, housing or health services.
- Avoids creating gaps where people lose other entitlements if they qualify for the payment.
- Be informed by the findings of Indecon Cost of Disability and the ESRI/IHREC reports in terms of the rate of a Cost of Disability Payment that is required to offset the costs of disability.
- Applying for a Cost of Disability Payment should not impose any financial burden on applicants, including costs associated with obtaining medical evidence to support an application.

Whole-of-Government Approach:
The National Human Rights Strategy for Disabled People 2025-2030 states that *'All Government Departments will develop and implement whole-of-Government solutions that will address the cost of disability experienced by disabled people. These solutions will acknowledge the disproportionate financial burden experienced by disabled people and their households in daily living'.*

This whole-of-Government commitment is critical to not only addressing the costs of disability, but in the progressive realisation of the UNCRPD.

Broader structural reforms that must be addressed in addition to the Cost of Disability Payment
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 (PAS). Without addressing these structural barriers, welfare reform alone will not negate the challenges faced by disabled people. Specifically, the following reforms, external to the Department of Social Protection are needed:

- **Address transport barriers for disabled people:** Disabled people and their families have waited for 13 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 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):** PAS are for any disabled person who feels that they need support to do the things that they want to do, inside and outside the home. PAS 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 PAS and there is no national system to standardise how services provided, funded, assessed and supported. We join with DPOs in calling for legislation and greater investment in PAS that will give disabled people the right to personal assistance and give them choice and control over their lives and the opportunity to work.[8]

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[8] Independent Living Movement of Ireland 'Not in the Driving Seat' (2023).

- **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. 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 6%. Public sector bodies are consistently advised that 6% is a minimum compliance target. The emphasis must be on exceeding, rather than meeting this target. Family Carers Ireland supports the NDA's call to introduce a similar employment target within the private sector, notwithstanding the challenges this would bring.

4. Strategic Focus Network Summit on the Cost of Disability

Family Carers Ireland welcomes the confirmation that the Strategic Focus Network Summit on the Cost of Disability will take place on 13 May 2026. We hope that Family Carers Ireland will be invited to attend, as the national representative body for family carers, alongside individual family carers themselves.

Family Carers Ireland recommends that a core focus of the summit in May includes a dedicated session to consider how existing schemes both within and outside the Department of Social Protection could be extended to help mitigate the costs of disability, for example, by extending thresholds for the Medical Card and Household Benefits Package, making children on Domiciliary Care Allowance eligible for free travel, reopening the Mobility Allowance scheme, providing more affordable housing options for people with a disability as well as extending tax credits and tax reliefs for people with disabilities helping to offset the costs they incur.

What issues would like to see discussed at the summit?
The summit should include discussion on the matters discussed in this submission, in particular:

- the definition of disability and medical threshold that will be set for eligibility,
- whether the payments should be tiered to reflect the severity or type of disability
- the age of eligibility - whether the payment will be a working age payment or available to children and older persons,
- how additional costs of disability could be offset using other policy measures, e.g. Medical Card, Household Benefits Package, etc.
- the role of other Government departments/agencies, e.g. Health, Transport, Revenue
- the role of tax credits and reliefs
- the role of personalised budgets
- the rate of payment and how it should be paid – weekly, monthly or (bi)annual grant similar to the Carer's Support Grant.

What format do you think the summit should take?
The voice of people with disabilities should be at the heart of the summit and adequate time should be given to ensuring all voices are heard

Duration: Given the importance and breath of topics to be discussed, the summit should be given at least one full day.

Participants: Attendees should include a diverse representation to ensure all perspectives are heard. The summit should include:

- Disabled people and their families
- Disability advocacy organisations
- Carer advocacy organisations

- Government policymakers / social protection officials and related agencies e.g. Revenue.
- Researchers and academics in disability studies or social policy
- Healthcare providers, energy providers and other relevant service organisations

Format: The summit should be in-person with a strong focus on persons who cannot attend due to their disability. Their voice must be given equal time and respect as to those present at the summit.

Opening session:	Welcome / objectives and context
Keynote:	Experts on disability costs and social policy / Evidence from research and lived experience from people with a disability
Panel discussions:	Focus on specific cost areas (energy, medical equipment, transport, etc.) / Include both policymakers and affected individuals
Workshops:	Smaller groups for deep-dive discussions
Q&A:	Plenary Q&A
Closing session:	Summary of findings and key takeaways / Follow-up actions

Accessibility:

- Ensure the venue is fully accessible, with appropriate disability facilities, including Changing Places toilets.
- Provide sign language interpretation, captioning and all materials in accessible formats.
- Offer virtual participation options to accommodate those unable to attend in person.