

# Submission - Public Consultation on the Cost of Disability

March 2026

## Introduction

Care Alliance Ireland welcomes the opportunity to contribute to the public consultation on the development of a Cost of Disability Payment.

Care Alliance Ireland is a national network organisation supporting family carers and organisations working with them. Family carers provide the majority of long-term care in Ireland, supporting people of all ages with disabilities, chronic illness and additional needs.

Whilst we have consulted with our membership of 100 organisations, our submission should not be taken as the collective opinion of the membership of Care Alliance Ireland, nor as representative of family carers across the country.

The introduction of a Cost of Disability Payment represents an important step in recognising the additional financial costs associated with disability and long-term health conditions. However, these costs are rarely experienced by individuals alone; they are typically borne at the household level, including by family carers.

This submission therefore also focuses on how the proposed payment should recognise the shared economic impact of disability within households and families.

## Our ideas on agenda and format for the summit

We do not have a strong view on the format and or agenda of the summit. Others are better placed to make suggestions in this matter.

However, to maximise the value of the summit we strongly recommend that accessible, authoritative and evidence-informed briefing and discussion documents are circulated in advance of the summit, speaking to the various items on the agenda.

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We suggest that such documents are made accessible through an open access portal, and that wide authorship of such documents is facilitated. This should include, at a minimum, documents that present:

- the international experience of delivering Cost of Disability Payments
- payment levels (with particular regard to England, Scotland, Norway, Denmark and Australia)
- challenges in implementation
- estimated costings
- assumptions made, etc.

If individuals and NGOs wish to make their own briefing documents available on the portal, this should also be facilitated, giving expression to real partnership.

Participants registered for the summit should be actively encouraged to set aside sufficient time to read these documents, well in advance of the May summit.

## Our views on the design of a Cost of disability Payment

Research commissioned by the Irish Government has estimated additional costs of disability to range between approximately €8,700 and €12,300 per year, depending on the severity and type of disability.

The cost of disability is significantly a *household* issue, and is best seen in this light and not exclusively as an *individual* issue. The cost of disability is not always borne exclusively by the disabled person. Where significant family carer support is provided, there can be a significant opportunity cost (meaning lost earning opportunity) for the family carer. Such opportunity cost is not fully compensated by Carer's Allowance or other income support measures.

Policy design must recognise the shared household impact of disability-related costs, particularly on unpaid family carers.

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Below we outline two key considerations and eight recommendations.

### Considerations

#### 1. Households frequently incur additional expenditure

This additional expenditure, often borne by family carers, may relate to:

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- transport to medical and therapy appointments
- supplementary private health care services such as occupational therapy, physiotherapy, speech therapy, etc.
- increased household energy use
- assistive technologies and home adaptations
- communication and digital access
- replacement care and respite supports
- reduced labour market participation

## **2. Services are important as well as payments**

- Cash payments alone will not solve the cost of disability. The most effective way to reduce disability costs is often through accessible services, not cash transfers.

## **Recommendations**

### **1. Ensure costs borne by family carers are explicitly recognised in the design of the payment**

As noted above, family carers frequently bear some of the costs of disability.

### **2. Adjust household poverty analysis for disability-related costs**

Similarly, any analysis of household poverty must be adjusted for costs related to disability.

### **3. Ensure there is a distinction between the two relevant policy objectives**

#### **Objective 1: Poverty prevention/income replacement**

Examples:

- Disability Allowance
- Invalidity Pension
- Illness Benefit
- Carer's Allowance
- Carer's Benefit

Purpose: Protect against poverty, and to some extent, replace lost earnings.

These supports are designed to address income replacement and income security, rather than the additional costs associated with disability. The reality is that this

income (and the income within the wider household, including Carer's Allowance) is often stretched to offset the additional costs of disability.

The new Cost of Disability Payment should address a broad range of disability-related costs, including the examples set out above under additional expenditure incurred.

#### **Objective 2:** Disability cost compensation

The new payment must not substitute for adequate income support payments for disabled people or for family carers. It should specifically address additional disability-related costs of the household. Many disability costs arise from the care arrangements required to support independent living.

Purpose: Cover the extra costs associated with disability.

#### **4. Ensure the payment is not means-tested**

Additional costs of disability arise regardless of income level. Considerations for excluding means-testing for the Cost of Disability Payment include:

- Means-testing creates work disincentives and reinforces poverty traps
- Many disabled people and family carers are in part-time/paid work but still incur high costs
- Means-testing excludes households that still face substantial disability-related costs

International comparators: Examples that are not means-tested include:

- UK Personal Independence Payment
- Australia Disability Support Supplements
- New Zealand Disability Allowance (partially means-tested but cost-linked)

#### **5. Ensure payments reflect different levels of need**

We recommend that – over time – a tiered payments model is introduced linked to level of need.

We appreciate the sensitivities of this. We recommend that in the first instance a Universal Supplement is introduced, and to ensure sustainability and equity, and that an additional tiered payment structure is implemented over time, reflecting:

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- complexity of disability
- level of functional impairment
- level of care/support required
- intensity of costs

A tiered payment structure would more accurately reflect the variation in disability-related costs. Such an approach is common in other jurisdictions and allows for greater equity between households.

The Indecon and ESRI research both show disability costs vary significantly.

**Possible Structure:**

Tier	Example
Level 1	Moderate additional costs
Level 2	Significant support needs
Level 3	High support needs/complex disability

Our recommendation for tiered payments will require careful and sensitive implementation and in no way infers that there is a hierarchy of disabilities or indeed a hierarchy of caring.

The issue of capacity, in particular with respect to children with disabilities, requires careful consideration. We would expect that a parent of a child with a disability would manage the receipt and use of any such Cost of Disability Payment, with due regard to the child’s age, cognition and expressed preferences.

**6. Design eligibility and assessment equitably**

Eligibility for an initial Universal Supplement should include all people with disabilities who incur material additional costs associated with daily living not already covered by existing state supports received, including those living in households supported by family carers.

Eligibility assessments for additional tiered payments should be based on previous existing assessments, be brief and be based on functional impact and support needs rather than medical diagnosis alone.

Consideration should be given to using suitably qualified private assessors to ensure that disabled people are not waiting unduly lengthy periods to secure an assessment.

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## **7. Implement improved data collection**

Care Alliance Ireland recommends that Government consider:

- regular measurement of disability-related costs within national surveys
- improved research on the economic impact of unpaid care
- development of a national evidence base to inform future policy

Options include:

- CSO module in SILC or Labour Force Survey
- Formal linkage with TILDA/NICOLA research
- Periodic cost of disability index to review the payment level

## **8. Adhere to key principles to guide the payment design**

Key principles should include:

- fairness
- adequacy
- recognition of household costs
- support for independent living
- recognition of the contribution of family carers

## **Summary**

The cost of disability is not borne by disabled people alone. It is experienced at the level of the household and particularly by unpaid family carers, who provide the majority of long-term care in Ireland. The design of a Cost of Disability Payment must recognise this reality, be non-means-tested, reflect differing levels of need, and complement rather than replace existing income supports and services.

Care Alliance Ireland would welcome continued engagement with Government as this policy is developed.

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**Author Transparency Note:** This submission was prepared with the support of ChatGPT. Specifically we used ChatGPT to support with the generation of ideas, edit, summarise and spell check. Care Alliance Ireland endeavours to use AI professionally and ethically and to minimise the risk of errors and bias, by using considered prompting, critical judgement and analysis and fact checking. The author has familiarised themselves with TU Dublin's Responsible Use of Generative AI in Research and with the HIQA Draft National Guidance for the Responsible and Safe Use of Artificial Intelligence in Health and Social Care Services . This is a quickly evolving area and as an organisation we commit to keeping abreast of key developments in relation to AI and Generative AI and how it can both support and potentially be a risk to our work in seeking to influence positive change in the lives of family carers and those who seek to support them.

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