



Citizens **Information** Board
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Submission to the Department of Social Protection on the Cost of Disability

Citizens Information Board
April 2026

Introduction

The Citizens Information Board welcomes the fact that the Department of Social Protection has initiated this public consultation on cost of disability to assist in:

- informing the format and content of the Strategic Focus Network Summit
- designing and developing a new cost of disability payment for Government to consider
- identifying ways that all Government Departments and Agencies can make changes to lower the cost of disability in the future

Supporting people with disabilities with information, advice, assistance and advocacy is an important element of the work of the companies that CIB funds to provide services to the public. CIB also has a specific remit to provide advocacy supports for people with disabilities. In that context, CIB funds and resources the National Advocacy Service (NAS) to meet the needs of people with disabilities who are in vulnerable situations. NAS has also made a submission in response to this consultation.

These Service Delivery Companies are:

- the Citizens Information Services (CIS)
- the Citizens Information Phone Service (CIPS)
- the Money Advice and Budgeting Service (MABS)
- the National Advocacy Service (NAS) for people with disabilities
- the Sign Language Interpreting Service (SLIS)

Issues relating to income support for people with disabilities are a regular feature of queries to CIS. In 2025 over 43,000 queries to CIS referred to disability payments. These include 23,000 Disability Allowance queries,¹ almost 9,000 Invalidity Pension, over 8,000 queries on Domiciliary Care Allowance and Carer's Support Grant, and 1,700 on Partial Capacity Benefit. In addition, there were over 12,000 queries about Illness Benefit, and almost 27,000 queries on Carer's Allowance, and Carer's Benefit. Disability Allowance queries were the third highest payments/entitlements category, after the Medical Card and local queries. Carer's Allowance had the fifth highest query numbers. Data on specific needs relating to disability² is also increasing, e.g. there was a 5.3% increase in queries about disability and illness payments from clients who had specific needs relating to disability.

¹ A further 4,000 disability payment related queries were raised with CIPS in 2025.

² Specific needs within the CIS context are issues that can hamper access to services and/or require additional support and time to be provided by the CIS. They include language, literacy, distress, disability and online access issues.

Designing and developing a cost of disability payment is a complex area and CIB recognises that overall, a multi-faceted and integrated approach is required in order to:

- mitigate the costs of living with a disability irrespective of whether or not the disabled person is in employment at any given time
- enable more people with disabilities to participate in the labour force

Previous research has highlighted the need for a broad focus on cost of disability, to take account of all the aspects of living with a disability, e.g. the need for personal assistance (PA) to allow for effective participation in training/education, work, leisure, social and cultural activities across people’s lives. Additional costs are linked to:

- maximising capacity and optimising well-being
- leading a self-determined life in an autonomous way
- asserting will and preference in all matters affecting the person³

This submission firstly makes some general contextual observations relevant to reform in this area. Secondly, the submission draws on the experience of the CIS and the NAS for people with disabilities to elaborate on the needs of persons with disabilities in accessing financial and other interlinked supports and to draw lessons from this information. Thirdly, the submission draws from CIB’s evidence and literature more broadly, to respond to the consultation questions on how a cost of disability payment could be designed and developed.

General observations

International and domestic research clearly points to a double penalty to the living standards of disabled individuals and households to do with the fact that their income from employment is lower, and their consumption needs are higher than their non-disabled counterparts.⁴ CIB has previously called for a cost of disability payment⁵ to help address the difficulties and challenges faced by people with disabilities in being able to live their lives on an equal basis to the rest of society.

It is important to note that the cost of disability is being framed within a human rights and equality framework, i.e. the National Human Rights Strategy for Disabled People 2025 – 2030. Article 28 of the UN Convention on the Rights of Persons with Disabilities (UNCPRD) requires states to ensure an adequate standard of living of all people with disabilities, “including adequate food, clothing and housing, and to the continuous improvement of living conditions”. It also requires the state to assist with the costs of disabilities, “including adequate training, counselling, financial assistance and respite care”.

³ [Submissions and Policy Recommendations 2019 - Citizens Information Board](#)

⁴ ESRI (2025) [Adjusting Estimates of Poverty for the Cost of Disability; Disability, Work and Inclusion in Ireland \(EN\)](#)

⁵ See previous Pre-Budget Submissions and other relevant submissions: [Submissions and Policy Recommendations - Citizens Information Board](#)

Cost of disability is intrinsically linked to equity of access and opportunity meaning that while people may differ in capacity, character, abilities, specific needs, they need to be able to have choices in line with societal norms and prevailing values. Therefore, community supports such as personal assistance, home supports, personalised budgets, digital and assistive technologies should be a central focus as they provide for and enhance independence and choice.

CIB wishes to highlight at the outset the need to move from the overall generic grouping *people with disabilities* in order to more fully comprehend the multi-faceted and heterogeneous nature of the population being referred to, the related costs of disability, and the supports that people will need in order to live meaningful lives whether fully employed or dependent (wholly or partly) on social welfare benefits for their income. Disability needs to be regarded as a secondary factor that does not define people. The label ‘disability’ almost certainly masks the individual attributes of each person.

Research by Indecon Consultants on the Cost of Disability in Ireland showed that the additional costs of disability vary significantly by type and severity of disability.⁶ This research was based on a statistically significant survey of more than 4,000 people with disabilities, and significant econometric modelling using CSO data. The report concluded that there should be a multifaceted approach to addressing the additional costs of disability involving increased cash payments,⁷ enhanced access to service provision, and specific targeted grant programmes. Survey evidence in the report showed a preference for additional income supports as they provide individuals with discretion to address additional costs associated with a disability. The costs of disability can also be provided through cash for services – personalised budgets.⁸ A personalised budget allows for independence and choice and provides an amount of funding to a disabled person, enabling them to make arrangements to access specialist disability services which best meet their individual needs, such as personal assistance services, respite etc.

While a demonstration pilot system of personalised budgets administered by the HSE was established and is being evaluated, there have been no recommendations from this evaluation published to date. The National Human Rights Strategy for Disabled People 2025 – 2023 contains a commitment to complete the independent review of the Personalised Budgets pilot to inform the development of an effective model for Personalised Budgets. CIB previously recommended that targets in relation to the introduction of personalised budgets for disabled people should be included in the next National Disability Strategy ([The Right Home - CIB/DFI, 2022](#)).

Another example of a policy option to address the additional costs of disability is the social insurance model developed in Australia, the National Disability Insurance Scheme (NDIS) which provides for individual funding to allow participants access to specialised disability supports funded directly by the scheme and allocated via individual budgets. The scheme is entirely publicly funded and not means-

⁶ [The Cost of Disability in Ireland – Research Report](#)

⁷ Note the DSP’s Green Paper on reform of disability payments draws from the Indecon report, i.e. the levels of disability payments and allowances should be changed to reflect the very different costs of disability by severity and type of disability.

⁸ [How to address the costs of disability in Ireland? - Public Policy](#)

tested. Receipt of support under NDIS does not affect a person's entitlement to income support payments, and people in employment can also receive support under the scheme.

The evidence from Service Delivery Companies

Evidence from CIS in relation to disability, illness and caring payments included the following issues based on Social Policy Returns⁹ recorded by CIS in 2025 and 2026. These examples demonstrate the existing challenges experienced by disability and caring welfare claimants in the current climate which serve to aggravate the financial hardship of additional costs associated with having a disability.

- (i) Impact on disabled households as Disability Allowance is means-tested at the household level which may also decrease the financial incentive to work for family members of people with disabilities.¹⁰
 - Disabled person on minimum income due to assessment of spouse's income. Need for increases to the income disregard and means test to allow them to keep more of their payment
 - Loss of Disability Allowance due to spouse's income, leaving person with a disability without an independent income and fully reliant on their spouse both financially as well as physically
 - Client considering ceasing their part-time employment, and their spouse reducing their hours in order to maintain client's Disability Allowance
 - Only married couples can share tax credits, but when a couple is living together, they are assessed as a couple by social welfare, and client's Disability Allowance is means tested on their partner's income. This anomaly disadvantages couples who choose not to marry or may be unable to marry due to previous relationship situations. This client is very stressed due to the cost of living and being unable to meet their bills. She feels discriminated against by the system that is not treating her as an equal to married couples

The NDA have observed that in our current disability benefits system, there is an implicit assumption that unmarried partners living together are expected to provide maintenance to cover the cost of disability. This occurs where a person who is in receipt of a disability allowance chooses to move in with their partner and their partner earns over a certain amount, which will be taken into account in the means test.¹¹

- (ii) Cost of living challenges for those living with a disability, as well as those in caring roles.

⁹ Social Policy Returns (SPRs) are case examples submitted by Service Delivery Companies relating to issues impacting on their callers and which are indicative of wider policy or public service administrative barriers.

¹⁰ [Adjusting Estimates of Poverty for the Cost of Disability](#)

¹¹ [Literature Review of Disability Payments - National Disability Authority](#)

- Having to give up work due to increased caring responsibilities, and inadequacy of Carer's Allowance to meet utilities, groceries and other bills.
- No entitlement to Free Travel for those in receipt of Carer's Benefit – struggling to pay for transportation costs involved in visiting spouse in hospital.
- Loss of Domiciliary Care Allowance when child with severe autism turns 16 years, with a reallocation of resources within the household.

(iii) Interaction of Social Welfare Payments.

- Loss of Fuel Allowance on taking up Partial Capacity Benefit – drop in income despite taking on part-time work and having to access a supplementary welfare payment to cover the cost of heating.
- Loss of half-rate Carer's Allowance for Widow's Pension claimant as daughter who has an intellectual disability was moving into full time residential care:
 - Caller is 60 years of age and is a widow. She has one child, a daughter who is intellectually disabled and for whom she has provided full time care for 30 years. She has been diagnosed with MS and cannot care for her daughter anymore. Her daughter is going into full time residential care. She is extremely worried about the future. She says that she is living on a Widow's Pension and had been used to half rate Carers Allowance for making ends meet. She says that it is impossible to live on €249.50 and €33 (fuel allowance) with the current cost of living. She says that the stress is making her MS worse.

Consultation questions

Specific additional costs to be covered by a cost of disability payment

Previous CIB submissions and reports have identified specific additional costs of disability from data provided by CIS, CIPS, NAS, and MABS. These include:

- **Care Needs**, inadequate provision for the care needs of disabled people and older people to live independently at home and in communities, including access to Personal Assistance, to Home Support, and to respite services.
- CIS and NAS disability advocates continue to report that many of their clients are falling through gaps in service provision – including older people, people with disabilities, and family members trying to offer care in stressful and difficult circumstances. These pressures can also push some younger people with disabilities as well as older people to access long-term nursing home care via the Nursing Home Support Scheme (NHSS) with the associated higher costs of care. Disability advocates have frequently encountered cases where lack of funding for personal

assistance hours for people with disabilities has led to individuals having to move into residential settings.

- **Cost of unpaid care and support by household members** is frequently a significant financial cost to families caring for a person with a disability. This can include employment foregone because of the caring role, payment for additional respite care, personal assistance or the cost of vehicle adaptations.
- **Additional costs in nursing homes**, retired pensioner required to pay costs of nursing medical services for adult son with a disability. The client had great difficulty meeting medical bills from their State Pension.
- **Transport Costs**, particularly with the closure of the Mobility Allowance for new applicants in 2013, and non-replacement of the Disabled Drivers and Disabled Passengers Scheme, which has been acknowledged by Government as no longer fit-for-purpose and needing replacement with a needs-based, grant-led approach for necessary vehicle adaptations.¹²
- The Mobility Allowance scheme assisted people who could not use public transport, who are unable to walk and who would benefit from leaving their home surroundings.¹³ One of the additional costs of disability is having to pay for taxi journeys due to inadequate, infrequent, and inaccessible public transport. Providing a support similar to the Mobility Allowance scheme for people who need to travel to work, who cannot avail of public transport, or work remotely, would contribute to improving the employment options of people who have a disability. There are a number of advantages to having a direct cash payment to cover these transport costs, including the element of choice it provides as to how to deal with specific transport and mobility needs; it addresses one element of the ‘cost of disability’, and helps people to maximise participation in society through work, training, education or involvement in social and community activities.¹⁴
 - The HSE transport to hospital service is very limited. This client is a wheelchair user following surgery, weekly appointments in a regional hospital but no transport available to her. She states she is at risk of missing appointments and very concerned of the long-term impact on her recuperation.
- **Energy costs**, impacting people with disabilities who may have higher heating costs associated with their disability. Despite recent improvements to Fuel Allowance,¹⁵ feedback from services has shown eligibility issues for some disabled households for Fuel Allowance and the Household

¹² [Tax Reliefs, Dáil Debate, 29 May 2025](#)

¹³ <https://www.citizensinformation.ie/en/travel-and-recreation/transport-and-disability/mobility-allowance/>

¹⁴ CIB (2013) Review Group on Transport Needs of People with Disabilities Public Consultation Submission by the Citizens Information Board; CIB (2019) Research on the Cost of Disability, Submission to Indecon by the Citizens Information Board. <https://www.citizensinformationboard.ie/en/publications/submissions/submissions2019.html>

¹⁵ For example, widening eligibility, and providing that people who are moving from Disability Allowance or Blind Pension to take up work will be able to keep their Fuel Allowance for 5 years (September 2026) [Budget 2026](#)

Benefits package connected with household composition. The level and duration of Fuel Allowance have also been raised as being inadequate to meet people’s heating needs.

- **Housing adaptations**, a recent CIB report showed that 20% of the social policy feedback on the Housing Aid for Older People Grant concerned the need for people who have a disability/chronic illness to access assistance for essential home repairs.¹⁶ As it currently stands, under the scheme clients who have a disability are only eligible for housing repair grants if they are over 66 years. In cases of genuine hardship, the local authority may help people under the age of 66.¹⁷ But what constitutes genuine hardship was raised as needing clarity. Many of the housing repairs that are covered under the Housing Aid for Older People grant could significantly improve the living conditions of those living with a disability or chronic illness.
- **Increased costs in accessing public services**, increased costs when there are delays or other problems in accessing public services including social welfare that those without a disability may not experience. For example, long waiting lists to access a consultant can have a knock-on impact on social welfare applications due to the delay in providing the required medical evidence. Typically, the only option left for people is to access private healthcare, and to borrow for this out-of-pocket expense. Some people with disabilities can afford to pay privately for services, but many cannot, highlighting the unequal impact of the additional cost of disability.
- Another example was a client who was struggling with the costs of replacing their boiler and who needed to access an Additional Needs Payment (ANP) to cover the cost of a heating technician. They faced delays of 3-4 weeks as well as administrative challenges (providing a letter from the local authority that they no longer assist with replacement of boiler and report from a heating technician on the state of the boiler) in accessing the payment. “This client is now doing without heat and left the centre distressed despite my best efforts to keep client in the centre to assist them with the forms.”
 - Client who has a disabled son is unable to complete her medical card application because her landlord refuses to give her a letter to prove she is paying her rent in cash. This will also delay her in applying for social housing and being accepted on GPs and housing list.
- **Communications**, desk-based reviews of eligibility can have a greater impact on clients with intellectual disabilities, who face greater challenges in understanding communications from the Disability Allowance section, which may not be accessible to them, or in compiling adequate information to demonstrate their eligibility.
- **Health related costs** are an example of general costs which may be higher for people with disabilities because of their specific needs. The Commission on Taxation and Welfare noted that

¹⁶ [Home Comforts](#). CISs submitted 2,699 social policy returns (identified policy issues with explanatory narrative) on housing in 2022 and 2023, accounting for approximately one-fifth of all social policy returns over that period. Of these, 152 related specifically to housing grants and schemes.

¹⁷ [Housing Aid for Older People Grant](#)

entitlements to secondary benefits and earnings disregards can often determine whether a household is above or below the at-risk of poverty threshold.¹⁸ Evidence from CIS has certainly found that the fear both real and perceived of losing secondary benefits can deter people from taking up employment which was highlighted in previous CIB submissions. Inadequacy in relation to a secondary benefit has also been raised.

- The client suffers from multiple chronic health issues, including heart problems and renal disease. He's no longer fit to work, and his only income is from Invalidity Pension. His treating consultants have prescribed him multiple medications. Although he's a Medical Card holder, he's still paying €70 per month (€840 per year) for some of his prescribed medications because they aren't all on the HSE's List of Reimbursable Items. His doctors may apply to the HSE to have these provided via the PCRS and thus on his Medical Card, but he has no entitlement to this as such as it's at the HSE's discretion. If the HSE isn't willing to cover these items on his Medical Card, he will have to keep paying €70 per month towards his prescriptions out of his very limited income. This anomaly partially undermines the rationale for the Medical Card.

The national and international research literature meanwhile has identified the additional costs associated with disability as:

- Living expenses, mobility, transport, and communications, care and assistance services, equipment, aids and appliances and medicines - additional costs associated with having a disability, which are not being met by existing programmes or by social welfare payments.¹⁹
- Day to day living expenses, transport, care needs²⁰
- Equipment, mobility and communication, living costs, medical, care and assistance²¹
- Aids and adaptations, charges for support services and assistance, higher fuel costs due to spending more time at home or needing to keep it warmer, additional costs for pharmaceutical drugs, higher costs of food for special diets, and higher transport costs²²

Eligibility for a cost of disability payment and amount of payment

Since the nature and level of additional costs associated with disability is likely to relate to some extent to the type of disability, the need to differentiate between categories of disability and the different costs associated with different types of disability is important. Previous research and policy analysis has observed that the severity of a person's disability, and household composition are important considerations in providing for the cost of disability:

¹⁸ [Commission on Taxation and Welfare, 2022](#)

¹⁹ [The Cost of Disability in Ireland – Research Report](#)

²⁰ [overview-of-uncrpd-article-28-adequate-standard-of-living-and-social-protection.docx](#)

²¹ Report of the Commission on the Status of People with Disabilities, "A Strategy for Equality" (1996)

²² [Estimating the extra costs of disability.pdf](#)

- Highest costs were observed among persons with severe disabilities, and among persons with disabilities living alone or in small sized households, due to informal caregiving and transportation support provided by the household.²³
- There is heterogeneity among types of households, employment status, and across levels of disability severity that is important in determining costs of living for a household with a disability relative to a typical family²⁴
- Those with disabilities who engage in work, on average, have lower extra cost estimates and those who combine disability benefits with work have about half as much extra costs of living, which suggests the benefits of creating opportunities for benefit recipients to combine market income with benefit receipts²⁵
- There is a need for recognition that the actual cost to some individuals who have specific needs may be significantly higher than the average. The NDA has observed, based on research findings, that a basic standard income support for all individuals with a disability is unlikely to adequately address the costs incurred by those most severely limited by their disabilities²⁶
- International evidence shows a clear link between the severity of disability and the scale of extra costs, so a cost of disability payment should be graded by reference to the degree of need²⁷
- A ‘costs of disability payment’ should be a graduated payment to meet the additional every day costs associated with disability. This payment would be made irrespective of whether the person is at work or not (report of the Commission on the Status of People with Disabilities, “A Strategy for Equality”)
- A once-off flat rate payment to people in receipt of long-term disability payments - similar to the ‘cost of living’ increase paid with disability payments in recent years (an annual top-up of €400-500) would be unlikely to meet any significant proportion of the actual costs of disability and would not vary according to those costs.²⁸

In light of previous research and policy analysis, CIB considers that a cost of disability payment should be adjusted to take account of differences in the nature and type of disability. Previous research has proposed that additional costs of disability should also be provided for those in paid work and not be confined to people in receipt of long-term disability payments only. Given that disability assistance payments are at the social assistance level regardless of the level of disability, targeting a cost of disability payment provides scope to provide for those with higher support needs.

²³ [Extra costs of living with a disability: A review and agenda for research - ScienceDirect](#)

²⁴ Research explored extra costs of living for adults with disabilities aged 50 – 65 across 15 countries of Europe. [Estimating the extra costs of disability.pdf](#)

²⁵ [Estimating the extra costs of disability.pdf](#)

²⁶ [Literature Review of Disability Payments - National Disability Authority](#)

²⁷ [overview-of-uncrpd-article-28-adequate-standard-of-living-and-social-protection.docx](#)

²⁸ [How to address the costs of disability in Ireland? - Public Policy](#)