



**National Disability
Services Association**
Equality through Quality

National Disability Services Association

Submission to

Department of Social Protection

Public Consultation on

Cost of Disability Payment

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Introduction

NDSA welcomes the opportunity to make this submission to the Department of Social Protection's consultation on the Cost of Disability.

The National Disability Services Association (NDSA) represents a network of seven of the largest national providers of disability services in the community across Ireland. Our member organisations include Acquired Brain Injury Ireland, Cheshire Ireland, Chime, Enable Ireland, Irish Wheelchair Association, Rehab Group, and Vision Ireland. Across our member organisations, over 8,000 dedicated staff provide key clinical and social services to over 40,000 individuals and their families every year. Collectively, NDSA organisations manage almost €400m on behalf of the HSE in providing essential and valued services across Ireland. We work across the widest range of community and social care services – Children's Disability Network Teams, education, training, personal assistance, community day care, employment, residential, respite and rehabilitation, and work with and for people across all ages, abilities and regions. The services provided by NDSA members are essential to ensuring the quality of life of those who receive them, providing dignity and enabling independence. NDSA works to ensure that the views and lived experiences of the people who use our services are heard and at the centre of policy and decision-making.

In preparing this submission, each of our organisations consulted widely with the people who use their services. Individual NDSA member organisations will be making their own submissions to the Department. However, we thought it important to come together as seven of the largest providers of disability services in Ireland to present a common platform. It is noteworthy that there was broad agreement across all services on the actions required by Government to tackle the cost of disability which demonstrates the strength of unity and agreement there is across the sector.

However, it is important that the Department recognises the diversity of needs and additional costs prevalent within the disability community and indeed, within one disability group itself. For instance, there can be a spectrum of different needs and associated costs for people with the same disability. Developing a Cost of Disability Payment that supports everyone who requires it, is a significant challenge, demanding sufficient time, coordination, meaningful consultation and co-design with disabled people and their representative organisations to reach collective solutions.

We believe that the process initiated by the Department should be given time to evolve and develop. While acknowledging the urgent need to allocate funding in Budget 2027, this should not be viewed as a final solution. It is crucial to continue the consultations, make adjustments as necessary, and develop a more comprehensive approach to a cost of disability payment.

Finally, we would propose a more inclusive title for the payment. A Cost of Disability Payment implies that people with disabilities incur additional expense on the state. As the IWA point out in their submission: "Costs arise from the interaction between people with disabilities and an environment that is not designed to accommodate them. They are ongoing, cumulative, and essential, not discretionary."

1. Purpose of the payment

- **Are there specific additional costs that should be covered by a cost of disability payment?**

A March 2025 study from the Irish Human Rights and Equality Commission (IRHEC) and the Economic and Social Research Institute (ESRI) showed that households with a disabled member face significant financial burdens related to disability and have very high **at risk of poverty (AROP)** rates. The study found that disabled people are economically disadvantaged, with additional weekly costs of disability ranging from **€488–€555**, amounting to **52–59% of their disposable income**.

Ireland ranks **20th in the EU for disability poverty (32.7%)**, with an **“at risk of poverty or social exclusion by level of disability (activity limitation)”** rate **4% above the EU average (28.8%)**.

Low employment participation rates (32.6%) also results in higher disability poverty rates in Ireland:

- One in six persons unable to work due to longstanding health problems are living in consistent poverty.
- **16.4%** of people unable to work due to longstanding health problems (disability) live in consistent poverty, compared to the national average of **5%**.
- **32.5%** of people unable to work due to longstanding health problems (disability) live at risk of poverty, compared to **5.4%** of employed people.

Vision Ireland notes that the **employment rate for people who are blind or severely vision impaired is only 26%**. This compares to **71% of people without a disability**. For someone who is vision impaired and is in employment, it is well established that salaries available can be lower than average. People who are blind or vision impaired estimate they would earn an additional **€24,000 per year if they were fully sighted**. As a consequence, the share of people who are blind or vision impaired with low or no earnings is high. Almost as a matter of course, Vision Ireland service users face a **higher risk of poverty and deprivation than the general population**. It appears to be an expected reality that someone who is vision impaired should live at or below the poverty line.

People with disabilities and families caring for a child with a disability face **unavoidable disability-related extra costs** that they cannot control, for example **higher heating and energy costs, medical supplies, specialised transport, personal assistance, housing adaptations, and specialised or adaptive equipment**.

Across the seven organisations, we have received reports of people being **unable to survive independently without financial support from family, dependent on food banks to meet food bills, or unable to cope with exceptionally high energy costs**. During our focus groups, participants highlighted the difficulties they face in ensuring they can afford even necessities, having to make difficult choices in prioritising their needs.

Family support covered essentials like **heating and eating**. In some cases, people have to make decisions between **heating their homes and charging essential disability equipment**, leaving them isolated and unable to leave their homes.

Implementing a **permanent cost of disability payment** would provide permanent, reliable financial supports and replace the inadequate once-off temporary payments previously made.

A permanent cost of disability payment is essential to uphold **human rights and equality** and ensure that disabled people can have **full participation in all aspects of their lives**, consistent with the **National Human Rights Strategy for Disabled People 2025–2030** and in line with the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**.

When asked about the cost of living with a disability, service owners in Enable Ireland strongly expressed the view that current financial supports are insufficient to meet the additional cost of living with a disability. Everyone agreed that the previous **once-off payment of €400** was not enough to meet rising costs.

Across all contributions, individuals consistently expressed that:

- The cost of living is rising beyond manageable levels
- People are being forced into difficult trade-offs between basic needs
- Current supports are insufficient, and more sustainable, long-term solutions are needed

The following common experiences were shared by adults with disabilities using NDSA member organisations services:

- Rising fuel and energy costs are driving up all prices, making everyday living much more expensive
- A once-off **€400 payment quickly loses value**, as prices are rising so fast that it would not go far in the near future. A much larger payment (around **€1000**) would be more realistic
- Financial support is essential; without it, families—especially those with disabilities—will struggle even more
- People may soon be unable to pay basic bills like electricity, affecting their ability to work and live normally
- Without financial help, people struggle to afford clothes, food, and personal care, showing how basic needs are at risk
- Rising costs are impacting independence, such as being able to buy lunch or small personal items, and social life, as activities like going out or attending events become unaffordable

These real-life examples illustrate why a more sustainable long-term solution is needed to address these costs:

“€400 is not enough. With inflation the cost of everything we use – groceries, oil, gas, medication – it’s all gone up. €400 is better than nothing but it is just a drop in the ocean. It should be an ongoing payment because the once-off payment is only going to help one time. We have to look at the long term. We need a regular payment.”

“I had a medical appointment at 11am in the GP surgery and I arrived at 9am because the surgery is always nice and warm and if I am not at home then I don’t need to pay to keep the heating on.”

“I have a family wedding coming up that I want to go to, but I have to pay for two PAs and to get a taxi there and back. I might not be able to go because I can’t afford the extra expenses. I have less money, so I am not going out as much as I used to.”

“I have to use an adapted van instead of a car so my wheelchair can fit in it. The diesel is more expensive now and it also costs more for servicing a van than a car.”

“You can’t switch it off because everything depends on it,” “everything in my house is electricity,” “I am broke by the Sunday.”

“There are times I have had to choose between paying my rent or oil or between topping up my electricity or buying groceries.”

“The financial pressure of managing ongoing costs related to my hearing loss has a direct impact on my wellbeing. Hearing aids and their maintenance are essential, but they are also expensive, and there is an ongoing awareness that these costs will continue long-term. This creates a level of financial stress and planning that others may not have to consider.”

Participants in Rehab’s focus groups referred to “Trial and Error Costs” – i.e. finding what works often involves repeated spending including trying different tools, apps, or strategies; switching therapists or medications; or sometimes just buying things that don’t end up helping. Other costs included additional expenses incurred when going on holidays or attending hospital appointments away from home including Personal Assistant support; paying additional fees for bigger rooms or extra rooms for PAs; rental of equipment like hoists, beds; shower chairs, etc.

Participants in Acquired Brain Injury Ireland’s (ABII) survey reported major obstacles in obtaining consistent and timely healthcare including:

- **Loss of Access to a GP**

One participant’s GP retired, and he was unable to find a new GP who would accept his medical card. This resulted in difficulty renewing necessary prescriptions and no access to a primary care doctor.

- **Long Waiting Lists for Specialists**

A participant waited 2.5 years to see a neurologist. During this period:

- -He continued receiving medication he no longer required, creating an avoidable cost to the State.
- -He was unable to be assessed and cleared to return to work, resulting in lost income and prolonged State dependency.

ABLI's survey participants highlighted that long waiting lists for neurologists impose financial and social costs both on individuals and the State. Another participant reported wearing incorrect lenses for six months due to glasses that had been improperly manufactured by a high-street optical provider. This error was not detected or rectified until he was seen by his consultant ophthalmologist. The error has delayed his eyesight recovery and his ability to return to work.

The participants also expressed appreciation for several existing State supports, which they described as essential for maintaining daily living standards:

- Fuel Allowance: acknowledged as vital, particularly given heightened heating needs.
- Free Travel Pass: highly valued, though not equally accessible for all due to mobility limitations.
- Medical Card, including: GP visits
- Access to medication

These supports were seen as important foundations but insufficient to meet the full cost of disability.

Vision Ireland reports that research shows that people in Ireland who are blind or vision impaired must spend **almost one fifth more on their essential items**, in order to achieve the same standard of living as someone who is non-disabled. Aids and appliances, such as computer software, accounted for **61% of additional living costs**. Compared to someone who was fully sighted, an extra **€1015 was spent annually on taxis**, while an extra **€400 was spent on home maintenance and cleaning**.

There are also extra costs, principally related to **housing and transport**, which an individual may be unable to meet altogether. According to the **Indecon report**, for vision impairment these costs are among the highest of any disability, totalling **€3,425 per year**. The total additional financial burden for someone who is blind or vision impaired reached **€13,609 per year**.

It is no surprise then that just **37%** of people who are vision impaired in Ireland report being able to regularly save some of their income. Rising costs have only exacerbated this precarity. A recent survey of Vision Ireland service users showed **81% experience additional costs from their vision impairment**. Of those, **97% have had to cut back on essential spending**, on account of the rising cost of disability.

In a recent Chime survey of Deaf and hard of hearing people, 44% received their hearing aids/cochlear implants free from the HSE, 61% of which are not satisfied with the quality of hearing aids provided to them.

66% pay for their own hearing aids, with the majority spending €4-5000, replacing them every 3-4 years. 71% of those paying for hearing aids received the Treatment

Benefit Hearing Aid Grant, and 49% stated that they were unable to afford the quality of hearing aids that they would prefer or require for their needs.

After the cost of hearing aids, adults with hearing loss reported the highest average annual expenditure on personal assistant costs (€1,558.14), transport support (€490.74), Irish Sign Language interpreter spend (€360.00), assistive devices (€345.38), medical costs without a card (€286.15), and hearing accessories (€195.70). 67% stated that they have had to go without essential items or services due to the extra cost of having a disability. These figures reflect the substantial financial burden across multiple areas related to managing hearing loss and disability.

2. Eligibility for the payment

• What eligibility conditions, if any, should be used to decide who should get the payment?

Across the seven organisations there was clear agreement that **eligibility should be simple, fair, and based on existing disability schemes**. Creating new assessments would recreate the administrative burden that all participants have consistently criticised.

Participants in Rehab’s focus groups contended that the core principle should be that everyone with a disability receives the payment regardless of their personal circumstance:

“A rights-based approach means shifting the mindset from: Do you qualify? to What do you need to live equally?”

Vision Ireland supports this position and states that a primary concern of the blind and vision impaired community is that the payment should not be means tested or dependent on low income. As a priority, **96% of Vision Ireland service users believe the payment should be universal to anyone who is blind or vision impaired (based on existing criteria for the assessment of sight loss)** as they bear an unjust burden of additional costs in their day-to-day lives. The payment must therefore not be restricted to existing social welfare recipients, those unable to work, or individuals aged under 66.

Participants in the Irish Wheelchair Association survey agree that **repeated reassessments are unnecessary and harmful, especially for lifelong conditions**. They stressed that a **doctor’s letter should be sufficient**, favouring a trust-based system.

“The doctor’s letter should be enough.”

Vision Ireland’s feedback is in line with this, stating that it is wholly inappropriate to have to recurrently prove one’s impairment when the condition is demonstrably not anticipated to improve. Given their very low number in Ireland (120), Vision Ireland state that applicants for the payment should not be mandated to provide evidence from an ophthalmologist, recommending that an optometrist’s report or letter from Vision Ireland (should they hold the medical record) should suffice.

The payment should be informed by **evidence gathered on the real lived experience of the actual additional costs of living with a disability**. Previous research conducted by the Irish Human Rights and Equality Commission and the Economic and Social Research Institute should be used to support this evidence base.

It must be **substantial enough to meet the real additional costs faced by individuals and families**. It should also be **index-linked**, so that the payment can keep pace with rising costs in **energy, food, transport, and the overall cost of living**.

The payment should be available to:

- People receiving disability payments
- People in employment
- People outside welfare systems
- People over 65 with disabilities

It is particularly important to ensure that **people over 65 are included in any payment model**. Disabled people often develop **more complex needs as they age**, yet many are no longer eligible for disability-related supports once they move from **Disability Allowance to the State pension system**.

It was also emphasised that whatever assessment method is used, it must **respect the dignity of the disabled person and should not be intrusive**. Any verification process should:

- Use existing medical evidence
- Be once-off verification for lifelong conditions
- Be reviewed only where circumstances materially change

Finally, there was an overwhelming belief across all organisations that the payment should be based on **need rather than means**. The payment should therefore **not be means tested**, as such a system penalises work, penalises family arrangements, and fails to reflect the genuine unavoidable costs associated with disability.

It is equally important that the payment is **not seen as a top-up to bridge Disability Allowance or other existing income supports**. Rather, it should be recognised as a **separate structural payment designed to offset the additional and unavoidable costs created by disability-related barriers in everyday life**.

3. How should the payment amount be decided?

- **The Government has limited money available – how should it target the payment? Is it better to include as many people as possible in the payment, even if that results in a lower payment rate? Or should a higher payment be made to a smaller number of people?**
- **Should different people receive different amounts?**

As emphasised throughout this submission, this payment must be viewed in terms of **how it contributes to improving the quality of life of the recipient**, including **health, inclusion, community participation, independence, and mental wellbeing**, rather than being narrowly framed as a “cost of disability.” It should **not be viewed as a top-up to disability or other welfare payments**.

The payment amount should be based on **evidence gathered from real people’s lived experiences of the actual additional costs of living with a disability**. Previous research conducted by the Irish Human Rights and Equality Commission and the Economic and Social Research Institute provides an important foundation to inform this approach.

Any agreed payment must be **substantial enough to meet the real additional costs faced by individuals and families**, and it should be **index-linked** so that its value keeps pace with rising costs in **energy, food, transport, assistive technology, and the wider cost of living**.

The **tiered approach proposed in the Green Paper** was not acceptable to many participants, as it appeared to **conflate the level of payment with the ability to work**. This risks reinforcing the harmful assumption that employment reduces disability-related costs, when in many cases work can generate additional expenditure in transport, personal assistance, technology, and support.

Nevertheless, there is an understanding that a **balance must be struck between broad inclusion and adequate support for those with higher and more complex costs**. Considerable thought needs to go into the design of any payment model, and whatever options the Department proposes should be **developed in collaboration with the disabled community who recognise that disability is a spectrum and that associated costs can vary depending on severity**.

The **co-design of the payment will take time and must be approached as a genuine partnership process from the outset**, ensuring that the final model reflects lived experience, protects equality, and does not unintentionally exclude people whose disability-related costs remain high regardless of employment or family circumstances.

4. How should the payment work?

- It should be a permanent, recurring payment and not a once-off, seasonal or annual payment
- A cash payment is preferable to a tax credit or similar. However, we do not rule out the option of a tax credit for those in employment, equivalent in value to the social protection payment. This should be available to all earners, regardless of income.
- It should be separate to, and complement, existing disability supports and not be used to replace or reduce them
- It should be compatible with employment and not become a disincentive to people with disabilities who can and want to work
- Over 65s with a disability must be included

Strategic Focus Network Summit on the Cost of Disability

1. What issues would like to see discussed at the Summit?

To support meaningful participation, the summit should begin with a Department-led presentation of the evidence base, including findings from the Indecon report; themes emerging from the public consultation; relevant evidence from the IHREC / ESRI research on poverty and cost of disability.

A discussion on Government spending and budgets; ‘How much is realistic in terms of a Cost of Disability payment’?

How can we ensure that any strategy regarding a Cost of Disability payment is co-created with Disability Organisations, and all stakeholders involved?

What research is currently being done by government departments about the Cost of Disability, and is there a way that stakeholders could contribute to any planned research?

A realistic timeframe for the introduction of a Cost of Disability

Comparisons with international solutions, policy models and comparative learning

2. What format do you think the Summit should take?

An organised mix of discussions and breakout sessions that allow for meaningful contributions from people with lived experience, disability organisations, and relevant stakeholders.

- Purpose of the payment – poverty reduction, equality, participation, independent living
- Eligibility – existing schemes, lifelong conditions, people in work, people over 65, children and family carers
- Payment amount and structure – universal, tiered, hybrid, tax credit interaction, index-linking
- **3-4 proposals of how the payment might work based on submissions and department input**
- Interim measures – urgent Budget 2027 supports while the full model is co-designed.
- A workshop format will support problem-solving, deliberation, and partnership-based design
- Solution focused discussions that include all relevant government departments (Not just DSP)
- Ensure people with disabilities lead the process.

The summit should be led by people with disabilities in both process and content, This includes:

- lived-experience speakers opening the summit.
- disabled facilitators or co-facilitators in breakout groups
- accessible communication supports.
- multiple ways to contribute, including written, verbal, and digital feedback.

This is essential to ensuring that the payment reflects the real additional costs of disability in everyday life.

The summit should conclude with clear next steps and timelines, including:

- publication of a summit outcomes report
- further structured consultation on draft Department proposals
- equality and poverty impact assessment
- agreement on an index-linking mechanism
- annual review arrangements
- continued involvement of disabled people and representative organisations before implementation

The development of a Cost of Disability Payment is too important to be rushed. A thoughtful summit process, grounded in evidence and genuine partnership, will give Ireland the opportunity to create a rights-based model that can become an international example of best practice.