

**Submission to the Department Social Protection**

**Consultation on  
Cost of Disability Payment**

**April 2026**

# REHAB GROUP SUBMISSION TO DEPARTMENT OF SOCIAL PROTECTION

## COST OF DISABILITY PAYMENT

### Introduction

Rehab Group is an independent voluntary organisation that has supported adults and children with disabilities for more than 75 years. As a campaigning and advocacy body, we represent the voices of the 12,500 individuals who currently access our services, as well as their families.

We would state at the outset that there was limited time for us to consult with people in our services given the short timeline of the six-week consultation period with two significant holiday periods, (St Patrick's Day and Easter) intervening. Despite the short timescale, we managed to conduct more than thirty in-depth focus groups, engaging well over 150 service users from across the country. To complement these insights, we also surveyed over 50 frontline staff members, including Care Workers, Instructors, Psychologists, Rehabilitation Officers, Supervisors, and Managers.

We also engaged in discussions with our colleagues across the disability sector including the National Disability Services Association and the Disability Federation of Ireland.

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 would like to emphasise that this submission outlines our initial thoughts on how to deliver a Cost of Disability payment which we hope is the start rather than the conclusion of a process.

The development of a cost of disability payment will take time and it will be important to continue the consultation process to ensure that whatever proposals are put in place are effective.

The National Human Rights Strategy for Disabled People advocates for a whole of Government Approach to disability to deliver on Ireland's commitments under the UN CRPD. Addressing the Cost of Disability is about more than just a single payment – it requires coordinated action across all government departments to meet the needs of people with disabilities.

Finally, we propose adopting a more inclusive name for the payment. The term “Cost of Disability Payment” carries associations that people with disabilities are a financial burden on the state. In reality, these additional costs arise from the interaction between individuals and their surrounding environment which is not designed to accommodate their needs. As such, they are ongoing, cumulative, and essential costs—not optional—and the language used should adopt a more accurate and respectful understanding.

## **1. Purpose of the payment**

People with disabilities in Ireland are substantially more at risk of poverty and deprivation than those without disabilities.

- 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%)
- 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 problem (disability) live at risk of poverty, compared to 5.4% of employed people.

The cost of disability is estimated to be between €488 and €555 per week. Additional costs include transport, communications, equipment, disability aids, assistive technology, medical care, and personal care.

Rehab adult service users report being unable to survive independently without financial support from family, being dependent on food banks to meet food bills or being unable to cope with exceptionally high energy costs. During our Focus Groups they highlighted the difficulties they face to ensure they can afford even necessities having to make difficult choices in prioritising their needs. Family support covered essentials like heating and eating.

### **Extra Costs Incurred Due to Disabilities**

Our service users and staff members outlined an extensive but not exhaustive list of additional costs that people with disabilities must contend with including:

#### **1. Healthcare & Therapy Costs**

Many people with disabilities need ongoing support that isn't fully covered:

- Private assessments (often expensive and long waitlists publicly)
- Therapy (e.g., occupational therapy, physiotherapy, CBT, speech & language therapy)
- Medication and follow-ups

#### **2. Transport & Accessibility**

- Reliance on taxis due to difficulties accessing public transport
- Driving lessons
- Vehicle adaptations

- Lack of transport also adds to daily living costs as people are forced to shop in local more expensive convenience shops rather than larger supermarkets

### **3. Home Energy & Heating**

- As many people with disabilities are more isolated, they spend more time at home meaning their energy usage is greater.
- Many disabilities affect heat regulation, so people require greater levels of heating to remain comfortable
- Many mobility items are electric and require either charging or continuous power – wheelchairs, beds, hoists etc

### **4. Education & Learning Supports**

- Extra costs often arise in school, college, or work training:
- Tutors or specialist educators
- Assistive technology (text-to-speech, dictation software, etc.)
- Learning materials in accessible formats
- Exam accommodations (sometimes privately arranged)

### **5. Housing and Living Environment Adjustments**

- Building or home adaptations
- Assistive technology including: noise-cancelling headphones; sensory tools; weighted blankets; lighting adjustments; environmental controls etc.

### **6. Employment Impacts**

- Reduced working hours or burnout leading to job changes
- Periods of unemployment
- Paying for workplace accommodations personally
- Career paths limited by lack of inclusive environments or disability awareness

### **7. System Barriers**

- Missing out on entitlements due to complex application processes
- Paying for advocacy or support to navigate systems
- Fines or penalties from misunderstandings or missed communications or missed deadlines

### **8. Time = Money**

- Neurodivergence can make everyday tasks more time-consuming:
- Missed deadlines or late fees
- Paying for convenience (e.g., food delivery, taxis)

### **9. “Trial and Error” Costs**

- Finding what works often involves repeated spending:
- Trying different tools, apps, or strategies

- Switching therapists or medications
- Buying things that don't end up helping

### **10. Additional costs of holidays/hospital visits**

Additional costs are often incurred when going on holidays or 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.

## **2. How would we decide which people would qualify for a Cost of Disability payment?**

### **Everyone with a Disability should receive the Cost of Disability Payment**

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?"

They stressed that the payment should be made to everyone with a disability.

Respondents stated that a payment should be available to all including those who are:

- On Disability Allowance
- Working or trying to work
- Living at home or independently
- Over 65 and in receipt of pension

Respondents highlighted that extra costs are universal, everyone with a disability faces additional expenses due to their disability and how society disables them. The overwhelming view was that the payment should be based on need rather than means. The payment should therefore not be means tested, which would penalise work and/or penalise family arrangements, and fails to account for the real, unavoidable costs associated with disability.

*"I think anyone with a disability should get it, because the extra costs are real no matter what your situation is."*

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.

For people with a disability income is often limited, and opportunities to earn are reduced due to systemic barriers to disability in employment.

Respondents felt very strongly that any assessments should be fair and transparent and avoid being overly complicated and making people feel intimidated or stressed.

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

*“Disabled people have been filling out forms in relation to their disability all their lives, surely we could have one place to store all that information linked to our PPS number and use it to calculate a payment, we are in the age of AI, why the constant forms?”*

### **3. How should the payment amount be decided?**

#### **Payment Should Reflect Real Costs**

Respondents emphasised that the payment must be substantial enough to meet the real additional costs faced by individuals and families. The amount should be determined in relation 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.

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 cost of disability is a crisis within a cost-of-living crisis. Respondents felt that current payments are not aligned with real life expenses and they do not want to see the same thing happening with a cost of disability payment.

#### **One Size Does Not Fit All**

Respondents acknowledge that not everyone’s needs were the same and that some people may need more support.

They stressed that everyone should receive the payment, but amounts should differ depending on the level of extra costs and that any assessment must be based on need rather than on means or on capacity to work.

An opportunity to appeal for somebody who requires greater support should be made available.

*“A comprehensive individual assessment should be conducted. The same payment should not apply ..... However, it should be presented not as a means test to prove how deserving someone is of it depending on how disabled they are, but rather costs associated with the barriers associated with the realisation of their rights as per UNCRPD.”*

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?**

The overwhelming view was that the Cost of Disability Payment should not be used as a top-up to disability or other welfare payments.

There was strong support for assessments to be individualised to the person, to be inclusive of the person as much as possible and to involve the people that know them best including their own doctors and support teams rather than the dehumanising effect of being assessed by a stranger. This was particularly important to people whose condition may be episodic or the severity of which may fluctuate.

*“When I was means tested for DA, I felt very threatened, I felt I could not talk, a family member had to talk for me at times.”*

There was strong opposition to any assessment of family or partner’s income. Some respondents had experienced becoming more dependent on a spouse due to a refusal

for disability allowance based on their partner's income. There was support for assessments to include bills and general living costs as well as medical reports.

### **Weekly Payment**

The majority of those we surveyed said they would rather a weekly payment as they had immediate and pressing payments to make and that a weekly payment would reduce these stresses.

A weekly payment would improve independence, reduce reliance on family, improve quality of life, allow participation in social activities with family and friends and would give a sense of security and dignity.

*“I think the extra money should be paid every week. I think it should be paid the same way as I understand it.”*

Other points made in relation to the administration of the payment included:

- It should be a permanent, recurring payment and not a once-off, seasonal or annual payment
- For those in employment, options could include a direct payment or tax credit equivalent in value to the social protection payment. This should be available to all earners, regardless of income.
- 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.
- It should be an actual payment to all who are eligible (as opposed to tax or other credits).

## Strategic Focus Network Summit on the Cost of Disability

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

We welcome that the first Strategic Network Summit of the new Human Rights Strategy will be devoted to the implementation of a Cost of Disability Payment. We are conscious that the Indecon Cost of Disability Report was first published in 2021 and that little progress has been made since then. We hope that the Summit will inject a greater sense of urgency into ensuring that the payment will be implemented in Budget 2027.

The Summit will provide an opportunity for the Department to share the key themes, findings, issues and concerns raised in the responses to the public consultation, and the Department's analysis of same, with the disability movement and sector.

It will also be important to see reflections on previous policy submissions on disability in the past number of years, including to the Green Paper consultation process, and the Department's analysis and synthesis of same.

This evidence and analysis can help avoid the need to repeat concerns that have already been well-documented previously and inform the selection of strategic areas of focus and discussion at the Summit.

It might be useful if the Department produced an "Options Paper" to outline their thinking on the possibilities for the payment.

A key issue identified by respondents in our focus groups was how to make independent living more attainable and to support people with disabilities in participating meaningfully in their communities, with due consideration given to geographic differences, such as rural and urban contexts. This needs to be a central focus at the summit.

It will also be imperative that the Department address what interim measures will be put in place in Budget 2027 supports while the full model is co-designed.

Ideally papers under discussion at the Summit should be circulated to participants in advance.

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

### **Nothing About Us Without Us**

The Summit should be as inclusive and accessible as possible. To ensure that this summit can be attended by as many people with disabilities as possible there needs to be a consideration of the barriers that people with disabilities face.

A hybrid format would help to address transport and mobility issues faced by people with disabilities who would like to participate in the summit.

The physical location needs to be fully accessible and ensuring that people with wheelchairs are not asked to enter via a back or goods entrance.

The summit should have a mix of presentations with workshops to tease through some of the options under active consideration for the Cost of Disability payment.