

Submission from Polio Survivors Ireland

Introduction

Polio Survivors Ireland welcomes this opportunity to submit our initial thoughts on the proposed Cost of Disability Support Payment on behalf of polio survivors in Ireland. Polio is a highly infectious viral disease that largely affects children under 5 years of age, causing nerve damage that leaves many people with **lifelong disabilities**. Approximately 85% of the members we represent are now over the age of 65, while we also have a number of younger members who have migrated to Ireland from countries where polio remains endemic. Many polio survivors still live with the effects of this disease (e.g. limb paralysis), may develop new neurological symptoms decades after disease onset (Post Polio Syndrome) or may be affected by the Late Effects of Polio (e.g. pain or arthritic changes due to wear and tear). Thus, the effects of living with a disability caused by polio are significant throughout the lifespan and often get **progressively worse** as people age.

Within the timeline given to make this submission, Polio Survivors Ireland had limited opportunity to adequately consult with our members to reach consensus and formulate a considered response as to what a disability payment should look like in real terms. Therefore, our response is based on previous research done within the organisation and feedback received from members about the cost of disability. More meaningful consultation with disabled people and their representative organisations is required in order to recognise the diverse needs and spectrum of costs that disabled people face. We hope that this is the first step in a process that gives disabled people the opportunity to participate fully in the consultation process and co-design a permanent Cost of Disability Support Payment that meets their needs. We also urge the Department of Social Protection (DSP) to commit to being transparent about the findings from the public consultation so that perspectives can be analysed and collective solutions agreed upon within the disability community.

Polio Survivors Ireland is also a member of the Disability Federation of Ireland and supports its broader submission on behalf of the federation.

1. Purpose of the payment

Many factors contribute to the cost of disability and any attempt to address these costs in a considered manner must involve a **whole-of-government** approach, that incorporates measures from multiple Departments in order to meet commitments made in the [Programme for Government 2025](#) and the [National Human Rights Strategy for Disabled People 2025-2030](#).

It is estimated that approximately 5,000 polio survivors remain in Ireland, many of whom are facing increasing needs as they age. The **severity of disability caused by polio varies** greatly from person to person and includes reduced mobility, pain, fatigue, cold intolerance and muscle weakness. Many of our members require mobility devices (e.g. walking aids, wheelchairs, leg orthotics, etc) and their cost of living is higher than average due to the added expenses of medicines, aids/appliances, heating, transport, housing adaptations, home supports and therapeutic interventions to manage their condition.

The [Indecon Cost of Disability Report \(2021\)](#) found that people with disabilities face significant additional living costs between €8,700 and €12,300 per year, depending on severity, although some had much higher costs. When adjusted for inflation, these figures rise to between €10,766 and €15,221. These costs exist regardless of whether one is employed or not, and do not cease when reaching retirement age.

In 2024, we completed an internal survey with a representative sample of polio survivors, capturing expenses that correlated with the cost categories in the Indecon report. One finding from our survey showed that both **heating and electricity costs** alone averaged €4,100 annually (€342 a month) for polio survivors. By comparison, the [CSO Household Budget Survey 2022–2023](#) reports that households spend an average of €3,017 annually on combined energy costs. Post-polio syndrome often causes **extreme cold intolerance**, requiring consistent heating for up to ten months of the year to manage pain. Without adequate support for heating and electricity costs, individuals may be unable to keep their homes warm, leading to increased pain, discomfort, isolation, and a reduced quality of life. Even if a polio survivor qualifies for the Fuel Allowance, which provided €33 per week for 28 weeks during the 2024/2025 season, totalling €924, the support falls far short of covering actual energy costs. This leaves a significant gap for polio survivors to meet their **medically necessary energy needs**. Disabled people who experience the debilitating symptoms of cold intolerance should have this cost addressed without delay via enhanced energy credits or grants.

Our survey also revealed that **periodic or once-off expenses** such as ramps, wet rooms, mobility aids, adapted vehicles, callipers and specialised footwear came to around €6,500 annually when averaged over expected lifespans. Despite recent increases in funding for housing adaptation grants, many remain underfunded, delayed or inconsistent, which leave individuals to shoulder much of the financial burden themselves to make their homes accessible and safe. Many of our younger members

have migrated from other countries and struggle to find **accessible, affordable accommodation** within the context of a national housing crisis. Investment in infrastructure and universally designed social housing is required to ensure that people with disabilities do not remain living in inappropriate, unsafe accommodation settings.

Transport costs also place a burden on our members' finances, which not only affects their ability to attend work and medical appointments, but also limits them from remaining active members of society, thus contributing to social isolation. Many polio survivors report that they must pay for private taxis due to a shortage of accessible, punctual and regular **public transport** in their locality. If driving their own cars, it is increasingly difficult to secure accessible parking due to lack of enforcement of fines for those using disabled parking spots without permits. Additionally, those reliant on wheelchairs or scooters often experience difficulties navigating their communities due to inappropriate parking on footpaths. These **infrastructural and enforcement issues** must be addressed at Department and local authority level in order to address the extra burden of cost they place on disabled people.

The [Motorised Transport Grant and the Mobility Allowance](#) were terminated in 2013 (for new claims) by the Department of Health and to date, no replacement schemes have been established to assist with transport costs. Eligibility for the Disabled Drivers and Disabled Passengers Scheme (tax relief on vehicles for drivers and passengers with a disability) is contingent on having a valid Primary Medical Certificate (PMC), however there have been calls for reform of this scheme which will require coordination between several Government Departments.

Another gap in the current welfare system is the exclusion of disabled asylum seekers from the Free Travel Scheme. Correspondence from the DSP in 2024 stated that there are 'no plans at this time to amend the qualifying criteria for the medical free travel pass to include those with disabilities in the International Protection System while awaiting a decision on their refugee status'. Amendments to this scheme to facilitate a temporary travel pass for disabled asylum seekers would alleviate some of the disability-related costs that exist regardless of **immigration status**.

Our survey findings also indicated that **health-related costs**, including medical consultations, therapies, home supports and medications averaged €5,560 per year for polio survivors. It is clear that existing services or supports are not addressing these costs of disability. Disabled people do not have universal access to medical cards, given that this is a means tested scheme. A 2022 survey of approximately 450 polio survivors found that 26% did not have a medical card at that time, but this figure is likely higher today. **Expanding medical card access** to more people with disabilities would be a first step towards lowering the cost of medicines, aids/appliances and health services.

A significant barrier to medical card access is that income thresholds have not kept pace with inflation or with increases to social welfare payments. For people under 70, the core

limits have not been updated since 2005/2006 and for those over 70, thresholds have only increased slightly since 2020. At the same time, core social welfare payments have continued to rise with each Budget. These increases, while helpful in principle, may not reflect a genuine improvement in financial circumstances and can push someone over the eligibility threshold for a medical card, even though their essential living costs have also risen. The Programme for Government 2025 has committed to **further extend income thresholds for medical card eligibility**. Polio Survivors Ireland's [Pre-Budget Submission to the Department of Health](#) urged for this step to be taken in 2026, but to date there has been no evidence of this commencing.

Our research also highlighted challenges when applying for a medical card due to limited clarity and detail when recording disability-related costs on the application form. Certain expenses such as rent, childcare and general healthcare are considered, but certain recurring and sometimes significant costs linked to disability are often overlooked. For example, energy needs, which may be medically necessary for polio survivors, are not currently considered an allowable expense in the medical card assessment process. This lack of specificity hinders applicants from presenting a full and accurate picture of their financial need. **Improving the structure and clarity of the application forms** would allow applicants to document recurring and once-off disability-related costs more effectively. A redesigned and more comprehensive form would support a fairer assessment process and help ensure that eligibility decisions reflect the genuine and ongoing financial pressures faced by people with disabilities.

However, even with a medical card, there is no guarantee of timely access to public health services. Many polio survivors report being on HSE **waiting lists** for months or years due to staffing shortages and cannot afford private healthcare to access the medical care and therapies they need. Greater transparency is needed regarding Primary Care **staffing quotas per population needs** in areas where long waiting lists exist in order to ensure that Sláintecare principles are being upheld to '*provide the right care, in the right place, at the right time*'. While there has been recent investment in neurological and neurorehabilitation services in specific regions across the country, significant **geographical inequities** remain, resulting in little or no access to these services for polio survivors and other people with disabilities. Other specific disability services (e.g. as Physical and Sensory Disability teams) have age cut-offs, excluding those over the age of 65 from accessing their services. This gives the impression that one's disability must cease to exist after the age of 65. A person with a disability should not be treated less favourably as they reach retirement age, as this reinforces an ageist belief that older persons do not require specialised supports or services, in comparison to their younger peers. As one of our members aptly stated, '**You can't retire from a disability**', yet national health policy reinforces this belief. Excluding over 65s from specialist disability services contravenes their rights under Article 25 (Health) of the [UNCPRD](#), for the State to 'provide those health services needed by persons with disabilities specifically

because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and **older persons**'.

In summary, it is clear that while a cost of disability payment is essential, there are many additional ways in which these costs should be addressed by enhancement of existing health services, establishment/optimisation of supports/schemes, introduction of specific energy/housing/transport measures and improvements in infrastructure. This requires **commitments from other Departments** to demonstrate how they aim to contribute to addressing the cost of disability within a whole-of-government approach.

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

Many people with disabilities are already excluded from getting a disability-related welfare payment for reasons such as being above the income thresholds when **in employment**, being in receipt of the **State Pension**, or not meeting **habitual residence conditions** (e.g asylum seekers awaiting decisions on their immigration status). Using the same eligibility regulations for the new cost of disability payment will reinforce inequalities rather than reducing costs and increasing participation in society. Therefore, future eligibility criteria must be available to a wider group and consideration must be given to the unique needs of these cohorts.

To provide context for one of these cohorts, disability can affect anyone at any stage of life, but its prevalence increases significantly with age. According to Census 2022, over 349,000 people aged 65 and older in Ireland are living with a disability. Despite this, financial supports for people with disabilities remain focused almost exclusively on those of working age, creating a **growing and overlooked gap for older people**. Once people reach 66, they lose access to targeted financial disability supports. Many of the polio survivors within our membership did not receive the Disability Support Grant provided in Budgets '23, '24 and '25, despite having very significant extra costs as we have already outlined. Others received it one year, but had aged out the next year, though their costs had not disappeared. There is a **clear structural inequity** where two people with the same level of disability face different financial realities simply because one has passed the pension age threshold. This practice contravenes Article 28 (2)(b) of the [UNCPRD](#) (Adequate standard of living and social protection) which obligates states 'to ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes'. This is not only discriminatory, but it also puts older people with disabilities at greater risk of poverty, health deterioration, and social exclusion. It is essential that a Cost of Disability payment must be available to people aged 65 and over. As confirmed in correspondence to Polio Survivors Ireland from the Department of Social

Protection, the Indecon Cost of Disability Report “focused on people of working age rather than pensioners,” and “no specific assessment has been conducted of any additional costs incurred by people aged 65 years and over due to disability.” This leaves a **critical evidence gap** that must be addressed in order to address the cost of disability for this cohort and we have called for the commissioning of this research in our [Pre-Budget Submission to the DSP in 2025](#), along with inclusion of older people in all future Cost of Disability Payment schemes.

Eligibility for this new payment should be **based on the existence of ongoing, unavoidable and essential disability-related costs that people incur in order to fully participate in society**. Means-testing should not be part of this process at all. People in employment should not be excluded, nor should people of retirement age or currently awaiting decisions on their immigration status.

Assessment of need for this support could use existing medical records to verify people’s condition, with minimal administrative burden and appropriately timed input from medical professionals to give insight into expected medical prognoses. Those who have lifelong conditions should not be re-assessed or insensitively questioned on their expectations of recovery.

3. How should the payment amount be decided?

Further consultation with disabled persons organisations is required in order to determine the payment amount, supported by the evidence from the Indecon Report and more recent ESRI and IHREC reports. Sustainability of the payment scheme must also be considered alongside determination of a meaningful and sufficient amount to support the real and additional costs of disability. Any proposed tiers of payment should be **based on need and costs** incurred due to disability, rather than one’s income or ability to work. Existing benefits/schemes already exclude many people due to means testing, and this is an opportunity to move towards a payment that does not penalise income, create financial dependence on partners or family members, or introduce disincentives to employment.

4. How should the payment work?

Further consultation is required to determine how this payment should work in practice, both on a national level and within our own organisation.

At a minimum, the payment should be:

- Non-means tested

- Automatically available for those currently in receipt of disability payments, but importantly not limited to these recipients only
- Non-taxed or reduced by other benefits
- Paid on a regular basis (ideally weekly or monthly)
- Tax credits should also be considered as an option for those in employment (matching the value of a regular payment)

Strategic Focus Network Summit on the Cost of Disability

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

There are many significant extra costs that people with disabilities face and a comprehensive overview of these must be transparently and efficiently presented, along with annual values as described in previous research (e.g. Indecon report). It should be stated from the outset that there is an **acceptance that these costs are true and unavoidable** for people with disabilities in order to allow appropriate discussion to evolve.

Engagement should focus on the practical **challenges and barriers** that people with disabilities face when trying to access supports, services and benefits, with **open dialog and co-design** sessions held in order to find solutions to these issues.

Representatives from other Government Departments should be present to hear testimony from the personal lived experiences of disabled people and to be involved in discussions about measures each Department should take to address these.

It is imperative that Government departments hear the perspectives of people who have experienced the assessment and application process of previous schemes, so that the new Cost of Disability payment does not follow the same process. It is important for all present to hear about the challenges faced both by applicants and by those administering the schemes so that consensus can be reached on the most practical and efficient approach.

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

The format should be collaborative and take a co-design approach, allowing input from relevant stakeholders to give their lived experience and to present data that supports the need for change. Models of good practice from other countries should be presented and analysed in order to spark ideas within structured breakout sessions. The format could include a combination of inclusive discussions, themed breakout sessions, and opportunities for case studies or presentations from organisations working on practical solutions.

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