Down Syndrome Ireland (DSI)

Submission to the Public Consultation on the Cost of Disability

Department of Social Protection

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Down Syndrome Ireland (DSI) welcomes the opportunity to contribute to the Department of Social Protection's Public Consultation on the Cost of Disability and to inform the development of a permanent Cost of Disability Support Payment. As Ireland's national organisation supporting people with Down syndrome and their families across the life course, we engage daily with individuals, parents, siblings, carers and self-advocates who experience the cumulative and ongoing financial impacts associated with disability.

We strongly support the recognition that disability gives rise to additional and unavoidable costs that are not faced by non-disabled people, and that these costs affect household income adequacy, participation in community life, access to opportunity and overall wellbeing. The design of a Cost of Disability payment must therefore be firmly grounded in human rights principles, robust economic evidence, fiscal sustainability and the lived experience of disabled people and families, in line with Ireland's obligations under the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

Through our ***Unity 26–30 strategy – "One purpose. One standard. Everywhere.",*** DSI has committed to a rights-based, evidence-led and life-cycle approach to advocacy and service delivery. This submission reflects that approach.

In our national consultations with members over the last few years, including structured branch engagement, surveys and policy roundtables, families have consistently articulated that the extra costs associated with Down syndrome are persistent across the lifespan, fluctuate depending on stage of life and support needs, and intensify at key transition points. Members describe a constant pressure of managing unavoidable additional costs alongside ordinary living expenses, particularly in the context of inflation, rising energy prices and inconsistent service provision. What members seek is not exceptional treatment, but fairness, predictability and recognition of unavoidable expenditure arising solely because of disability.

Question 1: Purpose of the Payment

The primary purpose of the Cost of Disability payment must be to recognise and offset the additional, non-optional costs that arise directly because of disability, and to break the structural link between disability and poverty.

Evidence demonstrates that the additional annual cost of disability in Ireland ranges between approximately €10,766 and €15,221, equating to €488 to €555 per week. Households with a disabled member require between 41% and 93% more disposable income to achieve an equivalent standard of living. These costs arise across all areas of life, including healthcare, therapies, transport, energy, communication supports, assistive technology and participation in education and employment.

For people with Down syndrome, these costs are lifelong and often higher due to the interaction between intellectual disability and systemic barriers. Our members consistently report that statutory supports do not adequately reflect the real financial burden, particularly where delays or gaps in public services require families to fund supports privately.

The purpose of the payment must therefore be to ensure that individuals and families are not left out of pocket for disability-related needs, and that disability does not result in a reduced standard of living.

However, the cost of disability is not solely about expenditure. It is also about reduced income and constrained participation, including:

- Reduced workforce participation due to caring responsibilities

- Loss of earnings and long-term pension impacts
- Barriers to employment for people with disabilities
- Fear of losing secondary benefits when entering work

Families have told us that they are frequently forced to make unacceptable trade-offs, including delaying therapies, reducing heating, or absorbing unsustainable financial pressure.

From a policy perspective, the payment must also be understood as preventative economic policy. When disability-related costs are not addressed, households are pushed toward arrears, crisis intervention, emergency healthcare usage and long-term dependency on State supports. A predictable and adequate payment reduces these risks, supports employment participation and lowers long-term public expenditure.

The payment must not replace or distract from addressing service gaps, regional inequities or systemic barriers, which continue to drive additional costs. Income support and service reform must operate in tandem.

The payment should also contribute to enabling participation in employment, supported by:

- Workplace adaptation supports
- Accessible transport, especially in rural areas
- Reform of income thresholds and secondary benefit rules

Finally, all policy must be disability-proofed, ensuring that no future measures increase the cost of disability or unintentionally exclude disabled people from participation.

Question 2: Eligibility for the Payment

Eligibility must be broad, inclusive and rights-based, recognising that disability-related costs are experienced across a wide population, including those not currently in receipt of disability payments. We support alignment with the definitions in the **Disability Act 2005 and the UN CRPD**, but eligibility must extend beyond existing schemes to include:

- Individuals in employment
- Individuals in education or training
- Individuals not currently captured within disability payments

Our members consistently report that the current system is complex, fragmented and overly burdensome, with repeated reassessment requirements even where conditions are lifelong and unchanging, such as Down syndrome. This creates unnecessary stress and undermines dignity.

Eligibility processes must therefore be:

- Simple, transparent and accessible
- Stable across the life cycle, with no disruption at transition points
- Designed to minimise administrative burden

Critically, the Cost of Disability payment must be:

- Non-means-tested
- Fully disregarded in the assessment of other supports, including medical cards and secondary benefits

Fear of losing supports is one of the greatest barriers to employment. The payment must remove this risk. Consideration should also be given to income smoothing mechanisms, allowing individuals to enter employment and increase income gradually without immediate loss of supports.

Question 3: Determining the Payment Amount

The payment amount must be grounded in robust national evidence while recognising variation across life stages and levels of need.

While a flat-rate payment offers simplicity and inclusivity, it must be:

- Set at a meaningful level that reflects real cost data
- Indexed to inflation and disability-specific cost drivers
- Additional to existing supports, not replacing or absorbing them

DSI supports a model that:

- Establishes a strong baseline payment
- Reflects the disproportionate impact of energy, transport and healthcare costs
- Allows for future progression toward a more responsive, needs-informed approach

Members have consistently highlighted the impact of inflation, particularly energy costs, which are significantly higher in households where additional heating is required for health and wellbeing.

Question 4: How the Payment Should Work

The Cost of Disability payment should be a standalone, clearly identifiable support, designed to provide stability and predictability.

It should:

- Be paid regularly (weekly or monthly), with flexibility for alternative structures
- Remain stable across life transitions
- Avoid repeated reassessment for lifelong conditions
- Be simple to access, with accessible application processes

The system must be digitally enabled but not digitally dependent, with assisted supports available. Administrative burden must be minimised, recognising that families already carry extensive coordination responsibilities across health, education and social systems.

Life-Cycle Impact of the Cost of Disability

The cost of disability evolves across the life course and must be understood in this context.

In **early childhood**, families incur high costs for therapies, childcare and transport, often alongside reduced workforce participation.

During school years, costs include education supports, transport, assistive technology and ongoing therapies, alongside hidden costs such as reduced working hours.

At transition to adulthood, families face significant uncertainty and financial strain, often described as a “cliff edge,” where structured supports fall away.

In adulthood, costs relate to independent living, housing, supervision and ongoing supports, with rural families facing additional geographic disadvantage.

In later life, costs increase further due to ageing-related conditions, including dementia and increased healthcare needs.

Across all stages, families provide extensive unpaid care and coordination, resulting in lost income, reduced career progression and long-term pension impacts. This invisible labour represents a significant economic contribution that must be recognised.

Whole-of-Government Accountability

The cost of disability is driven not only by individual needs but by systemic barriers, including:

- Service gaps
- Inaccessible transport
- Delayed therapeutic provision
- Fragmented support systems

The Cost of Disability payment must be supported by a whole-of-government approach, with:

- Clear implementation timelines
- Measurable outcomes
- Transparent reporting
- Formal involvement of representative organisations such as DSI

Data, Intersectionality and Ongoing Engagement

Policy design must be informed by updated national data and lived experience.A national cost-of-disability survey should be co-designed with representative organisations. Policy must also recognise intersectional disadvantage, including lone parents, migrant families and those without support networks.

Income support must be accompanied by measures that reduce costs at source, including:

- Accessible and subsidised transport
- Assistive technology provision
- Community-based therapies
- Personal assistance services

Strategic Focus Network Summit

DSI ask the Summit to address:

- The real cost of disability and inflation impacts
- Poverty and income adequacy
- Impact on families and unpaid care
- Complexity of current supports
- Housing and long-term planning
- Education, employment and transition pathways
- System reform and simplification

Format

The Summit must be fully accessible and inclusive, including:

- Roundtable discussions
- Easy Read and neurodivergent-friendly materials
- ISL interpretation and captioning
- Hybrid participation options

Conclusion

The Cost of Disability payment represents a critical opportunity to address one of the most persistent inequalities in Irish society. For people with Down syndrome and their families, the cost of disability is lifelong, cumulative and unavoidable, affecting every stage of life.

Our members have told us clearly that what they seek is recognition, fairness and stability. A permanent, predictable, non-means-tested Cost of Disability payment, grounded in evidence and lived experience, and delivered within a clear implementation timeframe, will be transformative. Delay will perpetuate avoidable poverty and exclusion. The time for delivery is now.

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