



Inclusion Ireland

The National Association for People
with an Intellectual Disability.

Inclusion Ireland's submission to the Department of Social Protection's Cost of Disability public consultation

April 2026

Contents

Abbreviations	1
Introduction and Executive Summary.....	2
Cost of Disability Payment.....	5
Purpose of the Payment.....	5
How would the Government decide which people would qualify for a Cost of Disability payment?	10
How should the payment amount be decided?	14
Strategic Focus Network Summit on the Cost of Disability	19
What issues should the Summit examine?	19
Format	20

Abbreviations

ADMCA – Assisted Decision-Making (Capacity) Act 2015

AON – Assessment of Need

AROPE – At Risk of Poverty and Exclusion

CDNT – Children’s Disability Network Teams

CoD – Cost of Disability

DEY – Department of Education and Youth

DPO – Disabled Person’s Organisation

DSP – Department of Social Protection

ESRI – Economic and Social Research Institute

EU – European Union

HSE – Health Service Executive

IHREC – Irish Human Rights and Equality Commission

MESL – Minimum Essential Standard of Living

PA – Personal Assistance

SVP – St Vincentian Partnership

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

Introduction and Executive Summary

Introduction

People with intellectual disabilities have the same rights as everyone else to live full, self-directed lives as equal members of their communities. Those rights cost money; this is not because disability is costly, but because systems, services, and supports have, in Inclusion Ireland's experience, persistently fallen short. As a result, people with intellectual disabilities and their families absorb costs year after year that the State was and is obligated to meet.

Inclusion Ireland's submission draws on the *1,000 Voices* research we published in June 2025 – with direct input from over 1,000 adults with intellectual disabilities, their families, and supporters nationwide – as well as the experience of our advocacy team working with people and families on the ground.

We welcome the Department of Social Protection's consultation and the Programme for Government's commitment to a permanent Cost of Disability payment. We should also be candid, however, that the six-week consultation window – spanning St Patrick's Day and Easter – did not allow adequate time for meaningful engagement with our members or for collective discussion across the disability sector. This is why the Strategic Focus Network Summit and the wider co-design process that follows must be given time, resources, and structure. Written consultations alone cannot provide this.

Inclusion Ireland submits this response as a contribution to a process that must go further than a single round of submissions. Only this will deliver a payment that is genuinely rights-based, person-centred, and equal to the task.

Executive Summary

A whole-of-government approach with clear accountability

The costs people with intellectual disabilities carry are generated across transport, housing, health, and employment – processes that have consistently failed to include

them. A payment that compensates people for those failures is a second-best solution; the Government has the power to fix the underlying problems directly.

Inclusion Ireland is asking for:

- **A cross-departmental accountability framework, with targeted action plans and measurable outcomes, holds each relevant department responsible for reducing the barriers that generate disability-related costs.**
- **Clear oversight of how Departments beyond DSP are contributing to the CoD reduction, with progress reported publicly.**
- **Recognition that the payment and wider structural reform are both necessary – one does not substitute for the other.**

A social model, human rights approach – including reform of support models

The costs of under-resourced supports are real: exclusion, loneliness, underemployment, and constrained independence. These do not always show up in household budgets, but they show up in people's lives and in our engagement with our members. A future CoD payment must enable a different model. Designing it to simply top up an unchanged group-based system would be a missed opportunity and a broken promise.

Inclusion Ireland is asking for:

- **The payment is designed to enable access to individualised, self-directed support.**
- **Personal assistance to be placed on a statutory footing, and personalised budgets made available across all avenues of state support.**
- **The payment's design and adequacy are assessed against Ireland's obligations under UNCRPD Articles 12, 19, and 28.**

Substantive co-design to determine eligibility and differentiation

Inclusion Ireland is not proposing a specific eligibility model here. Not because we lack a view, but because proposing one responsibly requires detailed modelling and direct input

from people with intellectual disabilities. This requires long-term dialogue and meaningful participation with those impacted. Any process that tries to flatten diversity of need and profile into a single on-size-fits-all model will produce a payment that works for some and fails others.

Inclusion Ireland is asking for:

- **A structured co-design process with DPOs and people with intellectual disabilities involved from the outset, published milestones, and a commitment that eligibility and differentiation criteria will not be fixed before that process has run, in line with Article 4.3 of the UNCRPD.**
- **The DSP to publish a thematic synthesis of what disability organisations have said in recent submissions before the Summit agenda is set, so that accumulated evidence informs the conversation rather than being relitigated from scratch.**
- **The Strategic Focus Network Summit in May to mark the beginning of that process, with a clear commitment from the DSP on what comes after, who translates Summit input into design decisions, and when participants will hear back.**

Cost of Disability Payment

Purpose of the Payment

The Programme for Government explicitly commits to a permanent, annual CoD payment and to developing a mechanism to incrementally increasing it¹. Both pledges build on the Joint Committee on Disability Matters' recommendation to introduce such a payment "to achieve the same standard of living as non-disabled people and to remove existing barriers to disabled people's financial independence and inclusion in the workforce"²; the Citizens' Assembly on Gender Equality's recommendation for "person centred financial supports to serve . . . individual needs"³; and on the Government-commissioned Indecon report⁴.

Inclusion Ireland welcomes both commitments and submits this response to help ensure the design process is equal to what those commitments require in equitable, rights-based practice.

The underlying case is straightforward, even if the policy response has been a long time coming. Disabled people in Ireland carry significant additional costs that existing services and social welfare payments do not cover, and their income is rarely adequate to absorb them – especially in a labour market where Ireland's 38.2% disability employment gap remains among the widest in the EU⁵. For many people with intellectual disabilities, this is their everyday financial condition and those of their families. The costs arise from barriers which are baked in across all institutions, creating inequality, exclusion, and poverty.

¹ [Department of the Taoiseach \(23rd January 2025\), Programme for Government – Securing Ireland's Future, pg.100](#)

² [Joint Committee on Disability Matters \(3rd March 2022\), Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities, pg.120](#)

³ [Citizens' Assembly on Gender Equality \(2nd June 2021\), Report and Recommendations of the Citizens' Assembly on Gender Equality, pg.13](#)

⁴ [Indecon International Economic Consultants \(7th December 2021\), Indecon Report on the Cost of Disability Payment in Ireland, pgs.128–129](#)

⁵ [Directorate-General for Economic and Financial Affairs \(4th June 2025\), 2025 Country Report – Ireland, pg.90](#)

Inclusion Ireland's 2026 pre-budget submission, drawing on over 1,000 responses from adults with intellectual disabilities, their families, and supporters nationwide, found that:

- **66% of adults with intellectual disabilities believe that their current social welfare payments do not adequately meet their daily living costs⁶.**
- **Nearly 80% of families and supporters reported that private spending on therapies, transport, or basic supports had at least a moderate impact on their household budget⁷.**
- **Among families of children with intellectual disabilities the picture was starker: less than 2% reported no financial strain; 59% said they were cutting back in other areas; nearly one in four said they could not afford any services at all⁸.**

These findings track closely with the Government's own evidence base. Indecon found that disabled people face additional weekly costs of between €176 and €279⁹. Subsequent ESRI-IHREC analysis found that for households where a person has significant support needs, disability-related costs can reach as much as 93% of disposable income¹⁰. For families with disabled children, Indecon estimated additional annual costs exceeding €14,000¹¹.

What sits behind these figures as lived – and often daily – experiences are worth stating plainly. Inclusion Ireland's *Progressing Disability Services Patient Experience Survey* documented a family in Galway paying €80 for a 45-minute private physiotherapy session because public waiting times were indefinite¹², and another family fundraising among extended relatives to fund basic supports that HSE had not provided¹³. These are not edge

⁶ [Inclusion Ireland \(20th June 2025\), 1,000 Voices, One Message: Invest in Our Rights! – Inclusion Ireland's Pre-Budget Submission 2026, pg.16](#)

⁷ *Ibid*, pg.18

⁸ *Ibid*, pg.12

⁹ Indecon International Economic Consultants (7th December 2021), Indecon Report on the Cost of Disability Payment in Ireland, pgs.106–107

¹⁰ [Doorley, et al. \(13th March 2025\), Adjusting Estimates of Poverty for the Cost of Disability, pg.16](#)

¹¹ Indecon International Economic Consultants (7th December 2021), Indecon Report on the Cost of Disability Payment in Ireland, pg.18

¹² [Inclusion Ireland \(February 2022\), Progressing Disability Services for Children and Young People – Patient Experience Survey Report, pg.30](#)

¹³ *Ibid*, pg.26

cases; they describe a system in which families routinely finance services the State was obligated to deliver.

From Inclusion Ireland's experience working directly with people with intellectual disabilities and their families, the cost profile of intellectual disability differs from other disability types in ways that a generic payment design may not reach. People with intellectual disabilities are more likely to rely on support workers or family carers to manage daily tasks that others handle independently. Many require supported access to leisure and community activities. Communication support needs are common and frequently unmet by public provision. Navigating bureaucratic processes often requires paid support that others do not need. These are structural features of what it means to live with an intellectual disability in a process that has not been designed with that reality in mind, and they are costs Inclusion Ireland's advocacy workers encounter consistently in their direct work with the people we represent.

Nowhere is the connection between service failure and out-of-pocket cost more direct than in accessing CDNTs. Our *1,000 Voices* research found that 75% of families identified access to therapies as their top priority for their child's support¹⁴ – yet the data consistently shows families waiting indefinitely for speech and language therapy, occupational therapy, and physiotherapy that CDNT teams are not resourced to provide¹⁵. Families who cannot wait tell us they often have no recourse but fund these privately – as one Cork family was forced to after spending three years on a waiting list following an AON¹⁶. Their own expenditure is a direct and measurable cost of the State's failure to resource the CDNT model adequately. It should be recognised as such, both in this consultation and in the broader policy conversation about what a CoD payment is for.

The same dynamic operates for adults. Access to day services, and the gaps in them, shapes the entire cost picture for many people with intellectual disabilities. *1,000 Voices* found that people on reduced day service hours, or on waiting lists entirely, need

¹⁴ Inclusion Ireland (20th June 2025), *1,000 Voices, One Message: Invest in Our Rights!* – Inclusion Ireland's Pre-Budget Submission 2026, pg.8

¹⁵ *Ibid*, pg.8

¹⁶ Inclusion Ireland (2nd September 2025), Inclusion Ireland's Submission to the National Disability Authority's Review of the Children's Disability Network Teams Service Model, pg.7

alternative arrangements that cost money: transport to activities, support to access community facilities, participation in leisure or social opportunities that day services would otherwise provide¹⁷. Three in five adults with intellectual disabilities in our survey said that better housing and support would improve their lives most¹⁸. The financial costs of inadequate support are inseparable from the broader picture of exclusion. In all of this, the model of support can further create disparities which add to the real” cost” of disability which is simply exclusion from community life. The group model frequently offered to people with intellectual disabilities lead to isolation, loneliness and disconnect.

The costs a payment should address include:

- **Transport costs arising from inaccessible public services and distance from what does exist**
- **Assistive technology and communication aids; continence products and other health-related consumables not covered by existing schemes; support worker costs not met by existing personal assistance provision**
- **The costs of accessing community life that day services do not cover.**

A CoD payment addresses the financial gap while wider service failures are being addressed. It does not replace the obligation to fund services properly, and it should not be designed or presented as though it does. Families paying privately for therapies their children were entitled to receive free of charge need both things addressed: the service gaps that created the expenditure, and financial support for the costs already incurred. Framing the payment as a substitute for service investment would be a misrepresentation of what it can do. This is also true of the availability of personal assistance. If people with intellectual disabilities had access to more individualised, community bases supports, their ability to access community and natural supports would be greatly enhanced. A change of model is urgently required so that the real costs of exclusion are taken seriously.

¹⁷ Inclusion Ireland (20th June 2025), 1,000 Voices, One Message: Invest in Our Rights! – Inclusion Ireland’s Pre-Budget Submission 2026, pg.21

¹⁸ *Ibid*, pg.19

People with intellectual disabilities are too often offered group-based models. These may include day services, residential arrangements, and congregated settings. In such models, individual goals are subordinated to group logistics and people are often forced to compete for support. When someone must wait for a place in a group service, or reshape their ambitions around what that service can accommodate, the costs go beyond finances. Individual around independent living, employment, and community participation become harder to realise, often followed by isolation, loneliness, and underemployment. A genuinely person-centred approach starts with the person and builds support from there. It is grounded in citizenship, belonging, and the right to live as a full member of one's community. Models like PA and personalised budgets give disabled people – including those with intellectual disabilities – the financial autonomy and flexibility to shape their own lives¹⁹. A well-designed disability payment could help enable that shift. But if designed as a top-up to an unchanged group-based system, it risks reinforcing the structural inequality it was meant to address.

As of April 2026, the maximum annual Disability Allowance of €13,208 falls more than €5,800 below the AROPE threshold of €19,060²⁰. The ESRI-IHREC analysis found that, once disability-related costs are factored in, between 65% and 76% of disabled people are living below the poverty line²¹. That is a disability-wide figure; for people with intellectual disabilities, who face unemployment rates of 29.4% compared with 33% across disability profiles generally²², and who encounter some of the most pervasive barriers to financial independence of any group, the reality is likely considerably worse. These figures are not consistent with Ireland's duties under UNCRPD Article 28, which requires the State to take concrete steps – including through targeted financial supports – to ensure an adequate standard of living for disabled people²³.

¹⁹ [Department of Health \(11th June 2019\), Advice Paper on supports to apply for and use personalised budgets, pgs.3–4](#)

²⁰ [Central Statistics Office \(11th March 2026\), Survey on Income and Living Conditions \(SILC\) 2025 – Impact of Cost-of-Living Measures on Poverty and Income](#)

²¹ Doorley, et al. (13th March 2025), Adjusting Estimates of Poverty for the Cost of Disability, pg. i

²² [National Disability Authority \(November 2024\), NDA Factsheet: Employment and Disability, pg.10](#)

²³ [United Nations \(13th December 2006\), Convention on the Rights of Persons with Disabilities, Article 28 – Adequate standard of living and social protection](#)

Expansion of existing supports should be considered alongside any new payment. Extending the Fuel Allowance to cover all disability-related social protection payments and recognising the disproportionately high energy costs faced by people reliant on assistive technology or 24-hour care, would address a specific and recurring pressure that a general payment may not reach adequately.

Inclusion Ireland supports the introduction of the payment. The evidence that it is needed has existed since at least 2021. The question now is whether the design process will be adequate to the task.

How would the Government decide which people would qualify for a Cost of Disability payment?

This is where the consultation will succeed or fail. Draw eligibility too narrowly and the payment misses large numbers of people who need it. Design the assessment process carelessly and it recreates the medicalised gatekeeping. Get the means-testing model wrong and it embeds further financial disincentives into a framework already full of them, doing active harm to the people it was meant to support.

Inclusion Ireland's position is that the answer to these risks is a properly structured co-design process with a committed and public timeline – not a shortcut to design decisions that can then be adjusted later.

The limits of an existing-recipient model

Restricting eligibility to people already in receipt of a disability-related payment has administrative simplicity on its side and would reach many people with intellectual disabilities currently on Disability Allowance. The problems are real, however. It would exclude people who are in work, people who have achieved some degree of financial independence, and people who have never engaged with the social welfare system – including those with perceived lower support needs who still face significant disability-related costs. It would also risk entrenching disincentives that already do considerable damage. Inclusion Ireland's submission on the successor to the Pathways to Work initiative sets out in some detail how the interaction between Disability Allowance,

secondary benefits, and employment income discourages people with intellectual disabilities from entering or maintaining work²⁴. A payment structured as a welfare top-up, available only to those outside employment, only compounds that problem.

A wider approach: genuine complexity, not an excuse for delay

Extending eligibility beyond existing recipients raises problems without ready solutions: how a broader group would be identified, and through what mechanism their entitlement would be confirmed. Inclusion Ireland is not proposing to answer those questions in this submission, and submissions that suggest the answers are straightforward are not engaging honestly with the difficulty.

An assessment process that requires disabled people to demonstrate the extent of their deficits to access a payment would be the wrong approach. The CRPD Committee's List of Issues in Ireland raised specific concerns about the State's continued use of medicalised and deficit-based frameworks²⁵, and recommended a shift toward functional, rights-based approaches consistent with the Convention²⁶. Any eligibility mechanism needs to be designed with that criticism directly in view.

For people with intellectual disabilities, there is an additional dimension that the design process must address explicitly – the accessibility of the process itself. If the eligibility mechanism requires individuals to self-identify, gather documentation, complete forms, and pursue review or appeal processes unaided, people with intellectual disabilities will be disproportionately excluded in practice regardless of what the criteria say in principle. Many people with intellectual disabilities, particularly those without strong family support networks and/or who are nonspeaking, will need assisted application processes, Easy Read materials, adequate time, and the right to have an advocate or support person involved at every stage. The ADMCA establishes a legal framework for supported decision-making that any new eligibility process must be consistent with²⁷. Accessibility

²⁴ Inclusion Ireland (30th September 2025), Inclusion Ireland's Submission to the Department of Social Protection's Public Consultation on the Successor to the Pathways to Work 2021–2025, pgs.12–13

²⁵ [UN Committee on the Rights of Persons with Disabilities \(23rd December 2025\), List of issues in relation to the initial report of Ireland CRPD/C/IRL/Q/1, para.33](#)

²⁶ *Ibid*, para.34

²⁷ [Assisted Decision-Making \(Capacity\) Act 2015, s.8](#)

of process is a core condition of a fair system for our community and must be built into the design from the outset.

The DSP should not reach these decisions alone. Article 4.3 of the UNCRPD obligates the State to closely consult with and actively involve DPOs in developing policy and legislation that affects disabled people²⁸. A public consultation does not discharge that obligation. **Inclusion Ireland is asking the Department to publish a co-design plan – setting out how DPOs, advocacy or representative organisations and disabled people, including people with intellectual disabilities, will be involved in developing the eligibility framework – before design decisions are taken. The timeline for establishing that process, not the complexity of the questions, is what needs to be kept tight.**

Means testing and financial autonomy

Inclusion Ireland is not taking a fixed position on universality versus a targeted approach at this stage and believe it requires further deliberation. There are, however, conditions any means-testing model would need to meet.

Disability-related costs do not diminish when someone enters employment. Indeed, in many cases they increase, as people incur travel, equipment, assistive technology, and other work-related costs on top of what was already there. A payment that reduces or disappears on employment, or that is income-tested against wages rather than against disability-related expenditure, functions as a tax on work for a group that already faces extraordinary barriers to employment. With an unemployment rate of over 29%, people with intellectual disabilities have the most to lose from a payment design that treats work as a reason to reduce support.

Parental and spousal income is a separate and more specific problem for our community. A CoD payment is directed at costs incurred by the disabled person. Means-testing it against parental income treats adults as financially merged with their household – an

²⁸ [United Nations \(13th December 2006\), Convention on the Rights of Persons with Disabilities, Article 4 – General Obligations](#)

approach that cuts against UNCRPD Articles 12²⁹ and 19³⁰, which recognise the right to legal capacity, financial autonomy, and independent living. Many adults with intellectual disabilities are likely to be living in the family home, less likely to have independent income, and more likely to have their financial affairs managed informally by a parent or sibling. Means-testing against parental income in that context does not simply raise a rights concern in the abstract. It specifically targets a group least likely to have achieved financial independence and treats that dependency as a reason to limit entitlement to a payment designed to address their costs.

The dependency itself is, in large part, a consequence of policy failure. Our *1,000 Voices* survey found that 44% of adults with intellectual disabilities who want to leave the family home cannot do so because the necessary supports are not in place³¹. The National Housing Strategy for Disabled People 2022–2027 commits to supporting disabled people to live with choice in the community³². The Action Plan for Disability Services 2024–2026 commits to expanding personal assistance and supported living³³. A CoD payment that applies a parental income test is difficult to reconcile with either of those commitments.

The interaction with other means-tested supports is worth flagging separately. Housing adaptation grants, student grants, personalised budgets, and other existing supports each carry their own income calculations. **A new eligibility framework needs to be modelled against the existing system to identify whether it would inadvertently reduce access to other supports or create new financial cliff edges for people already navigating significant complexity.**

Process as the substantive ask

People are already bearing these costs. The gap between the publication of *Indecon* in 2021 and this consultation in 2026 makes that clear enough. **Inclusion Ireland is asking**

²⁹ *Ibid*, [Article 12 – Equal recognition before the law](#)

³⁰ *Ibid*, [Article 19 – Living independently and being included in the community](#)

³¹ Inclusion Ireland (20th June 2025), *1,000 Voices, One Message: Invest in Our Rights!* – Inclusion Ireland’s Pre-Budget Submission 2026, pg. 19

³² [Department of Housing, Heritage and Local Government \(14th January 2022\), National Housing Strategy for Disabled People 2022 – 2027, pg. 11](#)

³³ [Department of Children, Equality, Disability, Integration and Youth \(14th December 2023\), Action Plan for Disability Services 2024–2026, pg. 11](#)

for a co-design structure with published milestones, DPOs, self-advocates and advocacy organisations involvement from the outset, and a commitment that eligibility criteria will not be settled before that process has run.

How should the payment amount be decided?

Before setting a payment level, the DSP must clarify what type of payment is being considered. A CoD payment is distinct from income support; treating one as the other would repeat a core mistake of the Green Paper on Disability Reform. Inclusion Ireland's response to the Green Paper's public consultation highlighted this conflation as a priority concern for our members³⁴. The money needed for daily living is generally consistent regardless of disability and should guide the setting of an adequate income rate. Extra costs stemming specifically from disability vary by individual and reflect unmet support needs; they require a separate solution. If a CoD payment simply increases or supplements Disability Allowance, it does not adequately address these distinct needs.

Payment amounts should not vary based on who is perceived as more or less disabled. They should vary based on the specific costs and barriers each person faces.

Payment Level

The UNCRPD's List of Issues on Ireland report flagged the Programme for Government's commitment to a permanent CoD payment annually as something it will monitor under Article 28³⁵, and explicitly requested information on measures to ensure Disability Allowance provides an adequate standard of living³⁶. The matter of payment adequacy will therefore form part of the State's next UNCRPD reporting cycle.

The evidence on what adequacy requires is stark. The ERSI-IHREC study found that households with a disability face an additional weekly cost of €488 to €555 on top of

³⁴ Inclusion Ireland (April 2024), Submission on the Green Paper on Disability Reform: A Public Consultation to Reform Disability Payments in Ireland, pg.7

³⁵ UN Committee on the Rights of Persons with Disabilities (23rd December 2025), List of issues in relation to the initial report of Ireland CRPD/C/IRL/Q/1, para.26(b)

³⁶ *Ibid*, para.26(b)

standard minimum living expenses³⁷, and that minimum has itself risen by 18.8% since 2020³⁸, meaning earlier estimates of disability-related costs are now significantly out of date. Of 145 social welfare test cases analysed by the SVP's latest MESL research, 133 came in below the minimum income needed for a dignified life³⁹. One in five people unable to work due to disability lives in consistent poverty, against roughly one in twenty in the general population⁴⁰.

A starting rate of at least €50 per week should be understood as a base rate floor and a minimum first step. Against a weekly disability cost surcharge of €488 to €555, it is a signal of intent rather than a solution and should be presented as such – with a statutory mechanism for incremental increases reviewed regularly against MESL data built in from the outset. The Programme for Government commits to an incremental approach; Inclusion Ireland is reiterating our ask that the commitment be given legislative teeth⁴¹.

Differentiation

The 41–93% range in extra income required by households with a disabled member⁴² makes clear why a flat rate cannot work. A single figure will always underserve those at the higher end.

The question is what differentiation should be based on. Tiering linked to perceived capacity to work is not workable. Ireland has one of the widest disability employment gaps in the EU at 38.2%⁴³, compared with the EU average of 24%⁴⁴. That gap reflects an inaccessible labour market, not individual incapacity. The UNCRPD Committee's List of Issues specifically sought information on measures to remove social protection

³⁷ Doorley, et al. (13th March 2025), Adjusting Estimates of Poverty for the Cost of Disability, pg.25

³⁸ [Thornton, et al. \(17th June 2025\), MESL 2025 Report, pg.23](#)

³⁹ *ibid*, pg.36

⁴⁰ [Disability Federation of Ireland \(20th January 2026\), Factsheet: Cost of Disability – The Lived Reality](#)

⁴¹ Inclusion Ireland (20th June 2025), 1,000 Voices, One Message: Invest in Our Rights! – Inclusion Ireland's Pre-Budget Submission 2026, pg.24

⁴² Doorley, et al. (13th March 2025), Adjusting Estimates of Poverty for the Cost of Disability, pg.16

⁴³ Directorate-General for Economic and Financial Affairs (4th June 2025), 2025 Country Report – Ireland, pg.90

⁴⁴ [European Commission, \(27th May 2025\), 'Employment gaps for women & people with disabilities'](#)

disincentives that limit access to employment⁴⁵. A CoD payment that reduces employment would add a new one.

Differentiation should be based on actual extra costs and access barriers, determined by what each person needs to fully participate. That cannot be pre-determined; it must be co-designed with disabled people and their representative organisations, in line with the Social Model of Disability, addressing barriers rather than further stigmatising or reinforcing negative stereotypes. Inclusion Ireland's members said it plainly during the Green Paper consultation process: poorly designed tiering leaves people feeling classified by their limitations, not their needs⁴⁶.

International Context and Lessons

Three examples are briefly worth noting. The UK's **Personal Independence Payment** – a tiered, assessment-based payment – has drawn extensive criticism for its high appeal rates⁴⁷, significant administrative burden⁴⁸, and disproportionate exclusion of people with intellectual disabilities who struggle to demonstrate need in standard assessment conditions⁴⁹. It is the clearest available illustration of what a deficit-based design produces in practice⁵⁰.

Scotland's **Adult Disability Payment**, developed partly in response to PIP's shortcomings⁵¹, asks what help a person needs rather than what they can or cannot do⁵².

⁴⁵ UN Committee on the Rights of Persons with Disabilities (23rd December 2025), List of issues in relation to the initial report of Ireland CRPD/C/IRL/Q/1, para.26(c)

⁴⁶ Inclusion Ireland (April 2024), Submission on the Green Paper on Disability Reform: A Public Consultation to Reform Disability Payments in Ireland, pgs.6 and 9

⁴⁷ According to a Ministerial response to a Written Parliamentary Question submitted in March 2025 ([UIN 39207](#)), the the PIP appeal overturn rate was 67%. As of the time of writing, this has decreased slightly to 64% ([Department of Work and Pensions, 17th March 2026](#)).

⁴⁸ [Cordis Bright \(16th May 2025\), Research study on the additional costs of living with a learning disability, pg.52](#)

⁴⁹ *Ibid*, pg.51

⁵⁰ [Mencap research \(18th June 2025\)](#) shows that 70% of people with intellectual disabilities would need to cut down on food if they lost their PIP, 60% said they would need to cut back on heating, and 45% feared they would be unable to leave their homes.

⁵¹ [Social Security Directorate \(31st July 2025\), Independent Review of Adult Disability Payment – Final Report, pg.89](#)

⁵² [Scottish Health Equity Research Unit \(29th November 2024\), New Awards of Disability Benefits for Adults – Comparing Scotland with England and Wales](#)

This framework is more consistent with the right-based approach Inclusion Ireland is advocating.

France's **Disability Compensation Benefit** (*prestation de compensation du handicap*, PCH) operates as a personalised payment separate from Disabled Adults' Allowance (*allocation aux adultes handicapés*, AAH) and Disabled Child Allocation Allowance (*allocation d'éducation de l'enfant handicapé*, AEEH), calculated around specific costs rather than as income replacement⁵³. It can also be paid to disabled children under 18 years of age who satisfy the criteria for the award of the AEEH and its complement, as part of the right to choose between the additional AEEH and the PCH⁵⁴. It is a structural illustration of the income/compensation distinction this response has set out.

How should the Payment work?

Periodic, not annual

A regular periodic payment, whether weekly or monthly, best reflects how disability-related costs actually arise. Transport, support worker hours, therapies, equipment maintenance, and the daily costs of participating in community life do not arrive once a year. The Carers Support Grant illustrates what an annual disability-related payment looks like in practice: useful as a contribution, but too infrequent to meet costs that arise every week⁵⁵. For people with intellectual disabilities, a periodic payment also reduces the financial management challenge posed by a large annual lump sum. **From Inclusion Ireland's direct experience working with people with intellectual disabilities and their families, many manage household finances on a weekly basis and would need supported budgeting to deploy a single annual payment effectively; support the current process does not routinely provide.**

⁵³ [Directorate-General for Employment, Social Affairs and Inclusion \(July 2025\), Your Social Security Rights in France, pg.14](#)

⁵⁴ *Ibid*, pg.14

⁵⁵ [Family Carers Ireland \(3rd July 2025\), Ensuring No One Has to Care Alone, pg.11](#)

Supported financial management

A direct cash payment assumes the recipient can independently manage and deploy funds. For people with intellectual disabilities – particularly those without strong family or advocate support – this requires specific design consideration that the DSP has not yet adequately addressed. Any new payment mechanism must be consistent with the ADMCA framework, which means embedding accessibility to supported financial management where a person needs it. This is not an argument for voucher systems or restricted spending mechanisms, which would undermine the financial autonomy that the payment is meant to support. **It is an argument that the right to receive and manage a potential cash payment must be genuinely accessible, and that for our community, accessibility requires active co-design rather than assumption.**

Removing employment disincentives

The UNCRPD Committee's List of Issues specifically sought information on measures to remove social protection disincentives that prevent or limit access to employment for disabled people, including implementation of the 2017 Make Work Pay report's recommendations⁵⁶. Those recommendations remain substantially unimplemented nearly a decade on. The mechanics of this payment offer a direct opportunity to act on them.

A payment that reduces or disappears when a person enters employment is not a CoD payment – it is a poverty trap with a different name. The costs a person with an intellectual disability carries do not diminish with employment. In fact, in many cases, they increase: transport to work, workplace supports, communication assistance, and the additional costs of participating in a working environment not designed with them in mind. The payment should remain at the base rate when a person takes up work, with any adjustment based on the actual cost change rather than employment status. Anything less compounds the structural barriers the Make Work Pay report identified, rather than addresses them.

⁵⁶ UN Committee on the Rights of Persons with Disabilities (23rd December 2025), List of issues in relation to the initial report of Ireland CRPD/C/IRL/Q/1, para.26(c)

On the design process

Inclusion Ireland is not in a position to propose a definitive payment model in this submission. A consensus has yet to be reached among the wider disability sector and the DSP on how universality, targeting, and varying levels of need can be reconciled in a workable design. Those questions require detailed modelling, adequate funding information, and a genuine co-design process with disabled people before responsible answers are possible.

The Strategic Focus Network Summit in May should mark the beginning of that process, not its conclusion. **Inclusion Ireland urges the DSP to treat the Summit as the opening of a structured co-design process – with DPOs and disabled people, including people with intellectual disabilities, involved in shaping recommendations from the outset – rather than as a mechanism for validating positions already formed.**

Strategic Focus Network Summit on the Cost of Disability

What Issues should the Summit examine?

The Summit agenda should address the design questions this consultation has raised but not resolved. Inclusion Ireland's priorities are:

- **How eligibility is determined and by whom.**
- **The distinction between income support and compensation for disability-related costs, and its impact on payment design.**
- **How differentiation can reflect actual costs and barriers rather than capacity to work.**
- **How employment disincentives are removed rather than replicated.**
- **How the payment interacts with existing supports without creating new cliff edges.**

The Summit should also address the critical issue of what specific model of support is the payment intended to enable. A payment designed to offset the costs of group-based provision functions differently from a payment intended to facilitate personalised, community-based support tailored to each individual. This distinction is fundamental, affecting the payment's design, its adequacy assessment, and whether it advances a rights-based support framework or simply perpetuates the current one. Citizenship, belonging, and community participation must be central focuses of the Summit and the wider development process of the payment.

Format

Inclusion Ireland recommends that DSP consult directly with the DEY about their experience organising the National Convention on Education's recent first session, which used small-group table discussions to make complex topics more accessible.

Key recommendations for the Summit format are as follows:

- Adopt a deliberative small-group table format rather than a plenary lecture structure, so that people with intellectual disabilities can engage with the substance of discussions rather than observing them.
- Employ graphic facilitators to map discussions in real time using icons and simple phrases, allowing people with intellectual disabilities who do not communicate primarily through text to follow the logic of debate as it develops and to point to images when expressing their views.
- Structure graphic recordings around the main cost-of-disability themes so participants can engage with the substance directly.
- The DSP should consult with the DEY before the Summit is designed about the practicalities of making this approach work.

Inclusion Ireland's Farrelly Commission report showed how non-speaking participants and those with high support needs are excluded from formal processes when specialist communication support is absent⁵⁷. Three actions are needed:

- Fund independent communication partners to accompany participants with intellectual disabilities who need them
- Brief facilitators clearly on the communication partner role: they help the person express their own will and preference when the pace of discussion accelerates.
- Define and circulate the communication partner role in advance so that facilitators, department officials, and other participants understand it.

On accessible materials and preparation:

- Circulate Easy Read materials covering the key issues and the Summit's purpose well in advance, with enough lead time for people with intellectual disabilities and their supporters to prepare.
- Provide a brief, accessible explainer on each agenda item, so participants are not encountering the issues for the first time on the day.
- Ensure a dedicated information desk is staffed by department officials who can answer questions in plain language throughout the event.

On financial and logistical barriers:

- Provide a stipend for a lived experience or, for disabled people contributing to the design of a major social protection payment, bringing expertise, and should be resourced as such. At minimum, DSP should provide prepaid accessible transport (taxis or vouchers) for attendees with intellectual disabilities; a participation stipend is the stronger option.
- Participants – especially those with intellectual disabilities – must know how their input will shape outcomes, who will make decisions, and when they will receive feedback. DSP should commit in advance to publishing a clear account of how

⁵⁷ [Inclusion Ireland \(30th September 2025\), The Right to Justice and Participation: Lessons from the Farrelly Commission, pgs.8–9](#)

Summit contributions influenced payment design, with a specific timeline. Without this, the Summit will be a formality.

One day will not settle these challenges. The Summit's role is to establish who is involved, on what terms, and toward what end, and to signal clearly that this process will be different from the Green Paper.

About Inclusion Ireland

Inclusion Ireland is the national organisation advocating for the rights and inclusion of people with intellectual disabilities. We work to influence policy and practice through rights-based advocacy, accessible information, and direct engagement with people with intellectual disabilities, their families, and key decision-makers. Our work is grounded in the values of equality, dignity, and self-determination, guided by the principles of the UNCRPD. We are committed to building a society where people with intellectual disabilities can live independently, participate equally in community life, and enjoy the same rights and opportunities as everyone else.

Our work is supported by:



Rialtas na hÉireann
Government of Ireland



Inclusion Ireland

The National Association for People
with an Intellectual Disability.

Unit C 2, The Steelworks, Foley Street, Dublin 1

01 8559891

info@inclusionireland.ie

inclusionireland.ie

