Inclusion Ireland

The National Association for People with an Intellectual Disability.

Our Rights, Our Voices.

Building an Ireland where everyone belongs: 1,500 voices for inclusion

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InclusionIreland.ie

A note from our CEO

Derval McDonagh, CEO, Inclusion Ireland

Welcome to our pre budget submission for Budget 2027.

1,500 people with intellectual disabilities and their families shared their stories. They told us about the daily exclusion and discrimination they face in education, housing, health, and their standard of living. Importantly, they told us what matters most to them: community, connection, and belonging.

One budget cycle alone will not remedy the deep-rooted inequities, but it is the Government's strongest annual signal of its priorities and values. Our submission makes it undeniable what people are demanding and what needs immediate action. Our community demands rights-focused, person-centred, community-based supports for all.

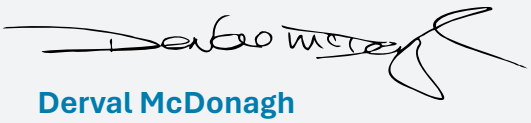
It's easy to get sidetracked by competing priorities, but disabled people and their families have waited long enough. Every single cent invested this year should go towards upholding people's rights. Every single cent should be invested in including people in their local communities.

The dark days of our institutionalised past must end now. Our community must be able to expect to attend their local school, receive health and social care when needed, have a decent quality of life above the poverty threshold, and live independently, connected to friends, family, and loved ones. This is not an impossible dream in today's Ireland; it is a fundamental expectation.

In Budget 2027, we want to see:

- Investment in planned housing and supported living
- Investment in children and families in the early years
- Investment in inclusive education
- Investment in removing barriers to a decent standard of living

For months, countless media stories have exposed the daily struggles people face as they fight for what many take for granted. Inclusion can wait no longer, and our community's voices will be heard.



Derval McDonagh
CEO Inclusion Ireland

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Abbreviations and Acronyms

AON	Assessment of Need
CAMHS-ID	Children and Adolescent Mental Health Services for Intellectual Disabilities
CDNT	Children's Disability Network Teams
DCDE	Department of Children, Disability and Equality
DHLGH	Department of Housing, Local Government and Heritage
DPO	Disabled Persons' Organisation
DSP	Department of Social Protection
EPSEN	Education for Persons with Special Educational Needs
ERSI	Economic and Social Research Institute
HIQA	Health and Information Quality Authority
HSE	Health Service Executive
IHREC	Irish Human Rights and Equality Commission
MESL	Minimum Essential Standard of Living
NCSE	National Council for Special Education
NHRSDP	National Human Rights Strategy for Disabled People 2025–2030
NHSDP	National Housing Strategy for Disabled People 2022–2027
SSHA	Summary of Social Housing Assessments
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Introduction and Executive Summary

From April to May 2026, Inclusion Ireland conducted a series of nationwide consultations to inform our Pre-Budget Submission for Budget 2027. Under the title *Our Rights, Our Voices*, three online surveys gathered the experiences of adults with an intellectual disability, families and supporters of adults with an intellectual disability, and parents and guardians of children with an intellectual disability.

The surveys build directly on our *1,000 Voices* consultation from 2025, using updated questions designed to allow year-on-year comparison. Where similar questions were asked in both years, we have tracked what has changed and what has not. On the measures that matter most, the picture has not improved. On several occasions, it has worsened, in fact.

The findings below reveal unmet needs across income, housing, timely supports, education, and the right to be heard. They show a persistent gap between what the State promises and what people with intellectual disabilities and their families actually encounter in their daily lives. The State promises these commitments through the Programme for Government, the National Human Rights Strategy for Disabled People 2025-2030, the National Housing Strategy for Disabled People 2022-2027, the Action Plan for Disability Services 2024-2026, and Ireland's obligations under the UNCRPD and UNCRC. The findings also respond to the UN Committee on the Rights of Persons with Disabilities' List of Issues for Ireland report, which raises concerns across many of the same areas.

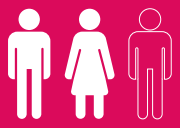
Our vision remains an inclusive Ireland where people with an intellectual disability are supported to live and participate as full and equal members of their communities. Budget 2027 is the opportunity to take clear, decisive action to close the distance between this vision and reality. We urge the Government to implement targeted measures that directly address the needs identified in our survey findings.

Executive summary

3/5
still live in the family home

Three in five adults with an intellectual disability still live in the family home – and fewer than one in five of those who want to move have a plan: 63% of adults said they still live with family. Among those living with family who want a home of their own, 35% want to move but lack the support to do so; only 19% have a plan in place.

2/3
say their social welfare payments are not enough



Two in three adults with an intellectual disability say their social welfare payments are not enough to meet their everyday needs – a figure that has not changed in two years: More than half (52%) reported disability-related costs not covered by their payments at all. Post-Budget 2026, nothing has replaced these supports. Adults told us that better social welfare payments, more money of their own, and the means to take part in their communities would most improve their lives.

1/3
of families with a child with an intellectual disability cannot afford services

Over a third of families with a child with an intellectual disability now say they cannot afford the services their child needs – up from one in four a year ago: 36% say they cannot afford essential disability-related services, compared with 24% in 2025. More than nine in ten (92%) report uncovered disability-related costs. Three in four (76%) privately fund therapies that they believe should be State-provided. Almost six in ten (59%) have reduced their working hours or taken time off to fill support gaps.

76%
of families prioritise accessing therapies

Most families now wait for therapies, not assessments – and the Assessment of Need backlog has grown by 42% in a year: Less than 2% of parents and guardians prioritised accessing an AON alone, compared with 76% who prioritised accessing therapies for CDNT support – unchanged since 2025. Almost two in three families (64%) reported that delays in HSE and CDNT services over the past year significantly or very significantly impacted their child or household.

81%
of respondents feel the Government doesn't listen

Across all three groups, most people do not believe the Government listens to them about Budget choices – and the proportion has grown: In 2025, 78% disagreed that the Government listens to their voices in making Budget decisions. In 2026, across all three groups surveyed, an overwhelming 81% of respondents feel the Government doesn't listen to them, with 93% among parents and guardians, 83% among families of adults, and 58% among adults with an intellectual disability.

Acknowledgements

This submission was made possible by the generosity of those across the country who took the time to fill out our surveys. For many, this meant sharing deeply personal and sometimes painful experiences. They trusted Inclusion Ireland to carry their experiences accurately and candidly into conversations with policymakers, and to centre the voices of people with intellectual disabilities and their families in everything we ask for. We are grateful to each and every one of them.

We also thank our colleagues and partner organisations across the Irish disability sector and beyond, who helped us reach them and the supporters who helped adults with intellectual disabilities complete the survey and have their voices counted alongside their peers.

This submission also draws on data gathered through Parliamentary Questions and Committee sessions by members of the Oireachtas. They have worked to secure and publicise information about the lives of people with intellectual disabilities that is not always captured in official reporting and is otherwise difficult to access. Their contributions have been essential to what this submission can say.

KEY INSIGHT

▲ up 3% from 2025

81% of people don't believe that the Government listens to their voices in decisions made about the Budget. This is an increase of 3% from our 2025 survey.

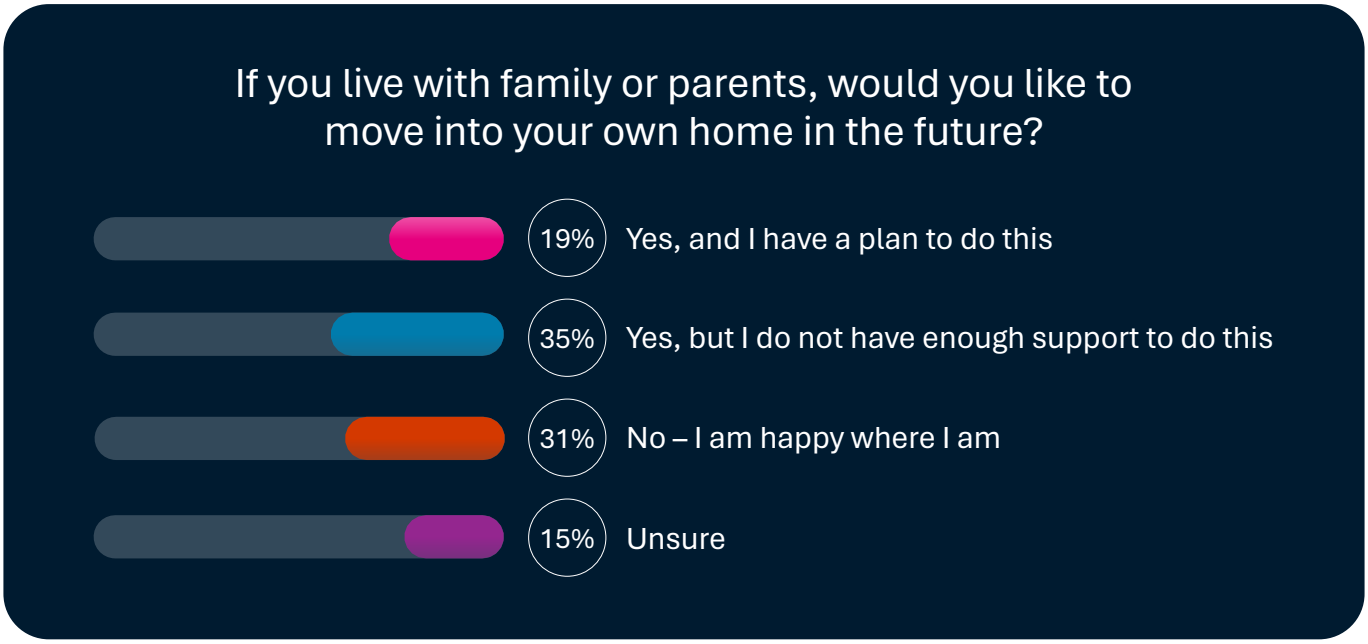
Adults with Intellectual Disabilities

In our national survey for 2026, we asked adults with an intellectual disability directly about their lives: where they live, what they spend their money on, what would make their lives better, and whether they feel listened to. 301 adults completed the questionnaire, one of the largest groups Inclusion Ireland has surveyed directly to date. Their answers, alongside those of their families and supporters, clearly show where the gap between policy commitments and lived reality is widest. This section leads with their own words because the rights at stake – to live independently and be included in the community, to an adequate standard of living, and to be heard in decisions that affect them – are theirs to vindicate[1].

A home of one's own

The most striking finding from our 2026 survey is how few adults with an intellectual disability have been supported to move into a home of their own. **Almost two in three (63%) still live in the family home, while 22% live in a supported living arrangement and only 12% live in their own home,** whether rented or owned. The responses from families and supporters tell the same story from the other side: across that survey, 74% reported that the adult they support lives with family.

[1] United Nations (13th December 2006), Convention on the Rights of Persons with Disabilities, Articles 19 (living independently and being included in the community), 28 (adequate standard of living and social protection), and 12 (equal recognition before the law).



Among adults living with family who want a home of their own, the desire is there yet the support is not: **35% want to move but lack enough support, while only 19% have a plan in place**[2] [3]. The contrast with families' views is worth noting.

> *Better plan and supports entering into adulthood and cost of living as there's not much information which cause anxiety and fear... Live with family but don't want to live with them forever, want my own house near them... The money I receive isn't enough given how much the cost of living is...*
>
> **Adult with an intellectual disability**

[2] This question was answered by adults currently living in the family home. The proportion with a plan in place to move was highest among those aged 45 to 54 (39%), the point at which ageing parents and the question of future care become most pressing.

[3] The proportion living in the family home falls as people get older – from more than nine in ten aged 18 to 24 to around four in ten aged 55 and over – but it falls slowly and without a plan.

Adults reported active planning to move at roughly four times the rate their families and supporters credited them with. Families consistently reported the desire to move but may underestimate the planning their adult son or daughter were already doing[4].

What adults want from a home is often overlooked in policy discussions. Irish policy often treats independent living as living alone with support[5], but survey responses show this is a minority preference. Only 18% of adults said living alone with support is important. Far more named **feeling safe (61%), living near friends and family (58%), living close to needed things, living with people they like (both 49%), and being part of a community (45%)**[6]. The families and supporters survey showed the same pattern, with proximity to family and community ranking far above individual living[7].

Feeling safe is the most frequently named priority. Among adults in supported living, it rises to 78%, compared with 58% living with family and 54% in their own home[8]**.** We do not draw a firm conclusion, but these findings warrant further examination. It may indicate that supported living settings do not always feel as safe as the family home, or that adults with higher safety needs are more likely to be placed in supported living. Either way, these insights highlight the importance of designing and resourcing person-centred supported living so safety is meaningfully felt rather than merely assumed.

[4] In the families and supporters survey, 6% reported that a plan was in place for the person they support to move, against 19% of adults reporting the same for themselves

[5] Brennan, D., et al (14th July 2022), 'Irish social policy to family carers of adults with an intellectual disability: A critical analysis', Journal of Intellectual Disabilities, 27(4)

[6] Question allowed multiple responses; percentages do not sum to 100%.

[7] Families and supporters identified living near family (79%), living near amenities (77%), and living in a community the person is part of (60%) as the most important features of a home, against 38% who identified living alone with support.

[8] Cross-tabulation of housing priorities by current living arrangement, *Our Rights, Our Voices* survey (Adults with an Intellectual Disability; May 2026).

Delivery has not matched commitments to create clear pathways for disabled people to access housing and independent living services. SSHA data for 2024 shows that nearly 2,000 households cite intellectual disability as their primary housing need, marking an 18% increase in one year[9]. Separate research shows that the number of social housing applicants with an intellectual disability rose from 4% to 6% between 2016 and 2021[10]; yet Budget 2026 covers only a fraction of the growing need. Many adults left waiting are those whose ageing parents can no longer provide support. To address this, Budget 2027 should allocate funding to implement the specific pathways and cross-departmental structures promised[11], ensuring that adults seeking a home of their own can access one.

The consequences of this gap are starkest for those in institutional settings. Around 1,200 people with an intellectual disability remain in HSE-designated congregated settings[12], and another 1,209 under 65 live in nursing homes – most over age 50[13]. These are adults living in settings intended for older people, often decades before they would otherwise need them, because the State has not provided the community alternatives it committed to. The scale of institutional provision still permitted to operate is wider still: HIQA records nearly 2,000 disabled people in congregated arrangements across the wider system as of January 2026[14]. The UN Committee's List of Issues report for Ireland signals concern at the pace of change, seeking clear timelines and independent measures of progress on deinstitutionalisation[15]. Budget 2027 must respond with funding and fast-tracked community alternatives, so that every adult with an intellectual disability can choose where and with whom they live.

[9] The Housing Agency (23rd April 2025), Summary of Social Housing Assessments 2024: Key Findings, pg.36

[10] Bairéad, C and Norris, M (22nd August 2025), Demographic and Socio-Economic Profile of Applicants for Social Housing and Recipients of Housing Assistance Payment, pg.72

[11] NHSDP Theme 2 (14th January 2022; pg.61) sets out outcomes "relating to the improvement of effective collaboration between local authorities and the HSE, better inter-departmental cooperation, aligning housing and support services and the sharing of relevant information between agencies."

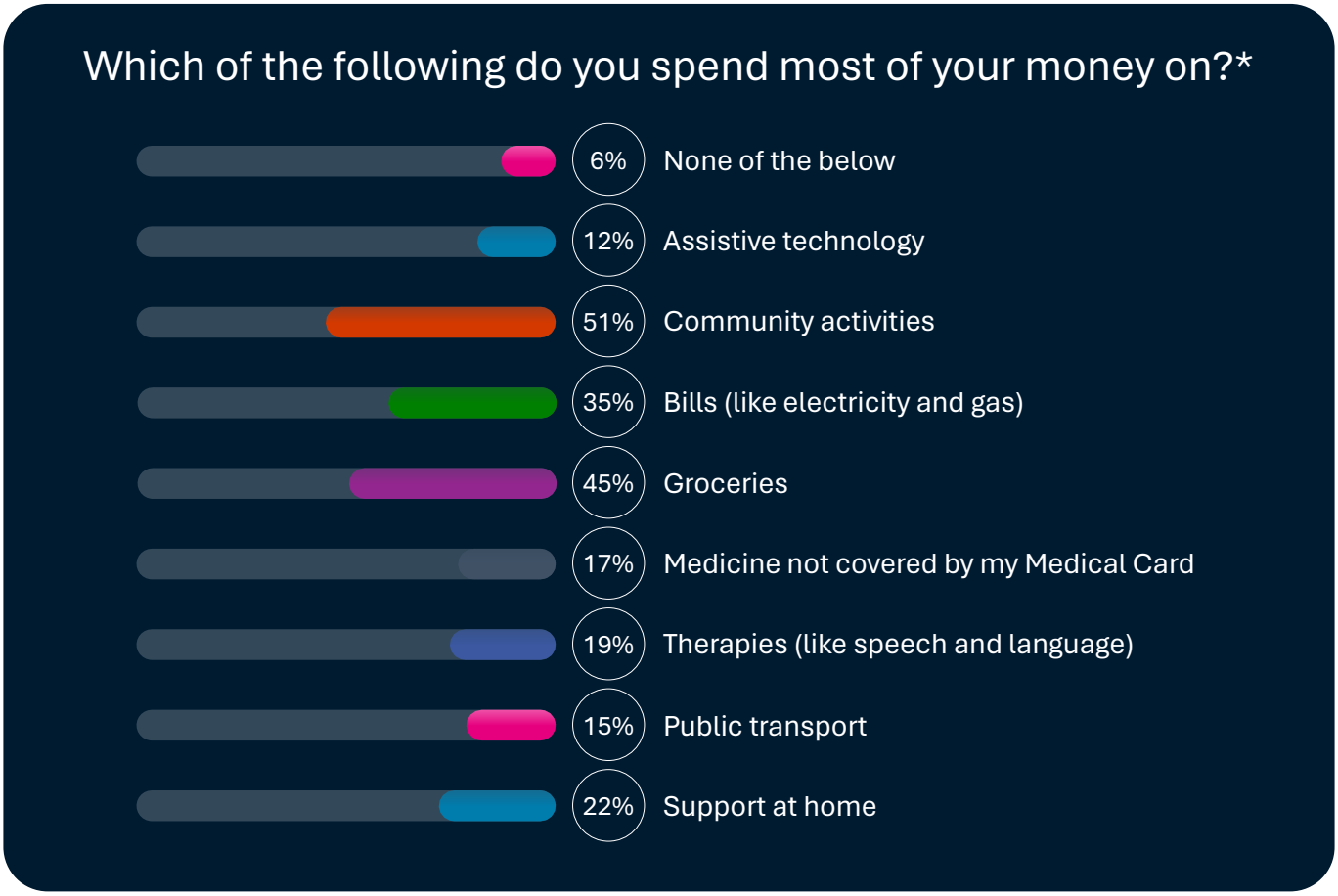
[12] Tully, G (12th March 2026), Letter to Richard Boyd Barrett TD regarding Parliamentary Questions 17976/26 –17982/26 and 18197/26

[13] Brady, J (26th February 2026), 'Written Answer 454: Nursing Homes,' Dáil Éireann Debate

[14] Colfer, F (28th January 2026), Opening statement by HIQA to Joint Committee on Disability Matters

[15] UN Committee on the Rights of Persons with Disabilities (15th April 2026), List of issues in relation to the initial report of Ireland, CRPD/C/IRL/Q/1, para.17(a)

Funding Community Participation



* Respondents could select more than one option

One of the clearest findings to emerge from the 2026 survey concerns the place of community life in adults' spending and priorities. **When asked what they spend their own money on, community activities were the most common category, named by more than half of respondents (51%)**, ahead of groceries (45%) and household bills (35%)[16]. When asked what would make their lives better, more of their own money was named by 47%, followed by better social welfare payments (45%), and "money to take part in my community" (44%). Read together, **these findings show adults with an intellectual disability are funding their own participation in community life from limited incomes**. They identify lack of money as a major barrier. Participation in community life is a fundamental right protected under Article 19 and core commitment under Pillar III of the NHRSDP[17]. The evidence gathered shows the State is currently leaving the cost of realising it to fall on people who can least afford to carry it.

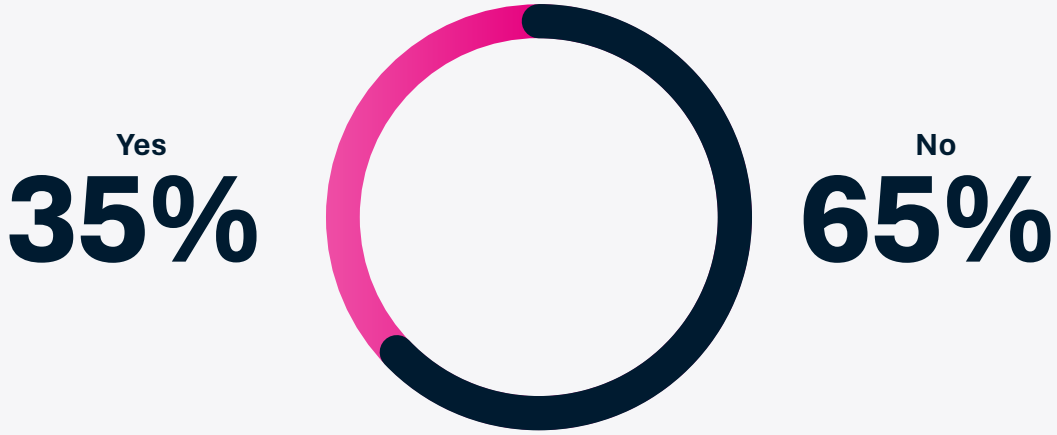
[16] Question allowed multiple responses. The figure reflects the proportion identifying community activities as a significant area of spending, not a ranking of absolute expenditure.

[17] Department of Children, Disability and Equality (3rd September 2025), National Human Rights Strategy for Disabled People 2025–2030, pg.31

Income Adequacy and the Cost of Exclusion

The financial findings are consistent across two years and both the adults' and families' surveys. **Almost two in three adults (65%) told us their social welfare supports are not enough to meet their everyday needs,** a figure that has changed little since 2025, when it stood at 66%[18]. **More than half (52%) reported costs related to their disability that are not covered by their social welfare payments.**

Do you feel that the social welfare supports you receive are enough to meet your everyday needs?



This lived experience is reflected in the Indecon report, which showed that disabled people face additional weekly costs of €176 - €279[19], now inflation-adjusted to €207 - €293[20]. Further ESRI-IHREC research indicates these costs can reach as high as 93% of disposable income for those with higher support needs[21]. When we asked families and supporters how a Cost of Disability payment should be designed, their priorities were clear: **it should focus on a person's needs (81%), enable them to live more independently (62%), and not reduce or disappear when they take up paid work (50%)**[22]. These are direct statements of what would make such a payment work for the people it is intended to support.

[18] Inclusion Ireland (14th July 2025), 1,000 Voices, One Message: Invest in Our Rights! – Inclusion Ireland's Pre-Budget Submission 2026, pg.16

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

[20] Adjusted for inflation by the Disability Federation of Ireland (January 2026), the updated annual figures (€10,766–€15,221) equate to a current weekly cost of €207–€293.

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

[22] *Our Rights, Our Voices* survey (Families and Supporters; May 2026), Q12; allowed multiple responses.

National data shows working-aged people with intellectual disabilities have the lowest median income of any disability group at €12,260[23], well below adequacy thresholds. Employment does not offset this because they face a 29% unemployment rate – one of the highest of any disability profile[24]. The recurring cost of disability, meanwhile, is estimated at between €10,766 and €15,221 a year.[25], deepening hardship for adults with intellectual disabilities and their families.

Both the Programme for Government and the NHRSDP commit to introducing a Cost of Disability payment and to removing anomalies in the means test that penalise work[26] [27]. The DSP's recent public consultation and Strategic Summit provide the mechanisms to act on it. Significantly, the List of Issues report itself underscores the importance of tackling the cost of disability and ensuring robust social protection to preventing poverty among disabled people, including through a permanent disability support payment[29].

Adults with intellectual disabilities told us they need better social welfare payments and more income of their own, including the means to take part in community life. Budget 2027 should introduce a permanent, adequate Cost of Disability payment and ensure that core disability and welfare payments reflect the real cost of living with a disability, in line with the right to an adequate standard of living and social protection under Article 28 of the UNCRPD .

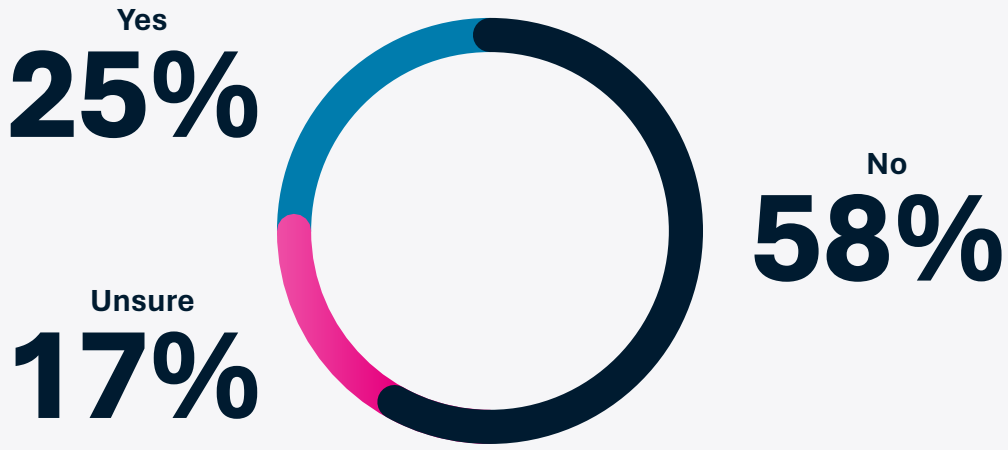
[23] Central Statistics Office (16th December 2025), Analysis of People Experiencing Long-Lasting Conditions or Difficulties 2022–2024
[24] Central Statistics Office (23rd September 2023), Census of Population 2022 Profile 4 – Disability, Health and Carers
[25] Disability Federation of Ireland (20th January 2026), Factsheet: Cost of Disability – The Lived Reality
[26] Department of the Taoiseach (23rd January 2025), Programme for Government 2025 – Securing Ireland's Future, pg.100
[27] Department of Children, Disability and Equality (3rd September 2025), National Human Rights Strategy for Disabled People 2025–2030, pgs.29 and 52
[28] Department of Social Protection (19th February 2026), Public Consultation on the Cost of Disability
[29] UN Committee on the Rights of Persons with Disabilities (15th April 2026), List of issues in relation to the initial report of Ireland, CRPD/C/IRL/Q/1, para.26(c)
[30] Inclusion Ireland (7th May 2026), Inclusion Ireland's Submission to the Department of Social Protection's Cost of Disability Consultation, pgs.5 and 14

Being heard

When we asked adults with an intellectual disability whether the Government listens to their experiences when making Budget decisions, **58% disagreed, 25% agreed, and the remainder were unsure**[31]. This is a lower level of distrust than we recorded among families and supporters but no less significant: the people most directly affected by these decisions are telling us, consistently across two years, that they do not believe their voices are heard[32].

This finding is reinforced by what adults told us in their own words. When we asked, without prompting, what one thing they would ask the Government to change, the call to be listened to ran consistently through the responses. Roughly one in ten responses spoke directly to consultation and being heard in decisions about their own lives[33]. One respondent's answer was simply: "To listen to my voice."

Do you agree with this statement?
"I believe the Government listens to people with intellectual disabilities when making decisions about the Budget."



[31] *Our Rights, Our Voices* survey (Adults with an Intellectual Disability; May 2026), on whether or not the Government listens to adults with intellectual disabilities. The equivalent question from *1,000 Voices* recorded 56% who felt the Government does not listen, indicating a stable finding.

[32] The equivalent figure was 83% among families and supporters of adults and 93% among parents and guardians of children. We would caution against reading the lower figure for adults with intellectual disabilities as lesser concern; it reflects, if anything, that families and supporters advocating on behalf of loved ones carry the accumulated frustration of years of doing so.

[33] Qualitative analysis of free-text responses (n=220). Consultation and decision-making were among the most frequent themes, alongside education and employment access and financial supports.

The right to be heard, and to be supported to participate in decisions, is protected under Articles 12 and 4 of the UNCRPD, the latter requiring the State to consult with and actively involve disabled people in decisions that affect them[34]. A statement repeated by hundreds of adults across two years of surveys – that they do not believe they are listened to – is itself evidence that this obligation is not being met.

KEY INSIGHT

65% of families and supporters say that "planning for the future" is the most important area the person they support needs help with.

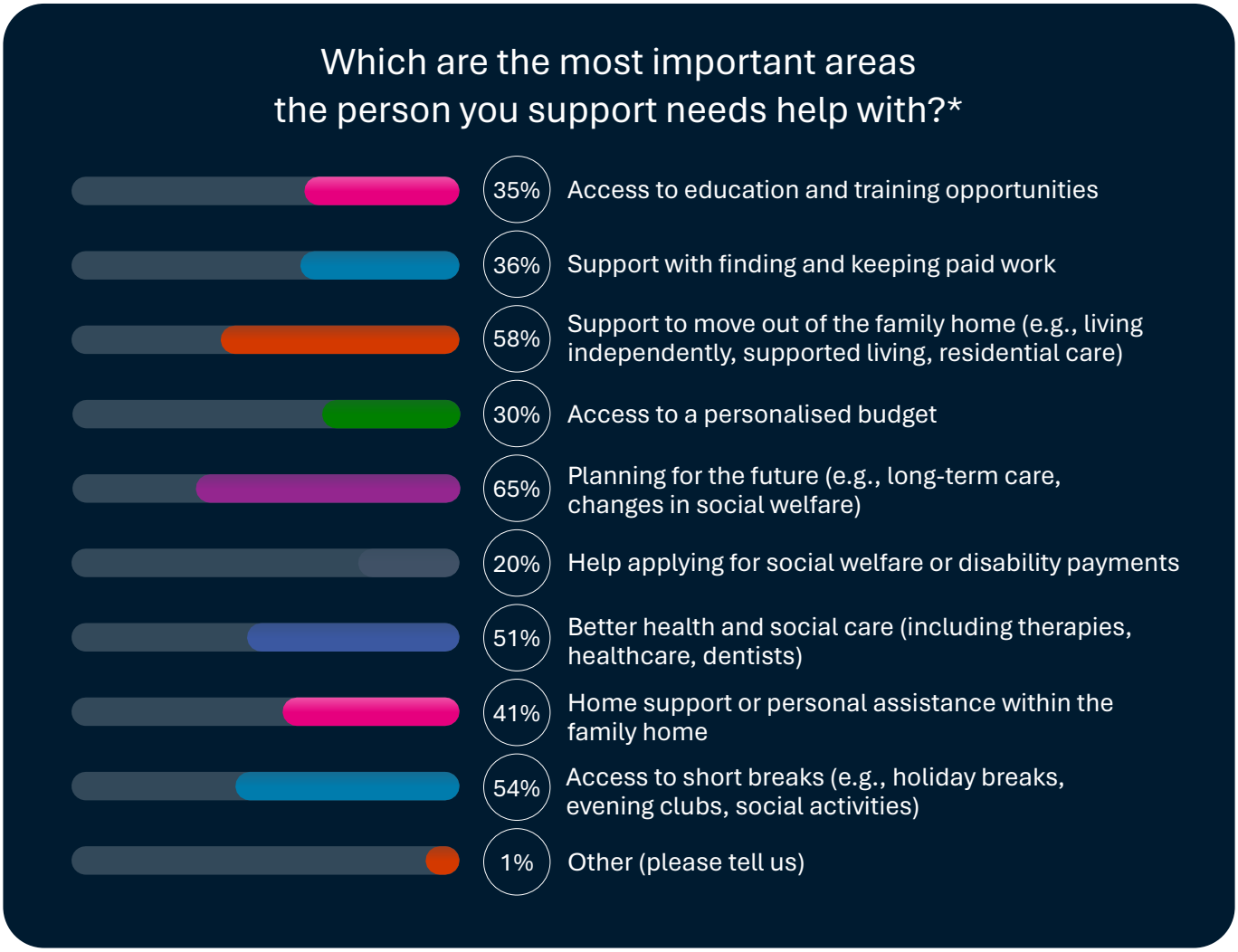
[34] United Nations (13th December 2006), Convention on the Rights of Persons with Disabilities, Article 4 (General obligations)

Families and Supporters of Adults with Intellectual Disabilities

This section draws on the responses of around 380 families and supporters of adults with intellectual disabilities. It is their perspective on the lives of the people they support, and in most cases, they are also the people providing the support that the State does not. Their answers describe a system that relies on them now while offering little assurance about a future in which they will not always be able to provide that support.

The fear of what comes next

When asked what the person they support most needs help with, almost two thirds (65%) of families and supporters are most concerned about a lack of planning for the future. This surpassed those who identified support to move out of the family home (57%) or access to short breaks (54%). Behind the 65% figure is a recurring fear in the responses, often described as: "What happens when we are gone."



* Respondents could select more than one option

That fear is not abstract. Figures released in May 2026 show what happens when a family can no longer provide support and no plan is in place. Of roughly 9,000 people with an intellectual disability in residential services, more than 600 have been placed outside the county where they grew up or where their family is based[35]. At least 193 live more than 100 kilometres from home, and at least 280 of these placements followed an emergency[36], such as the death or sudden incapacity of a parent or primary carer, requiring immediate placement wherever a spot was available. More than 300 have lived away from their home area for over five years[37]. These outcomes families try to avoid highlight the consequences when planned, local alternatives are lacking. The right to choose where and with whom one lives, set out in Article 19 of the UNCRPD, cannot survive in a system where placement is dictated by whatever vacancy exists at a crisis moment.

Future-proofing and genuine inter-agency cooperation must be the core litmus tests for any provisions Budget 2027 sets out to meet housing and community living targets. Crisis-driven responses. where families are forced to wait until an emergency dictates outcomes, must end.

> *Every parent of an adult with an intellectual disability asks the same question (what will happen when I am no longer here?). For too long, there has been no real answer.*
>
> Parent

[35] Brennan, C (16th May 2026), '"The distance is a problem": Parents of adults with intellectual disabilities forced to drive for hours to visit', Irish Examiner

[36] *Ibid.*

[37] *Ibid.*

A home and a way to reach it

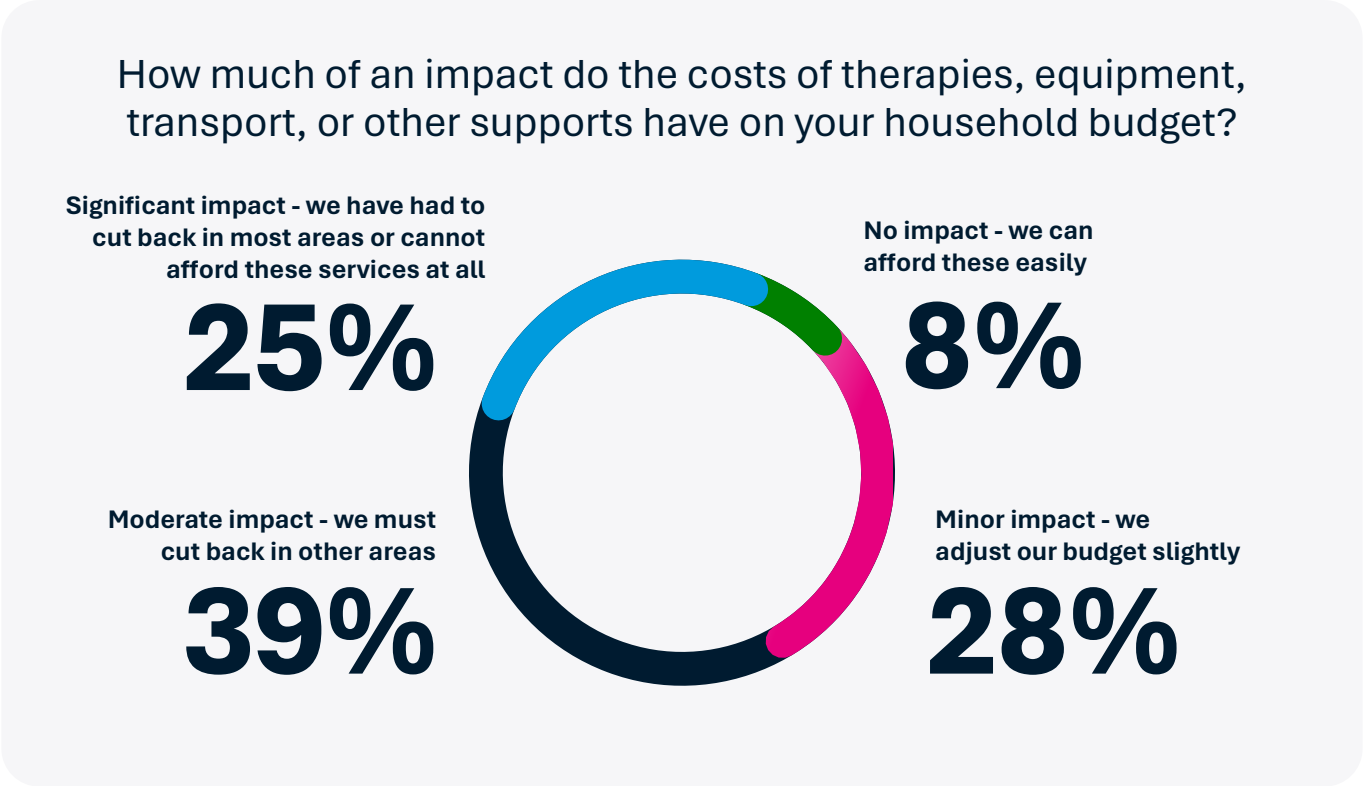
Most adults with an intellectual disability remain in the family home: **only 6% of families said they have a plan for the person to move into their own home, while 35% want to move but lack the necessary support**[38].

Where families identified barriers, they were overwhelmingly about supply rather than will. **The most common were lack of suitable or accessible housing in their area (54%), and long waiting lists for social or supported housing (52%), followed by an application process that families found too complicated to navigate (38%)**[39]. What families want from a home echoes what adults want: living near family (79%), living with people the person likes (69%), and being part of a community (60%), all ranked well above living alone with support (38%)[40]. The pathway the National Housing Strategy for Disabled People promised, and that adults are waiting on, is the same pathway families are asking for on their behalf.

[38] *Our Rights, Our Voices* survey (Families and Supporters; May 2026), on whether the person supported wishes to move into a home of their own.
[39] *Ibid.,* on barriers to finding suitable housing.
[40] *Ibid.,* on what is important about where the person supported lives.

The cost of exclusion

Supporting an adult with an intellectual disability places a sustained financial strain on households due to the very real barriers that people come up against. **Almost two in three families (64%) reported that the costs of therapies, equipment, transport and other supports have a moderate or significant impact on their household budget, and a quarter said the impact was significant or that they could not afford these supports at all**[41]. This figure has eased since 2025, when nearly 80% reported a moderate or worse impact[42], but **two in three families are still absorbing costs the State does not meet**.



[41] *Ibid.,* on the financial impact of disability-related costs on the household budget.
[42] Inclusion Ireland (14th July 2025), 1,000 Voices, One Message: Invest in Our Rights! – Inclusion Ireland's Pre-Budget Submission 2026, pg.18

Families were clear about what would help. Asked what a Cost of Disability payment should do, **81% said it should be built around the individual's needs, 62% that it should enable the person to live more independently, and 50% that it should not be reduced or withdrawn when the person takes up paid work**[43].

Two further findings belong here. **Awareness of personalised budgets has not moved: 40% of families had not heard of them**[44]**, almost exactly the proportion who said the same in 2025**, despite commitments to complete the pilot scheme's review[45] and expand the model[46]. Similarly, means-testing of carers' payments emerged again as a specific grievance, seen as a barrier that penalises family members – most often mothers – who have reduced or left paid work to provide care[47].

Being heard

Families do not believe the State is listening. Specifically, **83% of families disagreed that the Government listens to and hears their experiences when making Budget decisions**[48]. This sentiment is echoed in qualitative responses, where calls for transparent and accountable services are among the most frequent . Families and supporters want partnership in decision-making about those they care for and clear communication about what services will and will not be provided.

[43] *Our Rights, Our Voices* survey (Families and Supporters survey; May 2026), on what a Cost of Disability payment should do.
[44] *Ibid.,* Q9
[45] Department of Children, Disability and Equality (3rd September 2025), National Human Rights Strategy for Disabled People 2025–2030, pg.32
[46] Department of the Taoiseach (23rd January 2025), Programme for Government 2025 – Securing Ireland's Future, pgs.93–94
[47] *Our Rights, Our Voices* survey (Families and Supporters survey; May 2026), Q14 qualitative responses.
[48] *Ibid.,* on whether the Government listens when making Budget decisions.
[49] *Ibid.,* qualitative responses (Q14 'What is the one thing you would ask the Government to change to better support adults with intellectual disabilities and their families?'), service transparency and accountability theme.

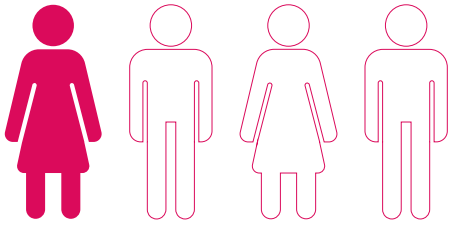
Parents and Guardians of Children with Intellectual Disabilities

This section reflects the responses of 463 parents and guardians of children with an intellectual disability, the largest group in our 2026 national survey. Their responses reveal a system that families sustain at their own expense, while confidence that the State is listening to them fades.

KEY INSIGHT

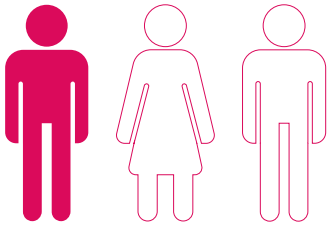
1 in 4

Couldn't afford services last year



1 in 3

Can't afford services now

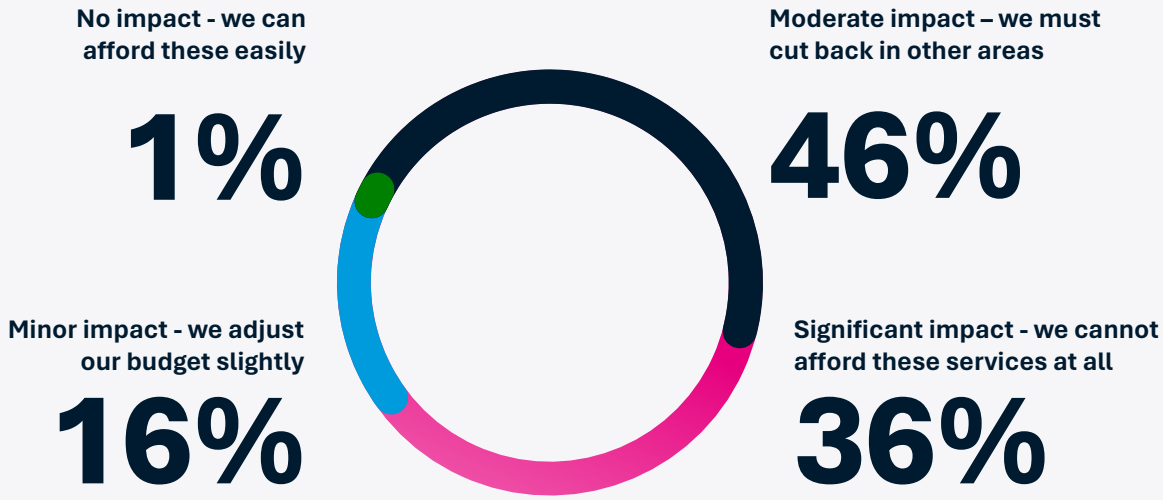


More than one in three parents and guardians now say they can't afford the services their child needs – up from nearly one in four a year ago.

A deepening financial crisis

The biggest change since last year is financial and is worsening. **Over a third of families now say they cannot afford the disability-related services their child needs**[50], up from 24% in 2025[51]. Including those who report cutbacks elsewhere, **eight in ten families say therapies, equipment, transport, and support costs stretch their budgets moderately or significantly**[52]. The proportion experiencing only moderate impact has dropped, not due to relief, but because families are facing outright unaffordability.

How much of an impact do the costs of therapies, equipment, transport, or other supports have on your household budget?



[50] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), on the financial impact of disability-related costs.
[51] Inclusion Ireland (14th July 2025), 1,000 Voices, One Message: Invest in Our Rights! – Inclusion Ireland's Pre-Budget Submission 2026, pg.8
[52] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), on the financial impact of disability-related costs.

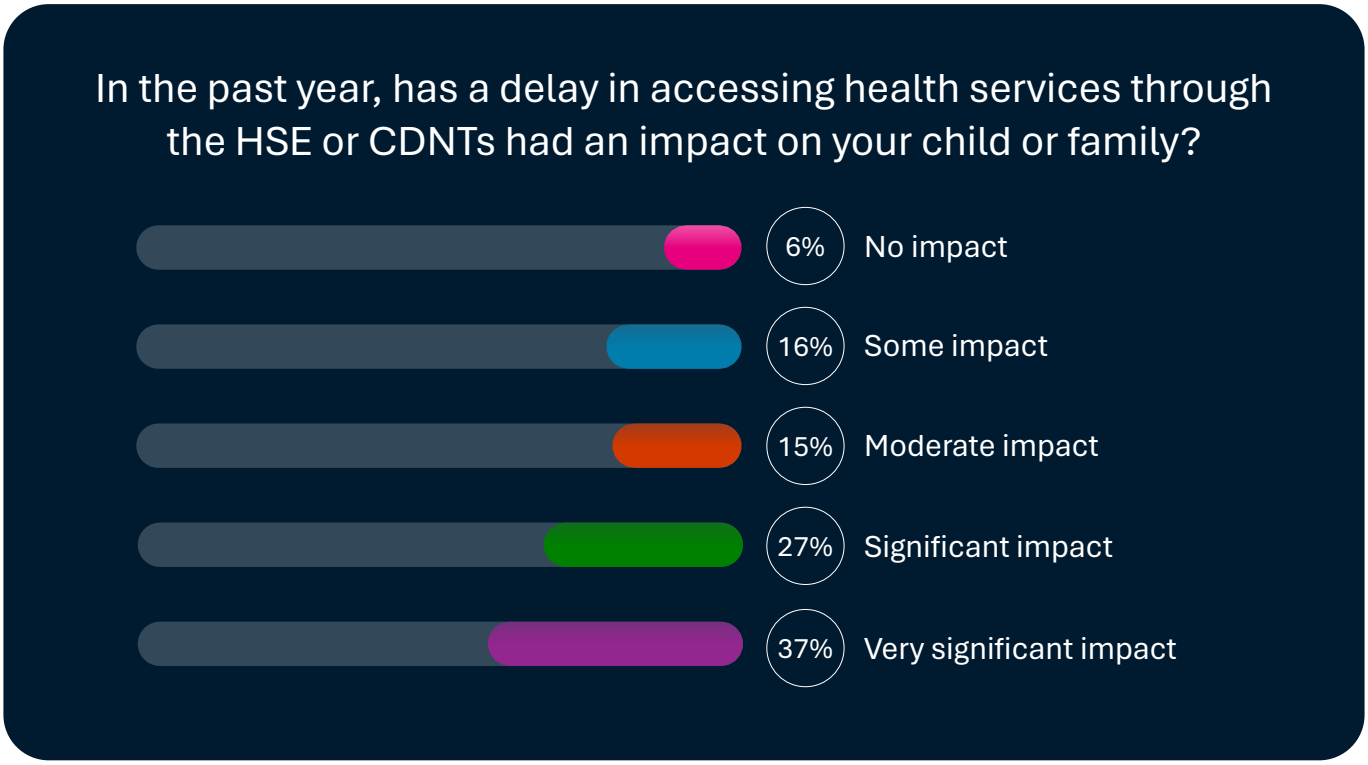
Families are paying for disability services both through taxation and out of their own pockets. **92% report disability-related costs not covered by public services, and three in four (76%) fund therapies privately that should be provided through CDNTs**[53]. The cost is not only financial; **almost six in ten (59%) have reduced working hours or taken time off to fill support gaps**[54]. MESL research puts this stark gap in household terms: the core cost of a minimum essential standard of living for a two-parent household caring for an adolescent with an intellectual disability is around 48% higher than for a comparable household without a disabled child, with the largest additional costs falling on transport, care, household goods and adaptations[55]. These are the recurring, structural costs that parents and guardians are absorbing where State services do not.

Absent and delayed therapies

When asked about their top priority for support through CDNTs, **three quarters of parents and guardians named access to therapies, with less than 2% solely prioritising access to an AON**[56]. This consistency over two years highlights that families are mostly waiting for therapies, not just assessments. Although a child has a statutory right to an AON, there is no corresponding right to the therapies it identifies[57], leaving families unserved.

The scale of unmet assessments is itself growing sharply. The most recent HSE data shows that 21,782 AON applications were overdue at the end of Quarter 1 2026[58], marking a 42% increase from the previous year[59]. With just 10% of assessments currently meeting the statutory timeline, this growing backlog shows why any changes to the AON process should strengthen procedures and protections for children, not create new ways for them to miss out on support." (pg.24)

[53] *Ibid.,* on uncovered disability-related costs and on out-of-school provision.
[54] *Ibid.,* on out-of-school provision.
[55] Vincentian MESL Research Centre (5th April 2022), Care at Home – Costs of Care Arising from Disability
[56] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), on CDNT support priorities.
[57] Burns, E et al., (26th February 2025), Exploring the Need for a Representative Advocacy Service for Children with Intellectual Disabilities in Ireland, pgs.19–20
[58] O'Sullivan, P (20th May 2026), 'Question 228: Departmental Data,' Dáil Éireann Debate
[59] Calculated using official HSE data cited in Dáil Parliamentary Question responses (20th May 2026). The percentage growth is found by subtracting the end-of-2024 baseline (14,221) from the end-of-2025 figure (20,209). Then divide that result (5,988) by the 2024 baseline and multiply by 100. This gives 42.11%, rounded to 42%. While the latest quarter (Q1 2026) shows 21,782 overdue applications, this 42% annualised growth rate reflects the most recent full-year reporting period available in the state's data.



The consequences of delay are felt across the family. **Almost two in three parents and guardians (64%) reported that delays in HSE and CDNT services over the past year have had a significant or very significant impact on their child or household[60]. Access to therapies was also the single most important support area parents and guardians identified, named by 83%, ahead of every other form of help[61]**. These gaps also affect children's mental health: by the end of 2025, 815 children with an intellectual disability across the country were waiting to be seen by CAMHS-ID – up 66% in a year and almost five times higher over two years[62]. The service has only 10 of the 16 specialist teams the HSE's Model of Services says are needed[63] and is funded at about 43% of the staff it requires[64]. The data confirms what families are saying: the system is not responding in time.

[60] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), on the impact of HSE and CDNT delays.
[61] *Ibid.,* on the most important areas the child needs support with.
[62] Brennan, C (20th May 2026), 'Children with disabilities 'being failed twice' by lack of services and system 'that doesn't recognise their needs', Irish Examiner
[63] Finnerty, S, (26th July 2023) Independent Review of the provision of Child and Adolescent Mental Health Services (CAMHS) in the State by the Inspector of Mental Health Services, pg.81
[64] Brennan, C (13th April 2026), 'Services for children with intellectual disabilities funded at half needed for functioning service' Irish Examiner

School, inclusion, and filling the gap

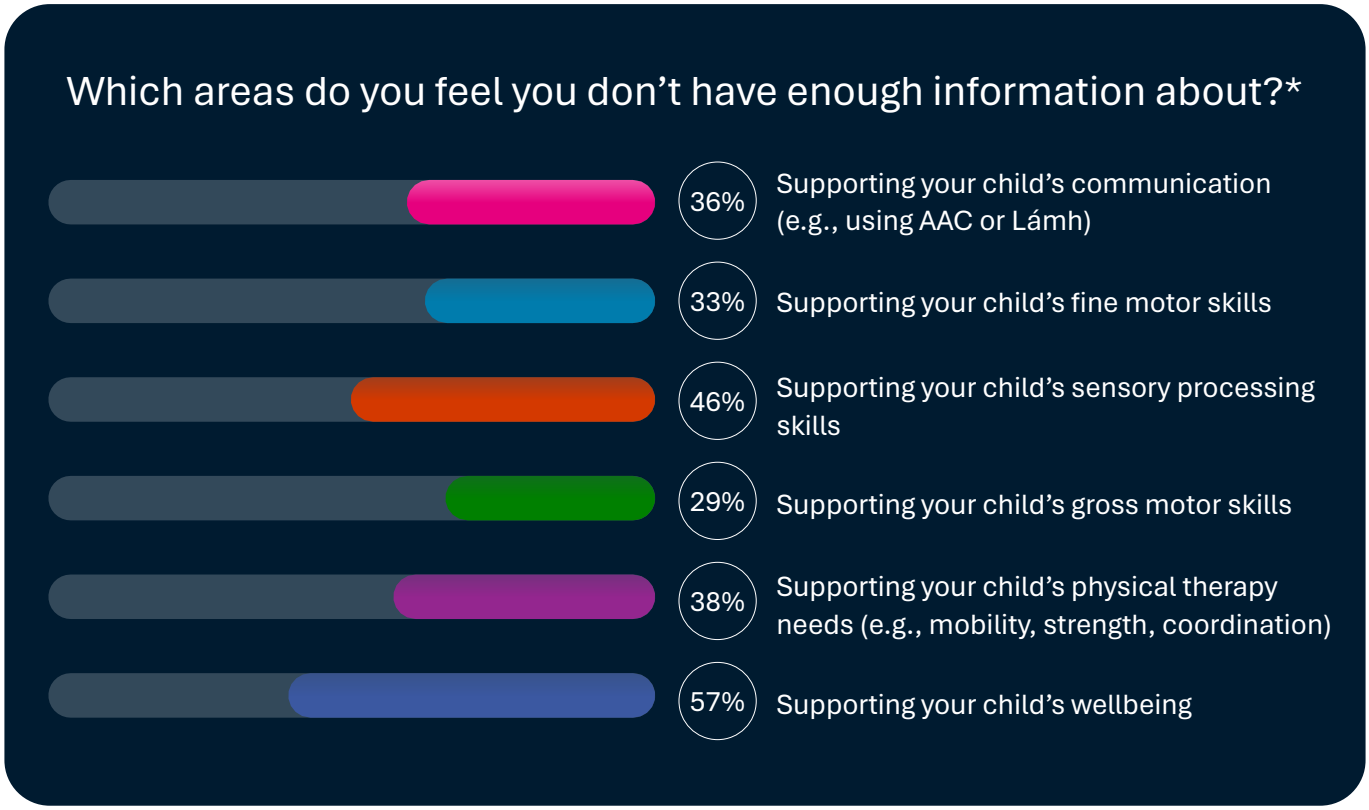
The picture in education is mixed and should be presented as such. Most (57%) reported their child is well supported and included in school. However, **a significant minority cited failures: over a quarter said their child's needs were dismissed, 17% that accommodations were refused or delayed, and 14% that their child's school was deemed unsuitable**. These findings reflect settings inadequately resourced for inclusion, not a failure of inclusion as a principle. **Where a child's needs were dismissed, this was more common in mainstream classes than in special classes or special schools**[65]. The reason is not that inclusion does not work, but that mainstream settings are asked to include children with an intellectual disability without sufficient support, training, and staffing ratios. **The risk is that under-resourced mainstream provision pushes families towards special settings by default, narrowing rather than widening genuine choice**. The answer is to resource inclusion properly.

Inclusion Ireland reiterates our calls from the National Conversation on Education: Budget 2027 should fund the outstanding actions of the EPSEN Review and commit to developing a statutory Inclusive Education Plan so mainstream becomes a genuinely supported option for children with an intellectual disability and their families[66]. This gives effect to the right to inclusive education under Article 24 of the UNCRPD[67] and Article 28 of the UNCRC[68], and responds directly to education concerns raised in the UN Committee's List of Issues for Ireland[69].

What families do to fill the gaps is striking. **More than three in four families report needing to privately fund therapies, regardless of where their child is taught**[70]. The burden of lost work and of advocating for summer provision falls heaviest on families whose children attend special schools and special classes: **among families of children in special schools, 67% have taken time off work or reduced their hours, and 46% have had to push for summer provision**[71].

[65] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), on what experiences their child has had in their educational settings.
[66] Inclusion Ireland (28th February 2026), Inclusion Ireland's Submission to the National Conversation on Education, pg.4
[67] United Nations (13th December 2006), Convention on the Rights of Persons with Disabilities, Article 24 (Education)
[68] United Nations (20th November 1989), Convention on the Rights of the Child, Article 28 (Right to Education)
[69] Several issues on education and early interventions are raised by the List of Issues report. It requests information on measures to address waiting lists and delays for essential community-based support and early intervention services (Art.19, para.17[f]) and asks about progressing an inclusive education strategy (Art.24, para.22[b]), the adequacy of individualised support in early childhood education settings, and the elimination of reduced timetables as a sanction (22[d]).
[70] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), cross-tabulation of out-of-school provision by educational setting.
[71] *Ibid*.

Access to information



* Respondents could select more than one option

Families still struggle to find the information they need for their child. This was also a key finding of our 2025 survey. One year later, official progress has improved, but families do not feel the change. The national online resource hub is live, and CDNT vacancies have dropped to 18% – yet the Single Point of Access is not fully in use across all HSE regions[72], services are still fragmented, and recruitment and retention rates remain a major challenge[73]. In our view, **official reports and family experience still do not match, and the information gap from 2025 continues in 2026**. Accessible, reliable information is essential for families to secure their child's rights to specialist care and effective services under Article 23 of the UNCRC[74].

[72] Health Service Executive (18th November 2025), Roadmap for Service Improvement 2023–2026, Disability Services for Children and Young People, Q3 2025 Report, pg.9
[73] O'Donohoe, A (13th May 2026), Opening Statement to the Joint Committee on Disability Matters
[74] United Nations (20th November 1989), Convention on the Rights of the Child, Article 23 (Children with Disabilities)

Carers and the means test

Among the changes families asked for in their own words, **the removal of the means test for Carer's Allowance was the second most frequent, raised by 16% of the families who responded to our open question**[75]. It is a demand that recurs across our surveys – families of adults with an intellectual disability raised it too – and it reflects a process that penalises family members, many of whom have reduced or given up paid work to provide care. The means test, the 18.5-hour limit on permitted work, and the household income threshold together form a poverty trap for the very households the State relies on to provide care it would otherwise have to fund itself. Removing the Carer's Allowance means test is among the most direct actions Budget 2027 could take to recognise that care, and it is an action the Programme for Government has already committed to in principle[76].

Being heard

No finding in any of our three surveys is starker than this. Among parents and guardians of children with an intellectual disability, **less than one in ten believe that the Government listens to them when making Budget decisions**[77]. This is near-unanimous trust deficit of 93%, deepening slightly since 2025, when 92% of parents and guardians said the Government does not listen. Alongside it, **82% of families agree that public attitudes towards disability are a barrier to their child having the same opportunities as other children**[78]. Families of children with an intellectual disability experience marginalisation from two directions at once: from a society they feel does not include their children, and from a State they feel does not hear them.

> *Listen to families/children's lived experience as part of decision making and strategies. Stop acting like they are supporting all when no significant change is made. Stop dressing up cuts as better supports or systems. Truly acknowledge the gaps and make tangible actions.*
>
> **Parent**

[75] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), qualitative responses (Q15 'What is the one thing you would ask the Government to change to better support children with intellectual disabilities and their families?').
[76] Department of the Taoiseach (23rd January 2025), Programme for Government 2025 – Securing Ireland's Future, pg.100
[77] *Our Rights, Our Voices* survey (Parents and Guardians; May 2026), on whether the Government listens when making Budget decisions – just 7 out of 463 respondents in raw numeric terms.
[78] *Ibid.,* parents and guardians survey, on public attitudes as a barrier.

Key Asks for Budget 2027

Across all three groups, the central message is clear: the gap between the State's commitments and people's lived experience is growing, particularly regarding affordability, trust, and timely support delivery. The asks below reflect what people told us and are largely delivered on existing State commitments.

Tackle disability poverty and the cost of exclusion

The cost of disability is the thread running through all three surveys. More than a third of families with a child with an intellectual disability can no longer afford the services their child needs, up from a quarter a year ago. Two in three adults say their welfare payments do not meet their everyday needs. And in Budget 2026, the one-off supports that had partially offset these costs were withdrawn with nothing to replace them. Budget 2027 must reverse that direction.

Inclusion Ireland calls on Budget 2027 to:

- Introduce the permanent Annual Cost of Disability Support Payment committed to in the Programme for Government, benchmarked to the €10,766 and €15,221 cost identified by the 2021 Indecon report (inflation-adjusted). It must be: (1) based on individual need and rights; (2) sufficient to support independent living; and (3) never withdrawn on taking up paid work or higher earnings.

- Restore and make permanent the income supports withdrawn in Budget 2026, specifically the Disability Support Grant and the additional Fuel and Living Alone payments. Recurring costs must be covered by permanent supports, not disappearing one-off measures.

- Raise and benchmark core disability and carer payments against the Minimum Essential Standard of Living. The €10 increase in Budget 2026 only tracked inflation; Disability Allowance (€254) and Carer's Allowance (€270) must rise against an adequacy standard rather than fall further behind the real cost of disability.

- Set a clear timeline for abolishing the Carer's Allowance means test and abolishing the 18.5-hour limit on work, study, and training for families of people with an intellectual disability.

- Expand the Fuel Allowance beyond the current €38 weekly rate and widen eligibility to recognise higher energy costs for disabled people reliant on assistive technology or care at home.

Deliver homes and independent living supports

The desire to move into a home of one's own is a clear expression of the right to independence. It is also one of the most consistently unmet needs. More than three in five adults with an intellectual disability still live in the family home. Fewer than one in five of those who want to move have a plan to do so.

Inclusion Ireland calls on Budget 2027 to:

- Establish and fund a national future-planning system with clear responsibilities across the HSE, the Department of Housing and other relevant departments, as set out in the National Housing Strategy for Disabled People. Fund named local coordinators to work across local authorities, the HSE and HSE-funded services, and directly with people and their families.
- Enable multiannual, aligned capital and revenue funding across the Department of Housing, the Housing Agency, the Department of Children, Disability and Equality, and the HSE, so that a home and its support package are funded together rather than separately.
- Fund housing people with intellectual disabilities have asked for: homes near family, friends and community, with chosen companions, that are rights-based and safe, upholding the Article 19 UNCRPD right to choose where and with whom to live. Provide a minimum of 300 funded, planned support packages in Budget 2027.
- Accelerate the move-out of 200 congregated settings and 100 inappropriate nursing home placements with a funded, milestone-based plan, delivering on Time to Move on from Congregated Settings goals for 2030 and making the National Human Rights Strategy for Disabled People's commitments credible through real community alternatives.
- Increase Personal Assistance hours for independent living, aligning with the Disability Capacity Review to 2031 by establishing a binding, milestone-based timeline to eliminate the documented shortfall of over 400,000 hours.
- Permanently fund the Personalised Budgets pilot, expand provision, and publish a plan for system-wide rollout, including dedicated support for people and families.

IN NUMBERS

Provide **300** funded, planned support packages

Accelerate the move-out of **200** people from congregated settings

Move **100** people out of inappropriate nursing home placements

Invest in timely and accessible supports

Hundreds of parents and guardians told us they are waiting for the supports that assessment is meant to unlock – therapies that do not arrive, home support that is not there, day services and respite that are oversubscribed. Delays are not mere administrative inconveniences; they have significant effects on children and their families and compound at every life stage.

Inclusion Ireland calls on Budget 2027 to:

- Resource Children's Disability Network Teams to turn assessments into timely therapy. Place the entitlement to therapy on a statutory footing alongside the existing right to an Assessment of Need as part of the Disability Act 2005's broader review.
- Fund more family support workers across every CDNT, building on the 150 new posts from Budget 2026, helping families coordinate care and easing pressure in the home for caregivers restricted by the 18.5-hour work limit.
- Invest in CAMHS-ID teams to close the clinical and administrative shortfall and meet the HSE standard of one team per 300,000 people, fully staffed at 11 posts each nationally.
- Increase sustainable funding for independent advocacy, with ring-fenced investment for DPOs and for a nationwide, statutory advocacy service for disabled children, giving effect to children's rights under Articles 7 and 12 of the UNCRPD.
- Fund rights-based, community-focused short breaks close to home, planned around each child's interests and needs rather than placement availability. Short breaks and out-of-school provision should be a core, predictable part of disability services, not an add-on that families must renegotiate every year.
- Roll out the Single Point of Access across all CDNT areas, adequately resource Family Resource Centres, and fund the national online information hub to ensure timely access and prevent crises for families.

Advance inclusive education

Most parents and guardians reported their child is well supported in their educational setting, but a substantial minority described needs dismissed, accommodations refused, and placements questioned. These experiences were most common in mainstream settings that are being asked to include children with an intellectual disability without the resources to do so. Put simply, inclusion must be properly funded for it to deliver.

Inclusion Ireland calls on Budget 2027 to:

- Fund all outstanding actions from the EPSEN Review. Commit to codesigning and resourcing an Inclusive Education Plan on a statutory footing. Work towards a targeted timeline for when all schools are appropriate settings, fully resourced to support children.
- Allocate €1 million for disability and human rights training, delivered by DPOs and advocacy groups, in line with Articles 8 and 24 of the UNCRPD.
- Expand the NCSE's Relate programme across all schools nationwide to build inclusive school communities and strengthen relationships with students of all ages with intellectual disabilities.
- Fund additional therapist posts in schools and special educational settings to meet the staffing targets set out in the Schools Inclusion Model, with a clear implementation timeline commencing in Budget 2027.
- Accelerate the transition of the primary school staffing schedule from the current 23:1 allocation down to the Programme for Government target of 19:1, bringing Ireland in line with European averages.
- Protect and further front-load the 19:1 staffing ratio in the post-primary sector, ensuring sufficient teaching resources are available to facilitate the inclusion and support of students with intellectual disabilities.
- End the use of reduced timetables as a response to children with an intellectual disability and establish an independent complaints mechanism so that families can challenge exclusionary practices and secure timely redress.

Appendix

Survey design and distribution

Our Rights, Our Voices is Inclusion Ireland's 2026 national survey to gather the lived experiences of people with intellectual disabilities, the families, and their supporters. Three surveys were developed: for adults (aged 18 years old and over) with an intellectual disability, their families and supporters, and parents and guardians of children (aged under 18) with an intellectual disability. All were promoted through Inclusion Ireland's members, partners, and social media channels. The surveys ran in parallel online from 27th April and closed on 18th May.

Across the three surveys, Inclusion Ireland received approximately 1,500 responses in total. Following standard quality checks – removing responses from those who did not meet the survey criteria, such as respondents who did not have an intellectual disability or were under 18, along with blank or incomplete submissions – more than 1,100 substantive responses form the basis of the analysis in this submission.

The surveys were developed to build directly on the *1,000 Voices* surveys from June 2025, with updated questions to allow year-on-year comparisons across the same areas. Where questions were redesigned, comparisons between years are indicative rather than precise. This is noted in the relevant sections of the submission.

Sample sizes and response rates

- **Adults with an Intellectual Disability:** 384 people began the survey. Of these, 350 confirmed they have an intellectual disability (91%), and 348 confirmed they were aged 18 or over. The substantive analysis is based on 301 respondents who completed the survey fully or in part; this is the most consistent base across the quantitative questions. 220 respondents completed the qualitative question (Q13). All percentages in this section are calculated against those who answered each question.

- **Families and Supporters of Adults with an Intellectual Disability:** Approximately 537 people began the survey; around 380 completed the substantive questions from Q4 onwards. Completion rates varied by the age of the person supported. Families and supporters of adults aged 55 and over completed the latter questions at about 59%, compared with 72–77% for those supporting adults aged 18 to 34. The experiences and perspectives of families supporting older adults may be under-represented in findings from Q4 onwards, especially regarding housing, transitions, and future planning, where pressures on older families are greatest. A similar drop-off pattern was observed in the 2025 survey, suggesting this is structural to this survey type and population rather than a reflection of the 2026 design. The qualitative analysis (Q14) is based on 327 cleaned responses after removing blank, non-substantive, or noise responses.

- **Parents and Guardians of Children with an Intellectual Disability:** 615 people began the survey; 463 completed the substantive questions. The geographic distribution of respondents is less Dublin-concentrated than in 2025, with the strongest responses from counties Dublin (23%), Cork (13%) and Galway (8%). The qualitative analysis (Q15) is based on 388 responses.

Analysis

Quantitative responses were analysed at the question level. Percentages were calculated against those who answered each question. The adults' quantitative data analysis was based on a corrected export that included both complete and partial responses. An earlier export captured completed responses only and produced a denominator of 281. This was identified and corrected during analysis.

Qualitative responses were thematically coded using a taxonomy of super-categories and sub-themes developed for this submission. A multi-theme counting convention was applied: a single response was counted under each theme it addressed. Percentages in the qualitative analysis sum to more than 100% and are expressed as proportions of total responses rather than distributions.

A small number of responses in the adults' qualitative survey (n=5, 2.4%) appeared to have been submitted by a family member or supporter on behalf of an adult with an intellectual disability. These were kept in the analysis but flagged in coding. Blank, noise, or non-responsive answers were removed before analysis.

Geographical concentration

Across all three surveys, responses were concentrated in counties Dublin, Cork, and Galway. This reflects broader population distribution patterns across Ireland and the reach of Inclusion Ireland's networks. Findings should be read as representative of families and adults engaged with disability services and advocacy organisations in Ireland. They are not a statistically weighted national sample.

Year-on-year comparisons

Where year-on-year comparisons are made with the *1,000 Voices* surveys, specific caveats apply in three areas. First, the question on government listening changed from a Yes/No/Not sure format in 2025 to a five-point agreement scale in 2026. The figures allow for directional comparison but are not directly equivalent. Readers should interpret findings as indicative rather than numerically precise. Second, several questions on children's information access and support priorities were redesigned between years. As a result, the 2026 findings on these topics are not directly comparable with the 2025 headline of 56% reporting no information access and are presented independently. Third, the 78% figure cited in *1,000 Voices* as the overall trust-deficit finding was a cross-survey average. The 2026 figures are reported by cohort and show a wider range across populations. These factors limit precise quantitative comparison across survey years.

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

HSE

Coimisiún na hÉireann um Chearta an Duine agus Comhionannas
Irish Human Rights and Equality Commission

pobal
government supporting communities

Rialtas na hÉireann
Government of Ireland

Click on the logo above to go to the organisation website

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