



AsIAM Pre-Budget Submission 2024

*“Investing in Creating the Same Chance for
Ireland’s Autism Community”*



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Introduction

Growth in Ireland's domestic economy is expected to remain strong for 2023 and 2024, according to the Economic and Social Research Institute (ESRI). The ESRI forecasts a surplus of €9.8bn this year (2023) and €15.5bn for 2024. The scale of this growth creates important and much needed opportunities for greater sustained investment towards building a more just, accessible, and inclusive Ireland, including building more opportunities for people from marginalised backgrounds such as Autistic people to have the same chance in Irish society. Despite this cause for optimism, Budget 2024 takes place in a landscape where significant financial challenges remain for many people and families across Ireland despite this promising economic landscape. The cost-of-living crisis is taking a toll on many families who are still feeling squeezed for meeting the costs of everyday essentials. This is very much the case for Autistic people and families, who are both exposed to the rising cost of living, but who also experience significant barriers to employment, accessing an education in our community, and an adequate standard of living. These were all prominent issues that were investigated by the [Joint Oireachtas Committee on Autism](#) and were reflected in its findings and recommendations contained in its recently published [Final Report](#).

Budget 2023 brought in welcome changes which made progress in dealing with some of the additional costs borne by our community. Last year's Budget included some much-needed investment into our public services which were aimed at reducing class sizes, setting up additional autism classes, recruiting more teachers

and Special Needs Assistants, in adjusting qualifying criteria for particular social protection payments, and around thresholds with employment schemes. However, whilst AsIAM welcomed the numerous positive measures included in the package, we believed that that the increases to core social protection payments were not enough to meaningfully address our community's needs. We also believed that the incremental approach to these increases fell short of addressing the more deep-rooted inequalities that impact our community.

To ensure that these outcomes are not repeated for our community for Budget 2024, AsIAM believes that the Government should take a more redistributive approach which includes more targeted increases to core social protection payments and moving towards introducing a weekly Cost of Disability payment. This is to ensure that our most marginalised in society are protected against both the medium-term consequences of inflation and economic hardship and to ensure that people still receive an adequate income as we go through this ongoing cost-of-living and energy crisis.

Over the year-long lifecycle of the Joint Oireachtas Committee on Autism, many Autistic people and families gave testimony on their experiences living in Irish society as an Autistic person or raising an Autistic person. The Committee took these testimonies on board and reflected the overall frustration felt by the community over the lack of supports, in their Final Report's recommendations and findings.

The theme of this year's AsIAM Pre-Budget Submission is on 'Investing in Creating the Same Chance for Ireland's Autism Community', reflecting the everyday living experiences of Autistic people and the wider community living in Irish society, working towards an ambitious vision on what a more accessible and accepting society looks like.

This is why a core request from AsIAM in our Pre-Budget Submission for 2024 is for greater investment, to realise the full implementation of the Final Report from the Oireachtas Autism Committee, including both immediate and medium-term actions to better support our diverse community. Budget 2024 presents an opportunity for greater investment in reducing social and economic barriers.

Our recommendations reflect this overarching vision expressed to us by our community and outlined in the Joint Oireachtas Committee on Autism's Final Report. Implementing our recommendations would make real progress towards creating a more accepting and inclusive society which supports Ireland's autism community.



Recommendations for Budget 2024

The Same Chance to Live a Happy, Healthy Life

- Invest in the **full implementation** of the Joint Oireachtas Committee on Autism Final Report.
- **Legislate for the Autism Innovation Strategy** within the lifetime of this Government.

The Cost of Not Having the Same Chance

- **Increase Disability Allowance by an additional €25 per week.** Commit to index any future social protection increases to inflation and the cost of living.
- **Increase the rate of Carers Allowance payment by €25 per week** by investing an additional €99.1 million and removing the means test for present and future applicants.
- **Increase Domiciliary Care Allowance by €25 per week** by investing an additional €85.3 million.
- Invest €22.6 million to increase the **Carer's Support Grant payment by €150.**
- **Extend the eligibility of the Home Carer Tax Credit** to include single working hours.
- **Increase the Incapacitated Child Tax Credit from €3,300 to €3,500.** The cost of the State of this measure is €6.4 million.
- **Introduce a Cost of Disability Payment of €20 per week for people with disabilities, as recommended in the Indecon Cost of Disability Report.** This will require an initial €225 million to introduce this payment, with a view to incrementally increasing this payment in future years.
- **Invest €30 million to reduce class sizes to 20:1** over the next two years in line with the European average class size.
- **Provide adequate financial supports to families who access assessments and supports privately** due to their unavailability in the public health system until such time as vacant positions within CDNTs (Children's Disability Network Teams) have been filled.

- Provide a **€500 monthly payment to families of children in receipt of AIMS** (Access and Inclusion Model Scheme), to assist with additional childcare costs.
- **Increase the Housing Adaptation Grant** to support individuals and families from €30,000 to €60,000.
- Provide up to **€3 million in funding to the legal system** to support individuals with additional needs who find themselves coming into contact with the law. This would include training to the judiciary and officers of the court and supports to individuals.



The Same Chance to Be Accepted and Included in the Community

- **Invest €15 million to develop and implement the Autism Innovation Strategy,** under the remit of the Minister of State with Special Responsibility for Disability at the Department of Children, Equality, Disability, Integration, and Youth.
- **Provide €6 million to deliver a 'one stop shop' pilot** as highlighted in the Joint Oireachtas Committee on Autism Report, and to financially support local Autistic-led groups.

The Same Chance to Live a Happy, Healthy Life

Many people and families across Ireland, including Autistic people and the wider community, want the same chance to secure an adequate standard of living needed to live a happy, healthy life. However, through our engagement with the community, we know that this is not the case for many Autistic people and families who are experiencing significant levels of financial hardship, and who are facing a more uncertain and precarious future than this time last year. Many people are still feeling squeezed as the post-pandemic inflationary cycle and subsequent rises in the cost of everyday essentials such as food, energy and clothing continues, and the impact of these increases often leave people and families having to make difficult decisions. These persistently high living costs, making Ireland the most expensive country in the EU with prices 46% more expensive than other EU countries (European Commission, 2023), is pushing more families and individuals closer towards poverty or into poverty. This insecurity is keenly felt by many Autistic people and disabled people and families.

Addressing poverty and deprivation, and particularly child poverty, has been a persistent problem for Ireland. This was highlighted as a key issue by the European Commission. On a positive note, we have seen some very welcome and timely progress in tackling child poverty over the past year with the introduction and expansion of the free schoolbook scheme to primary and secondary school pupils, and with the expansion of the free school meals scheme in DEIS schools and special schools.

This also included proposed further reductions in childcare fees and with the Child Poverty Unit set up within the Department of the Taoiseach to coordinate policy and take concerted action on addressing this critical issue.

However, problems persist when we look at tackling poverty across the board. The incremental approach taken by the Government to tackling disadvantage in areas such as social protection and unemployment has been shown to be inadequate and ineffective, having been outpaced by bigger increases in living costs and by widening employment gaps between disabled people and non-disabled people. This is reflected in the Government's Roadmap for Social Inclusion Progress Report, which Ireland is ranked 24th out of 27 EU Member States for tackling disability poverty, and where 39.3% of disabled people in Ireland were At Risk of Poverty and Social Exclusion (ARPE) – 10% higher than the EU average. These stark findings show that many among our Autistic and disabled communities do not have the same chance to fully participate in Irish society and are often left to bear the cost of this lack of access and opportunity in many aspects of their lives.

As the Disability Federation of Ireland notes in their Pre-Budget Submission:

*'To be disabled is to experience a much higher risk of poverty, and/or deprivation; where affording the ordinary things in life is a major challenge – securing a home, taking a holiday, buying new clothes, or keeping up with your utility bills. The inflation and cost of living crisis has exacerbated the ongoing, systemic economic vulnerability faced by disabled people who rely on our social protection system to survive.'*¹

Whilst reforms to the social protection system to index social protection payments to the cost of living and average wages are in the works and would be welcomed by AsIAM, as with 2023 the Government needs to introduce a significant social welfare package with targeted measures to both protect disadvantaged members of society.

1. Disability Federation of Ireland, 'Pre-Budget Submission 2024' p. 11. https://www.disability-federation.ie/assets/files/pdf/dfi_pre-budget_submission_2024.pdf accessed 05 Jul 2023.

As the Vincentian MESL Research Centre highlights in their recent Pre-Budget Submission, a significant increase in core social protection payments in line with inflation and living cost increases is needed ‘to maintain their real value, in line with inflation and the impact of living cost increases impacting households on low incomes’.²

Whilst inflation impacts everyone in society, in all parts of Ireland, and across all social classes, communities and backgrounds, Autistic people, disabled people and families are acutely familiar with struggling to make ends meet. The CSO highlights that nearly one in two disabled people (44.3%) who are unable to work live in deprivation.³ This is one of many statistics which reflect the reality for many Autistic people’s families who have been feeling the financial squeeze for many years. Many families are dealing with the longer-term consequences of cuts to disability services which happened during the economic crisis and subsequent recession – including changes to medical card eligibility, respite services and home support, and changes to necessary grants which have not been fully restored. This is reflected in the latest European Commission statistics for Ireland where disabled people are twice as likely to experience poverty and social exclusion as non-disabled people.⁴

Adding to this picture is that family carers provide a significant amount of informal support which is neither formally recognised nor fully recompensed by the State.

The Indecon Cost of Disability Report states that

“There is a need to recognise the impact on families of individuals with a disability and in particular, the loss of earnings and sacrifices made by families in caring for those most in need.”

This was also echoed by both the Joint Oireachtas Committees on Gender Equality and Autism respectively, who found that care should be valued by the State and that carers should receive proper compensation for caring for our loved ones.

In our Pre-Budget Submission, AsIAM includes proposals which will address both cost-of-living and quality-of-life issues that many in our community have been experiencing in recent years, which we set out earlier in this submission.



2. Vincentian MESL Research Centre, ‘Pre-Budget 2024 Submission’, p. 1, https://www.budgeting.ie/download/pdf/vincentian_mesl_research_centre_-_pre-budget_2024_submission.pdf accessed 03 Jul 2023.

3. Disability Federation of Ireland, ‘Pre-Budget Submission 2024’ p. 2, https://www.disability-federation.ie/assets/files/pdf/dfi_pre-budget_submission_2024.pdf accessed 05 Jul 2023.

4. European Commission, ‘Ireland 2023 Country Report’, p. 57 https://economy-finance.ec.europa.eu/system/files/2023-05/IE_SWD_2023_607_en.pdf accessed 05 Jul 2023.

The Cost of Not Having the Same Chance

Having to manage the additional costs of disability is a common experience that many Autistic people and disabled people experience. Advocacy groups such as Disabled Persons Organisations, self-advocates, organisations representing people with disabilities and families, service providers, and wider civil society, have put into the public domain the obstacles that can come with having to meet the additional financial costs of meeting a disability, as well as the often-interdependent relationship between poverty and disability.

Many Autistic people apprise AsIAM that they do not have the same chance to belong, feel accepted or take part in Irish society, and that they face the cost of this exclusion in many aspects of their lives. For example, many families are faced with a situation that they must give up their job or cut short their working hours to support their family member, because of the lack of supports available. Many disabled people also share stories of having to use a significant part of their income to pay for additional expenses, such as access to private therapies and supports, additional clothing, or heat or light over the winter months, for assistive technology, for accessible taxis or other forms of transport in suburban or more rural parts of the country.

This hardship has been brought into sharp focus as the cost-of-living crisis came to the fore. Autistic people have been very much affected because of social exclusion and by experiencing barriers to access and participation in areas such as education, employment, and in making transitions between these two areas.

Research has suggested that overall disabled people have a significantly lower income compared to the general population – many disabled people receive an annual income of around €8,000 per year.¹

Research commissioned by the Department of Social Protection and Indecon estimates that the additional costs of living with a disability is between €9,500 and €11,700, including unmet needs of around €2,522 - €3,821 per year due to the higher cost of everyday living expenses such as fuel and electricity, transport, medical and therapeutic expenses, transport, domestic services, equipment aids and appliances, clothing, food.² Additionally, research from the ESRI (Economic Social and Research Institute) on poverty in Ireland shows that households with one or more disabled adults, and those supported by lone parents, experience some of the highest poverty levels in the State.³

These costs can be particularly high for Autistic people and families in Ireland, which are estimated to be as high as €28,464.89 due to the cumulative loss of earnings experienced by families having to give their job or curtail their working hours, the financial costs of accessing supports and assessments within the private sector, and all the additional costs that come with living as a disabled person or Autistic person in Irish society.⁴

Budget 2024 must recognise the daily work carried out by carers around Ireland and significantly increase the financial supports available to carers and families. The below key asks in our Pre-Budget Submission if implemented would mitigate some of the financial challenges that families and individuals are currently enduring and brings our community closer to having the same chance to fully take part as active citizens in Irish society.

1. Indecon, 'The Cost of Disability in Ireland', p. vii, <https://www.gov.ie/pdf/?file=https://assets.gov.ie/206636/f8e1b2af-af48-442b-9ca0-aff9efd35bd7.pdf#page=null> accessed 05 Jul 2023.

2. Indecon, 'The Cost of Disability in Ireland', p. viii, <https://www.gov.ie/pdf/?file=https://assets.gov.ie/206636/f8e1b2af-af48-442b-9ca0-aff9efd35bd7.pdf#page=null> accessed 05 Jul 2023.

3. Economic Social and Research Institute, 'Identification of Skills Gaps among Persons with Disabilities and their Employment Prospects' p. 21, https://www.esri.ie/system/files/publications/SUSTAT107_1.pdf accessed 06 Jul 2023.

4. A. Roddy, C. O'Neill, 'The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?' (2019) (23)(5) Autism 1106, 1106.

A key objective which is important for the success of the Autism Innovation Strategy, which AsIAM urges the Government to legislate for in its lifetime, is to increase investment on actions which support Autistic people and the wider community to have the same chance, to be accepted, and included, as themselves. Through our engagement with the community across our Autism Information Line and our Adult and Family Support Programmes, we highlight that there are many barriers to access and inclusion which shape how Autistic people and families experience living in Irish society.

In our 2023 Same Chance Report, we highlight the extent of these barriers that Autistic people and the wider autism community deal within Irish society, including:

- 38% of Cardholders have experienced some form of discrimination because they or their family member is Autistic.
- 30% of Cardholders reported that a lack of services and supports were the biggest barriers to inclusion and participation.
- 86% of respondents believed the Irish public understand enough about Autism to support their inclusion and participation.
- 81% of Cardholders believed that the realities of being Autistic in Ireland have made the cost-of-living crisis more challenging for them personally.
- 95% of respondents want a National Autism Strategy to be enacted or implemented.

Autistic people and their families experience specific barriers across different strands in Irish society. These barriers were highlighted in the [Same Chance Report](#), where 78% of respondents did not believe the social protection system is inclusive of Autistic people based on their experiences.

In accessing social protection, we highlight in our advocacy that there are inconsistencies when classifying who among the disability and Autistic communities may be entitled to supports. We also highlight across several submissions that Ireland uses a medicalised system of functional assessments which organisations like the [European Disability Forum](#), an organisation who advocate for the rights of the disability community across Europe, believe to be incompatible with the United Nations Convention on the Rights of Persons with Disabilities, and its provisions around social protection found in [Article 28](#) of the Convention.

AsIAM believes that the Government should include measures in Budget 2024 which focus on building more inclusive communities, some of which are included above. We also recommend that the Government puts in place the following measures which aim to address isolation, social exclusion, poverty experienced by Autistic people and families.



From the Joint Oireachtas Committee on Autism Final Report, ASIAm would like to see further investment into delivering the following actions:

- Enact legislation which requires the State to publish an autism strategy every three years. Establish a committee or monitoring group featuring Autistic people to participate in drafting and monitoring the strategy and require the Minister with responsibility for disability to address both the Dáil and the Seanad every year to provide an update regarding its progress.
- Run a national acceptance campaign which supports Autistic people to participate and be included in all aspects of social and cultural life, including specific campaigns supporting Autistic people in areas such as education, healthcare and employment.
- Ensure that the needs of Autistic people are considered with designing all public services and include the Autistic community when designing autism-specific services.
- Introduce mandatory autism training for all staff in the public sector who work with Autistic people, particularly in health, education, and social care settings.
- Set up a 'One Stop Shop' programme where Autistic people or people who self-identify as Autistic can access information and to support them to access any services or supports, they need.
- Recognise the work of autism groups who support Autistic people and families by setting up a funding stream to support these groups in their work and for more autism groups and Autistic led groups to be set up to support Autistic people across communities in Ireland.
- Set up a 'One Stop Shop' programme where Autistic people or people who self-identify as Autistic can access information and to support them to access any services or supports, they need.
- Recognise the work of autism groups who support Autistic people and families by setting up a funding stream to support these groups in their work and for more autism groups and Autistic led groups to be set up to support Autistic people across communities in Ireland.
- Ensure that the needs of Autistic people are taken into account when designing all public services and include the Autistic community when designing autism-specific services.
- Establish a dedicated cross-departmental unit in the Department of the Taoiseach to facilitate a whole-of-government approach to autism and to embed joined-up cross-departmental services.
- Establish a clear pathway to accessing Alternative and Augmentative Communication (AAC) and assistive technology and ensure that Autistic children and adults can access and retain AAC devices and supports throughout their lives.
- Increase the funding allocated to Alternative and Augmentative Communication (AAC) and assistive technology to ensure that there are sufficient devices available to those who need them as well as training for the families of AAC-users.

With the core disability budget and responsibilities transferring from the Department of Health to the Department of Children, Equality, Disability, Integration and Youth, and with the publication of Joint Oireachtas Committee on Autism's Final Report, this is an opportunity for the Department to deliver transformative change for Autistic people by working on putting into practice the recommendations contained in the Report.

This Government has two Budgets left to deliver on its Programme for Government commitments for disabled people, and when contrasting between the overall health of the economy and the increasingly insecure and uncertain situation that many Autistic people, disabled people and marginalised groups experience, our community rightfully expect the Government to make more concerted progress to deliver its commitment to building a more accessible, equal and inclusive Ireland for Autistic people in this Budget, with a key focus on the Autism Committee's Recommendations via a National Autism Strategy. Delivering on AsIAM's recommendations means that the Government makes significant progress on realising its ambition towards building a more inclusive Ireland for every citizen, including our community, by taking a more proactive approach to supporting our community and tackling barriers to access and participation.

This would create opportunities and remove barriers which would instil more trust among Autistic people and the wider autism community which was highlighted as a key issue within the Autism Committee. Using this Budget as an opportunity to deliver for the at least 1 in 27 people which now comprise Ireland's Autistic community by way of both rolling out both AsIAM and the Joint Oireachtas Committee's recommendations will help fulfil the community's aspirations and have the same chance to belong, feel accepted and be active citizens in our communities and across all strands of Irish society.



Testimonies



“I wish everyone knew how hard I am trying every day to fit in, to be accepted, to have people like me and feel like I am valued as a member of the community”

(Autistic Adult)



“His school offer no alternatives to activities that an Autistic child might find overwhelming (zip lining, arcades, tug of war) My son is just told to stay at home or sit it out”.

(Parent of an Autistic Child)



“My son is waiting for services for the last 6 years; this delay is having a negative impact on his development”

(Parent of an Autistic Child)



“At work, indirect discrimination is rife”

(Autistic Adult)



“Inclusion is not one action, but a multitude of small actions taken across society in different areas to ensure that no matter what service, sector, employer or employee an Autistic person encounters that there is at the very least some understanding that they may need some accommodations or additional time so that both parties can leave the situation happy, and that the other person understood their needs”

(Autistic Adult)



“Manager accused me of lying for not looking in her eyes and would not accept explanation. As a result, I no longer work at the company”

(Autistic Adult)