

FASD Ireland

for everyone living in Ireland with
Foetal Alcohol Spectrum Disorder

Pre-Budget Submission 2026



Awareness | Education | Prevention | Support



September 9th 2024: Ceann Comhairle, Deputy Seán Ó Fearghaill and Cathaoirleach of Seanad Éireann, Senator Jerry Buttimer illuminated the Kildare Street façade of Leinster House red to acknowledge International FASD Awareness Day.



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Tristan Casson-Rennie
Chief Executive Officer



I would like to begin by thanking the dedicated team at FASD Ireland for their work in developing this pre-budget submission. Their expertise, insight, and commitment to improving outcomes for people, their families and carers living with Foetal Alcohol Spectrum Disorder (FASD) are the foundation of this document.

This year, the Taoiseach spoke of a promised step-change in how disability is addressed in Ireland. That promise is both welcome and long overdue. However, words must now be followed by action. This pre-budget cycle offers an important opportunity to demonstrate meaningful progress - however it must not be just through new spending, but also through informed policy choices and strategic investment.

At a time of great economic uncertainty, it is more important than ever that we do not punish our most vulnerable people by delaying or deferring essential support and guidance. The recommendations outlined here are both realistic and are cost-neutral. Each can be fully funded through our proposed ringfenced Alcohol-Related Harm Fund, ensuring that our efforts to support the impact of living with FASD do not place additional strain on the Exchequer.

We recognise and welcome the positive progress made across the disability sector in recent years, and we commend the Government on its renewed focus through the forthcoming New Disability Strategy. But there is always more to do.

This Government has a unique opportunity to leave a lasting legacy - one that takes a whole-of-Government approach to FASD. A National Strategy on FASD would be a transformative step forward, ensuring that no child, no adult, and no family or carer affected by this wholly preventable condition is left behind.

We look forward to working together to make that vision a reality. Thank you for your continued support.

Tristan



About FASD Ireland

FASD Ireland is the national organisation for people living with Foetal Alcohol Spectrum Disorder (FASD) in Ireland, also providing families, caregivers, and professionals with advice, training and signposting. FASD Ireland is part-funded by HSE MidWest Disability Services. We strive to create awareness about the risk of prenatal alcohol exposure at all levels and in turn, work to lower prevalence of FASD. We also work with professionals and provide training that will help them in their work to support people living with FASD – particularly in Education, Health & Social Care and the Justice sector.



Pre-Budget Asks

1. Establish a Whole-of-Government Strategy on FASD
2. Fund a National Prevalence Study of FASD
3. Implement the FASD Aware Schools Programme
4. Introduce a Ring-Fenced Alcohol Harm Reduction Fund
5. Address the Economic Impact of FASD through Strategic Investment

Sustainable support from Government would strengthen the capacity of FASD Ireland and also contribute to broader Government goals of inclusion, early intervention, and improved outcomes for people living with disabilities, in line with the commitments in the Programme for Government.



Critical & Essential Investment

This request for increased core funding is essential for our organisation's sustainability and effectiveness. It supports the fundamental infrastructure needed to deliver our core mission. FASD Ireland is a not-for-profit social enterprise and this ensures our focus on cost effective and appropriate services for the FASD community.

The required increase in funding prioritises our most critical resources: our people and premises. Salaries and associated costs make up over 70% of the budget, ensuring we retain a highly skilled, knowledgeable, dedicated team. The balance supports essential operational costs, including utilities, communications, and professional services - enabling productive and secure work.

Funding for travel and conferences maintains our national presence, engages communities, and ensures our work remains informed by international best practice. It also supports vital messaging and amplifies the voices of people living with FASD. The investment in FASD Ireland will provide stability essential to operate efficiently, safeguard services, and maximise the impact of every euro spent on our programmes.

Investing in FASD Ireland's sustainability is a strategic and cost-effective measure. It enables early identification, reduces pressure on crisis services, and empowers families and professionals to effectively support children and adults living with FASD.

This approach aligns with international best practice and fulfils the principles of the UN Convention on the Rights of Persons with Disabilities (UNCPRD) by actively involving civil society in disability policy and delivery.

Ask 1:

Developing a whole of Government response to FASD

Issue: Foetal Alcohol Spectrum Disorder (FASD) is the most-prevalent neurodevelopmental condition in Ireland. It remains significantly under-recognised and, in many cases, misdiagnosed as one of the 428 co-morbid conditions of FASD. Despite estimates from the HSE suggesting that between 2.8% and 7.4% of the population live with FASD, there is no national standard for diagnosis, no framework of support, and no recognition by the State that FASD is a current public health epidemic.

Recommendation: A whole of Government response to FASD is needed. The Government are asked to:

- Provide core annual funding to FASD Ireland which in Budget 2026 would be €410,000 to sustain the organisation and allow significant growth in service provision, including peer support, advocacy services and extended hours of FASD Hub Ireland.
- Formally recognise FASD as a neuro-developmental disability (NDD) and include it in national health and disability strategies.
- Develop a cross-departmental National Strategy on FASD, in partnership with FASD Ireland and relevant agencies.
- Mandate professional training across the public sector.
- Fund timely and engaging public awareness campaigns to reduce stigma and prevent alcohol use in pregnancy.

Rationale: Ireland has one of the highest global FASD prevalence rates however lacks coordinated support. A national response would ensure recognition, early intervention, and cost-effective responses in education, healthcare, welfare and justice. This aligns with UNCRPD principles and supports scalable services already in place through FASD Ireland, including helplines, training, and advocacy.

International Example: Australia has implemented a National FASD Strategic Action Plan (2018-2028), which provides a comprehensive framework for addressing challenges faced by the FASD community through:

- National diagnostic guidelines and clinical pathways
- Government-funded national support organisations.
- Mandatory training for frontline professionals.
- Public health campaigns targeting alcohol use in pregnancy.
- Cross-sectoral collaboration between Government, researchers, and community organisations.

The model has improved diagnosis and support while reducing stigma—demonstrating the impact of coordinated national leadership on FASD. A similar response in Ireland is crucial for people who live with FASD and their families.

Ask 2:

FASD Prevalence Survey

Issue: There is no definitive data on the prevalence of Foetal Alcohol Spectrum Disorder (FASD) in Ireland. While the HSE estimates 2.8%–7.4% may be affected, this is based on international data from 2017. Without Irish-specific evidence, policymakers, healthcare providers, and educators lack the information needed to plan or deliver services effectively.

FASD is often missed at birth, as less than 10% of the cohort present with visible facial features, or Foetal Alcohol Syndrome (FAS). For the remainder, symptoms emerge during primary education, making early identification difficult, especially without standardised diagnostic protocols. The absence of national diagnostic guidelines leaves families and professionals without direction or support.

Recommendation: Fund a national prevalence study led by the Irish Centre for Autism and Neurodevelopmental Research (ICAN), University of Galway, in partnership with FASD Ireland.

- Sample: 30 randomly selected primary schools, screening children aged 12 and under.
- Children who screen positive will receive full diagnostic assessments.
- Duration: 12 months
- Budget: €250,000

This will provide Ireland's first accurate FASD estimate and establish national research capacity for ongoing studies and training.

Rationale: Reliable data is essential to design effective public health, education, and social care supports. Current estimates are too broad and based on other countries, limiting policy planning. A national study would identify the scale of FASD, highlight regional trends, and guide targeted interventions and future policy, including diagnostic guidelines and awareness campaigns.

The HSE already acknowledges the urgency - citing up to 600 babies born with facial dysmorphism annually, and 9–10 times more with other FASD conditions. This research will transform indirect estimates into actionable evidence.

International Example: The UK's Greater Manchester study (2021) successfully used school-based screening and diagnostics to identify prevalence rates of 1.8%–3.6%, many previously undiagnosed.

Key strengths of that model:

- Feasible school-based design
- Local health and education collaboration
- Population-based data now informing UK policy

Ireland can replicate this success, using a targeted study to finally understand and address the national impact of FASD.

Ask 3:

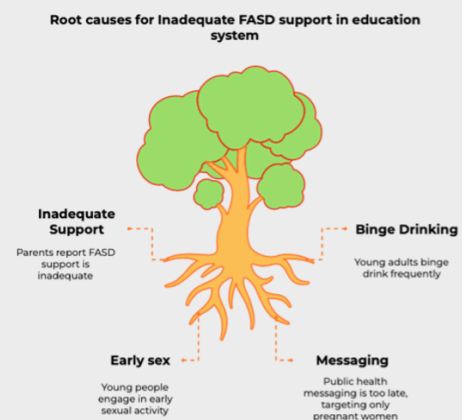
FASD Aware Schools

Issue: FASD prevalence in the education system is high, yet supports remain generic. A 2023 survey led by Dr Katy Tobin at Trinity College Dublin, found 89% of parents/carers felt school support for FASD was inadequate. Over half of children struggled with schoolwork, and 61% were receiving SNA support.

Young people aged 15–24 remain the most likely to binge drink (38%). Though exact data is lacking, national studies confirm a significant proportion of students become sexually active during school years, increasing the risk of prenatal alcohol exposure. Despite this, education on FASD, its risks, and prevention is not part of the school curriculum. Most FASD cases go unrecognised due to delayed symptoms and lack of awareness.

Recommendation: FASD Ireland proposes an awareness programme for Transition Year students.

- One 40-minute session annually in all 722 post-primary schools.
- Content covers FASD symptoms, risks of alcohol use before or at conception, and importance of alcohol-free pregnancy.
- This promotes empathy, inclusion, and better understanding of neurodiversity while supporting national prevention efforts.
- Total programme cost: €215,000



Rationale: Teaching FASD awareness during TY reaches students as they begin engaging in drinking and sexual activity. It builds early understanding, combats stigma, and encourages healthy choices. It also fosters peer empathy and school-wide support for students with FASD.

Existing public health messaging has a narrow focus - often targeting women already pregnant. We now understand that FASD is a conception issue and the risks are present for both men and women. This programme addresses the information gap earlier, empowering students with knowledge to avoid risk.

Example: FASD Ireland piloted the FASD Awareness session in an Ennis secondary school with 60 TY participants. Core information about FASD, its causes, how to prevent the condition, and a presentation from a person living with FASD were all included. Scaling this initiative nationally would create a network of schools that promote inclusion, prevention, and informed decision-making around alcohol and pregnancy.

Ask 4:

Ring fenced Alcohol Related Harm Fund

Issue: Ireland has one of the highest global rates of alcohol use during pregnancy, with 82% of women reportedly consuming alcohol while pregnant - far above the global average of 10%. This is a major contributor to FASD, estimated to affect up to 7.4% of the Irish population, compared to 1.98% in the WHO European Region.

Despite this public health issue, there is no dedicated fund to support FASD prevention, education, or services. Alcohol-related harm costs Ireland €2.4–€3.7 billion annually, yet investment in harm reduction remains limited and fragmented.

Recommendation: FASD Ireland proposes introducing a social responsibility levy known as 'The Alcohol Related Harm Fund' on alcohol sales, based on the "polluter pays" principle. The proposal is:

- 1% levy on on-trade sales (pubs, restaurants)
- 2% levy on off-trade sales (off-licences, supermarkets)

Using 2021 CSO data, this could raise over €100 million annually. A portion should be ring-fenced for FASD-focused services, prevention, and education, with the balance being shared amongst other related providers. This mirrors models like the Gambling Regulation Bill 2022 and recommendations from the Joint Oireachtas Committee on Justice.

Rationale: This levy would shift the financial responsibility of alcohol-related harm onto the industry, not taxpayers. It would make all FASD-related recommendations in this submission cost-neutral, while reducing long-term burdens on the health, education, and justice systems. Ring-fencing funds for FASD would ensure sustainable support, transparency, and public trust.

International Example: New Zealand operates a government-administered alcohol levy, now generating NZD \$16.6 million annually. Collected from alcohol producers and importers, it funds public health campaigns and treatment services under the Pae Ora Act. Ireland faces similar challenges, and this proven model offers a feasible, transparent approach that could be adapted domestically to combat FASD and related harm.



Economic Context:

FASD And The Irish Economy

Issue: FASD impacts all areas of a person's life, resulting in widespread costs across education, healthcare, and justice. While no Irish-specific study has yet been completed, we used prevalence estimates and Canadian data to calculate likely economic impacts. Using the HSE's estimate that 7.4% of the population may be affected, the projected costs are significant—yet remain hidden due to underdiagnosis and lack of recognition.

Education (€2 Billion): Students with FASD face diverse challenges—learning difficulties, ADHD, sensory processing issues—and often require full-time support. Based on CSO figures, around 71,000 students in Ireland could be living with FASD. If each required a full-time Special Needs Assistant (SNA), this would cost approximately €1.9 billion annually. These costs already exist due to unmet needs and misdiagnosis.

Disability (€1.97 Billion): The Indecon report (2021) estimated a cost of €5,148 annually for individuals with developmental disabilities such as Autism or ADHD. People with FASD often present with overlapping needs. In Canada, annual costs exceed €15,000 per person. Given Ireland's higher prevalence, our system is likely incurring similar or greater costs without specific diagnosis or support frameworks.

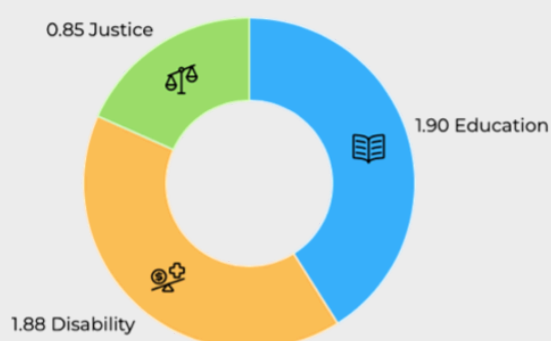
Justice (€89 Million): People with FASD are 19 times more likely to interact with the criminal justice system. Contributing factors include impulsivity, executive dysfunction, and poor judgement. Estimated justice costs—including prison, legal aid, and policing—amount to €89 million annually.

Total Estimated Annual Cost to the Irish Economy: €4.6 Billion

This figure highlights the financial burden of inaction.

Our Ask: A national FASD response, early intervention, and proper supports would reduce long-term costs across sectors, improve outcomes, and provide dignity to affected individuals and families.

Distribution of FASD Economic Costs in Ireland (€Billion)



FASD Ireland is proud to be members of:



FASD Ireland CLG, 51 O'Connell Street, Ennis, Count Clare, V95 YY19

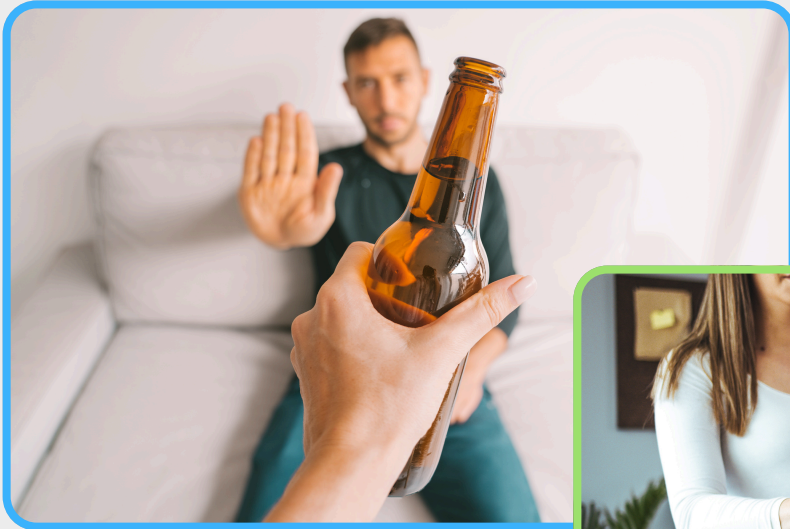
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Plan an alcohol free pregnancy.

No amount of alcohol is safe to drink by the father in the 64 days prior to conception, by both parents at the time of conception, or by the mother at any time during pregnancy.



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