Foetal Alcohol Spectrum Disorder (FASD) in Ireland:

Wellbeing, Living Experience, and The Need for Change

FASD Ireland

RCSI
UNIVERSITY
OF MEDICINE
AND HEALTH
SCIENCES

centre for
positive health
sciences

An Roinn Leanaí, Comhionannais,
Míchumais, Lánpháirtíochta agus Óige
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Foreword

I'm proud to introduce this ground-breaking research into Foetal Alcohol Spectrum Disorder (FASD) in Ireland, carried out by Professor Jolanta Burke with the assistance of Angel Harper, both of the Royal College of Surgeons in Ireland, with valuable insights and contributions from Professor Farhana Sharif.

For too long, FASD has been a hidden disability in Ireland – it's present in every community, but too often it's gone unnamed, misunderstood, or ignored. This report isn't just about numbers; it puts shape on the real lives and challenges behind them. This report shows very clearly where people are falling through the cracks, and it gives us the solid evidence we need, as a country, to put that right.

One priority shines through loud and clear – Ireland needs a national FASD clinic. A place where people of all ages suspected of living with FASD can access the right assessment and diagnosis without having to fight to get a referral to a clinician, or worse, receiving an incomplete or inaccurate diagnosis, and as a result, the wrong care or medication. Without that first step, families are left wandering in the dark, clinical appointments and services are being overwhelmed, lacking the knowledge or ability to help, and people with FASD are denied the understanding and opportunities they should have. A national FASD clinic isn't just a building – it will be a centre of excellence, a lifeline, a place where expertise, compassion, and hope come together.

But getting the diagnosis is only part of the story. This research makes it clear we also need a proper national framework of support – something that wraps around the person living with FASD and their family for the long haul. That means early intervention, real support in school, access to both child and adult mental health services, breathing space when it's needed, and a system that listens to and supports carers. We need to stop leaving families to battle for every scrap of help and instead build a structure that works from day one. My hope is that this report will be the turning point – the moment Ireland finally says: we see you, we understand you, and we'll stand with you every step of the way.

Tristan Casson-Rennie
CEO, FASD Ireland

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Executive Summary

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This report examines the experiences of people living with, or caring for someone with, Foetal Alcohol Spectrum Disorder (FASD) in Ireland. It identifies key themes throughout their FASD journey, evaluates current awareness of FASD among the general public, reviews the literature, and highlights urgent gaps in policy and services.

Why does this matter?

Ireland has the 3rd-highest estimated FASD prevalence in the world. Whilst Ireland lacks enough prevalence research, it is estimated that 1 in 10 people are living with FASD (O'Regan, 2022). No national policy, data collection, and no dedicated services currently exist. Without urgent action, prevalence will increase and outcomes will worsen.

Key findings

1. Insufficient Policy & Healthcare Support

- No national prevalence data.
- Low public awareness.
- Caregivers are dissatisfied with healthcare provision.

2. Public Awareness Gap

- Most people know alcohol should be avoided in pregnancy, but knowledge of FASD/FAS is undocumented.
- There was limited awareness that fathers should not drink pre-conception.
- Online poll: 82% aware of FASD.
- In-person Dublin poll: 82% unaware of FASD.

3. Persistent Challenges for Families

- Social, educational, and emotional difficulties are widespread among the FASD community.
- Healthcare and education systems are unsupportive of people living with FASD.

4. Strengths Amid Challenges

- People living with FASD and their families/carers face significant emotional, social, and systemic challenges, including challenges with emotional regulation, sensory issues, bullying, stigma, and extremely limited access to services.
- It is challenging for families/carers and people living with FASD to recognise their strengths amid their challenges, as they are both stigmatised by their condition and subsequently self-stigmatise. Despite this, many of them have developed a range of character strengths, such as resilience, kindness, and gratitude. Furthermore, they experienced personal growth when supported by informed family members/carers, educators, and communities.

Part 2 of 2

5. Strengths of People Living with FASD and Their Families/Carers:
- Advocacy skills: In the absence of systemic supports, carers and people living with FASD become persistent and knowledgeable advocates of FASD, navigating complex systems to secure support.
- Creativity & problem-solving: People living with FASD often find innovative ways to regulate their emotions and communicate, such as through physical activity, drawing, or music.
- Talents & passions: They demonstrate remarkable talents in music, dance, sports, and trades. These strengths often serve as a source of their self-worth, help them develop an ability to focus, and foster social connection.
- Kindness & empathy: Many people living with FASD demonstrate deep compassion, situational awareness, and protectiveness toward others, which is what they have often learnt from their parents and carers.
- Adaptability: Families/Carers and people living with FASD have developed a range of strategies to help them adapt to new circumstances, learn when to step back, adjust their communication, and create calmer home environments.
- Community building: Families/Carers and people living with FASD seek and form a range of supportive networks, helping them reduce isolation and share knowledge about FASD.
- Self-awareness & acceptance: Over time, some people living with FASD develop insight into their strengths and challenges, using this understanding to advocate for themselves and others.

Urgency

Mental health issues, homelessness, addiction, experiencing the judicial system, including prison, and youth suicide are disproportionately high in the FASD community. Without intervention, these issues will escalate, increasing social and economic costs.

Main Recommendations

1. Education, Training, and Resources - Arrange compulsory FASD-specific training for healthcare professionals. Provide targeted education and training about FASD for families/carers and teachers, alongside better access to resources and support, so they can more effectively meet the needs of people living with FASD.

2. Public Awareness Campaigns - Develop nationwide initiatives to educate the general public about the prevention of FASD, the shared responsibility of both parents, and early intervention where FASD is identified.

3. Dedicated FASD Services - Establish an FASD-specific clinic and secure targeted funding for assessment, diagnosis, treatment, and a lifelong framework of support for people living with FASD and their families/carers.

3. Wellbeing resources - Provide wellbeing resources for people living with FASD and their families/carers that do not solely focus on deficits, but help them to develop psychological, emotional, and social resources to thrive in life.

Authors

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Professor Farhana Sharif is a Consultant Paediatrician with a special interest in Developmental Paediatrics at Mullingar Regional Hospital, Ireland. She is a leading advocate for advancing FASD awareness, diagnosis, and care pathways across Ireland. She has set up Early Intervention Teams in Longford / Westmeath, now called CDNT, which have streamlined care for children with disabilities. She has designed and introduced "The happiness toolkit " - a novel model of care for children with mental and behavioural problems. She is RCSI Clinical Professor of Paediatrics and Regional Teaching Lead. She is also a UCD Clinical Associate Professor and the Clinical Lead for CDNT in Longford, Westmeath, and is academically affiliated with Maastricht University, Netherlands.

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Introduction

Foetal Alcohol Spectrum Disorder (FASD) is a range of adverse neurodevelopmental conditions associated with alcohol consumption. Ireland has one of the highest prevalence rates globally, with approximately 2.8 - 7.4% of people living with FASD (Lange et al., 2017). Despite this, public awareness remains low, and the condition is frequently misdiagnosed or left undiagnosed. The risk of FASD results from any amount of alcohol consumption (1) by the father in the 64 days prior to conception (Roach et al., 2024), (2) by both parents at the time of conception, or (3) by the mother at any time during pregnancy. Prenatal alcohol exposure can cause irreversible physical, cognitive, and behavioural impairments. Most importantly, however, FASD is wholly preventable.

AIMS & OBJECTIVES

FASD Ireland commissioned this report with the primary aim of examining the current supports and challenges faced by individuals living with FASD in Ireland and providing informed recommendations for improvement.
Four key objectives guided this report:

1. To review and assess current organisational and governmental policies relating to FASD in Ireland.
2. To identify gaps in knowledge and establish a research agenda to address these needs.
3. To investigate the effects of FASD on the health and wellbeing of people affected by FASD in Ireland.
4. To develop actionable recommendations for enhancing support for children, young people, and adults living with FASD in Ireland.

Background

Alcohol consumption is deeply embedded in many cultures. It is often perceived as a way for people to celebrate, relax, or unwind after a long day. Social customs such as toasting with clinking glasses, pairing wine with cheese, or grabbing a pint after work reflect its societal acceptance and living a fulfilling life. Yet, despite the global prevalence of drinking, little is known about the impact of alcohol on a developing baby. Historically, this uninformed culture of drinking was passed on by generations. In France, drinking moderate amounts of red wine during pregnancy was seen to stimulate a healthy appetite and blood flow. In Japan, women were encouraged to drink sake during Shinto rituals to pray for a safe delivery. Across Europe and America, alcohol was often given directly to infants and nursing mothers to calm their nerves and stimulate their appetites. Ireland was no different, as it was common for medical professionals to recommend a bottle of stout to pregnant women to boost their iron levels and prevent anemia. Subsequently, the prevalence of FASD is alarmingly common worldwide, as it has become an endemic in several countries, including Ireland.

In this section, we will clarify the definition of FASD and examine its impact on individuals' development, cognition, and behaviour. We will then address the prevalence of FASD, with a particular focus on rates in Ireland compared to global estimates. Then, we will explore the process of how individuals are diagnosed with FASD, examining international assessment protocols and identifying key differences in how diagnosis is approached in Ireland. We will delve into the existing support systems and services available to people living with FASD and their families/carers, highlighting international best practices and comparing them with current provisions in Ireland. Finally, we will examine the existing research on the living experiences of individuals and families/carers affected by FASD, providing insight into the challenges and support needs associated with daily life.

UNDERSTANDING FASD: DEFINITION

FASD is a neurodevelopmental condition which arises from consuming any amount of alcohol by the father in the 64 days prior to conception, by either parent at the time of conception, or by the mother at any time during pregnancy. Contrary to common belief, women's drinking is not the only danger to foetuses; paternal drinking can alter the epigenetic information carried in sperm, resulting in long-term health risks. Using a mouse model, it was found that male alcohol exposure induces mitochondrial stress and epigenetic changes in sperm, which can result in FASD symptoms (Basel et al., 2024). FASD is best understood as an umbrella term that includes a spectrum of lifelong functional limitations and impairments. The diagnostic subcategories under FASD include:

- Foetal Alcohol Syndrome (FAS) - affecting 10% of the overall FASD cohort
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Static encephalopathy/alcohol-exposed
- Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association, 2013), ND-PAE can be diagnosed if alcohol exposure has occurred and if the child demonstrates impaired neurocognitive functioning, self-regulation, and adaptive functioning. Those who meet the criteria for FASD may also meet this criteria.

FASD can look very different from person to person. With roughly 428 co-morbidities (Popova et al., 2016), there are many associated traits. Some of these include: motor difficulties, deficits in cognition, memory, attention, hyperactivity, emotional regulation, and poor social skills (Healthcare Improvement Scotland, 2021). Damage to the developing brain caused by prenatal alcohol exposure can reduce overall brain volume and impact structures critical for executive functioning, memory, and emotional regulation. These effects influence a child's cognitive, social, and emotional development throughout their lifespan (Astley & Clarren, 2000). Moreover, alcohol can impair multiple organ systems, including the liver, kidneys, heart, and endocrine, immune, and gastrointestinal systems (Caputo et al., 2016). The extent of impairment is dose-dependent, and co-occurring exposures (e.g., drug use, domestic violence, poor nutrition) further influence outcomes (Boa-Amponsem et al., 2019; Kleiber et al., 2013). Emerging research also indicates a genetic component to phenotypic susceptibility in FASD, though these pathways remain poorly understood (Sambo & Goldman, 2023).

The most recognisable characteristic of Foetal Alcohol Syndrome (FAS) are facial abnormalities: small eyes, a thin upper lip, and a smooth philtrum (the area between the mouth and nose) (see Figure 1). These traits can vary slightly by ethnicity, but can be easily identified and used as a diagnostic basis (Moore et al., 2007; Senturias et al., 2009). Nonetheless, these facial traits are only found in 10% of the FASD population. This provides a challenge for diagnosis of the condition. A study of 156 children found 80.1% have received a misdiagnosis (Chasnoff et al., 2015); FASD may not always be presented physically, yet neurodevelopmental delays and impairments are still significant. Therefore, it is important to provide better training for professionals. Symptoms of FASD can appear much like autism, ADHD, and other neurodevelopmental disorders, so many people may go their whole lives without knowing they are living with FASD.

Overlap with ADHD and ASD

FASD stands out among neurodevelopmental disorders (NDDs) due to its unique etiology-prenatal alcohol exposure, and a distinct neurocognitive and behavioural profile. While it shares some features with Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and Intellectual Disability (ID), these similarities can lead to underdiagnosis or misdiagnosis. Uniquely, individuals with FASD often exhibit pronounced impairments in executive functioning, memory, language, adaptive behaviour, and motor coordination, which are symptoms that sets them apart from other NDDs.

Figure 1. Examples of the University of Washington 4-Digit Code Rank 4 FAS phenotype (small eyes, smooth philtrum, and thing upper lip) across three races: (A) Caucasian, (B) Native American, (C) African American. Copyright 2025, Susan Astley Hemingway

A key diagnostic challenge lies in the significant overlap between FASD and ADHD. Both conditions commonly present with impulsivity, attentional deficits, and memory impairments; Fryer et al. (2007) reported that up to 63% of individuals with FASD also meet the diagnostic criteria for ADHD. However, while ADHD is understood as a behavioural disorder with presumed neurobiological origins, FASD results from a known teratogenic exposure leading to more diffuse neurological injury (Kingdon et al., 2016). This distinction is crucial, as it implies differing treatment needs and prognoses.

There is also symptom overlap between FASD and ASD, particularly in social communication difficulties and restricted or repetitive behaviour. However, individuals with FASD typically exhibit more externalising behaviour, fewer stereotyped interests, and greater variability in social skills compared to those with ASD (Carpenter et al., 2014). Thus, care needs to be taken when diagnosing young people.

Neuropsychological profiles further help differentiate these conditions. Children with FASD often exhibit marked difficulties in memory encoding and retrieval, and broader executive dysfunction, whereas children with ADHD primarily struggle with attention regulation and working memory (Rasmussen et al., 2006). Neuroimaging studies have shown that structural brain abnormalities such as reduced overall brain volume, corpus callosum thinning, cerebellar anomalies, and atypical cortical thickness are more consistently observed in FASD than in either ADHD or ASD (Norman et al., 2009).

One of the most persistent deficits in FASD is in adaptive functioning, which is a critical domain for individuals' long-term resilience and their independence. While adaptive challenges may be present in other NDDs, individuals with FASD often show more severe and persistent impairments, which become increasingly apparent during adolescence and adulthood as demands for autonomy continue to grow.

Importance of Differential Diagnosis

It is crucial that individuals are given an accurate diagnosis of FASD to guide appropriate interventions and avoid treatments that may be ineffective or even harmful to them. For instance, stimulant medications commonly prescribed for ADHD can have inconsistent or adverse effects in children with FASD, such as heightened anxiety or sleep disturbances (O'Connor & Paley, 2006). Hence, the importance of differential diagnosis in the field of neurodevelopmental disorders. Individuals with FASD have different pathways for treatment, as they tend to benefit more from structured, multidisciplinary interventions that are typically delivered through Children's Disability Network Teams or Primary Care community services. These interventions target core challenges such as executive functioning, emotional regulation, adaptive behaviour, and social skills. Pharmacological support, such as the use of melatonin capsules or clonidine, may also be effective for managing sleep and behavioural difficulties, as in some children with ASD.

Without an accurate diagnosis, individuals with FASD are at significantly higher risk of adverse outcomes, including mental health challenges, school failure, substance misuse, high-risk behaviours, and increased interaction with the criminal justice system (Streissguth et al., 2004). Misdiagnosis may also result in misplaced expectations, lack of tailored support, and further marginalisation. Given these risks, improving diagnostic accuracy and awareness of the nuanced differences between FASD and other NDDs is not only clinically important, it is essential for improving life outcomes for affected individuals.

UNDERSTANDING FASD: IMPACT

People living with FASD are at far greater risk of experiencing difficulties with their mental health, substance abuse, and to face the criminal justice system. Due to the vulnerability of this group, appropriate support needs to be readily available for them. Those with FASD have an average life expectancy of 34. This is remarkably concerning given 15% of deaths are caused by suicide, 7% from substance abuse, and 4% from mental and behavioural disorders (Thanh & Jonsson, 2016). Furthermore, Dirks et al. (2019) found that 26% of participants living with FASD had made at least one attempt on their life, and 35.2% of US teenagers had experienced suicidal ideation within the last year; most alarmingly, only male participants reported a serious suicide attempt (O'Connor et al., 2019). Those living with FASD pose as high risk for mental health issues, with men in particular at higher risk of attempting suicide. It is vital to recognise them as high risk so that early intervention can be made.

Patients in America demonstrate a multitude of adverse life outcomes as a consequence of late diagnosis (see Figure 2). A series of surveys and interviews found patients often demonstrated inappropriate sexual behaviours, disrupted school experiences (such as suspension or expulsion), and trouble with the law. Furthermore, drug and alcohol abuse were occurrent in 35% of those aged 12 and over. These adverse outcomes became apparent from a young age (mean age of onset was 9 years old). They found that the age of diagnosis significantly affected the likelihood of these outcomes to occur, with the chances of these outcomes occurring increasing by 2-4 times if they received a diagnosis after 12. Similarly, home environment, such as instances of abuse, increased the likelihood of adverse outcomes. The authors argue that "the longer the delay in receiving the diagnostic information, the greater the odds of adverse outcomes" (Streissguth et al., 2004). Thus, early intervention is crucial.

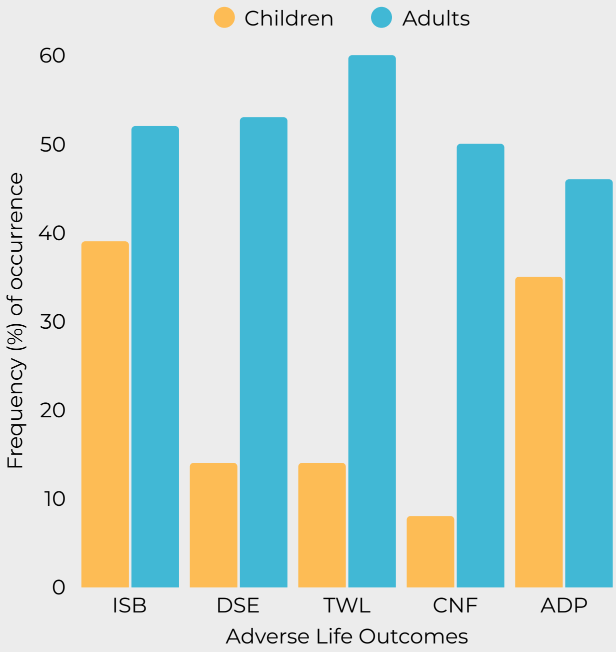


Figure 2. Bar chart to show reports of adverse life outcomes across different ages: inappropriate sexual behaviours (ISB), disrupted school experience (DSE), trouble with the law (TWL), confinement (CNF), alcohol and drug problems (ADP) (Streissguth et al., 2004)

Stigma towards parents whose children live with FASD can significantly hinder care. Parents, and in particular biological mothers, often face judgment from society. They are labelled “child abusers” and are often met with anger or disapproval (Corrigan et al., 2018). This stigma tends to discourage them from seeking help, it obstructs children's diagnosis, and perpetuates FASD misinformation. Furthermore, healthcare providers frequently lack FASD training, do not prioritise diagnosis or misdiagnose it as ADHD or ASD, and show little interest in developing relevant expertise. As a result, many cannot recognise FASD, make referrals, or provide effective treatment. Such attitudes reinforce negative stereotypes, undermining prevention and care efforts.

People living with FASD also experience positivity and strength, factors which are important to acknowledge amidst the stigma of the condition. Flannigan et al., (2021) investigated the role of strengths in those living with FASD across 19 studies focusing on their lived experiences. They discovered that children living with FASD were reported to thrive in a school environment, that they engaged in sports and art, and that this success was largely due to their positive relationships with their parents/carers. Adolescents living with FASD were reported to have particular skills in art, music or sports, and that they were kind and compassionate towards others. There was an overwhelming message of the strengths of human connection, self-awareness, and perseverance when facing challenges. Such strengths illicit hope for the future, and demonstrate that those living with FASD are not condemned; stigma and societal challenges are not the only traits that define FASD.

IDENTIFYING FASD: DIAGNOSIS AND ASSESSMENT

The prevalence of this condition is difficult to assess for several reasons:

- Many prevalence studies rely on parents/carers answering truthfully in questionnaires, and given the stigma around the topic, this may be difficult to obtain.
- FASD is frequently misdiagnosed with other conditions such as Autism or ADHD (Chasnoff et al., 2015; Ergun et al., 2021). Therefore, those living with FASD may not be aware and may never receive the appropriate support for their condition.
- There is little to no accessibility for patients to receive a diagnosis of the condition in Ireland. This can have a devastating long-term impact on mental health or adverse life outcomes, including challenges with the law (Streissguth et al., 2004).

Despite these limitations in prevalence estimates, the Health Service Executive (HSE), the Irish healthcare system, reports that between 2.8 and 7.4% of the Irish population live with FASD (HSE, 2022a). In a review of 24 studies worldwide, the global prevalence of FASD is estimated to be 7.7 in 1000. South Africa had the highest prevalence with 111.1 per 1000, second was Croatia at 53.3, and third was Ireland at 47.5 (Lange et al., 2017). This is a very high rate given FASD is a preventable disorder.

Timely diagnosis is critical for improving outcomes and providing appropriate support. However, diagnostic services for FASD remain limited globally, and in Ireland, the absence of a national framework has created further barriers to early recognition and intervention.

Internationally recognised models include:

- The Canadian Diagnostic guidelines (Cook et al., 2016) involve the use of a multidisciplinary team to assess impairments in three or more neurodevelopmental areas.
- Adapted from the Canadian guidelines, the Scottish Intercollegiate Guidelines Network (SIGN) (Healthcare Improvement Scotland, n.d.) uses a multidisciplinary approach covering physical examinations, risk factors, criteria for diagnosis, neurodevelopmental assessments, medical assessments, and more.
- The 4-Digit Diagnostic Code developed by Dr. Susan Astley at the University of Washington (Astley & Clarren, 2000), which is widely adopted and includes a facial dysmorphology scoring system

Part One: Background Research

This section consists of two components. The first is a scoping review of government and healthcare reports regarding FASD from the United States, Canada, the United Kingdom, and Ireland. The second is a needs analysis conducted to assess public awareness of FASD in Ireland.

A Review: Organisational and Governmental Policies

It is important to explore international government policies and organisational responses to FASD to help us identify best practices, highlight gaps in Ireland's current approach to FASD, and support research-informed policy development. Other countries offer models of effective diagnosis, support, and public awareness that Ireland can learn from. Comparing these systems is useful so that we can help advocate for stronger services, reduce stigma, and promote better supports for individuals and families living with FASD. It also ensures that Ireland's response to FASD aligns with international standards of care, equity, and human rights.

We will begin this section by outlining the methodology used to explore policies and organisational actions across Canada, the United States, the United Kingdom, and Ireland. This will be followed by a review of the relevant literature, focusing on public awareness campaigns, prevalence and diagnosis, current alcohol consumption guidelines, and associated costs. The section will therefore address the first objective of this research, which is to review and assess current organisational and governmental policies relating to FASD in Ireland.

METHODOLOGY

This review assessed governmental reports and documentation regarding FASD. The United States of America, Canada, and the United Kingdom were selected because they have a significant body of accessible FASD policy documents in English and are influential in shaping international discourse on FASD.. Governmental and healthcare websites were accessed from each country, where specific keywords relating to FASD were used (see Table 1). Any documents pertaining to FASD/ FAS were included for this review.

Table 1
Key Words Used for Review

Key Words	
AND	"FAS" OR "FASD", OR "Foetal Alcohol", OR "Fetal alcohol"
	"alcohol", OR "alcohol guidelines", OR "drinking", OR "resources", OR "statistics", OR "prevalence", OR "campaign", OR "awareness", OR "support", OR "diagnosis"

THE PUBLIC: AWARENESS AND CAMPAIGN IMPACT

FASD is completely preventable; therefore, public education and awareness are paramount. The more educated the public, the less likely there will be instances of inappropriate alcohol consumption leading up to and during pregnancy. A systematic review of 10 studies found support that increasing FASD awareness decreased the likelihood of drinking during pregnancy (Jacobsen et al., 2022). Thus, awareness campaigns can become effective strategies for preventing FASD. Let us explore the campaigns:

For Health Canada, Environics Research Group Limited (2000) conducted a national survey of 1,205 people across Canada and found that many participants were aware that alcohol should not be consumed during pregnancy. However, 51% thought that a small amount was safe, and 11% men and women who tended to drink more frequently were more likely to hold inaccurate beliefs. Furthermore, while 71% were aware of the term "FAS," understanding of its meaning was limited. Following this, a review commissioned by the Public Health Agency of Canada (Burgoyne, 2006) evaluated FASD campaigns conducted by the Canadian government between 2000 and 2004. The campaigns' prevention strategies varied from broad public announcements in the newspapers or billboards to targeted programmes for high-risk individuals. Participants were followed up with a phone call to identify their recall of the main messages. The Born Free campaign reported 73% recall and a 68% recall. The With Child campaign found a 78% recall and a 69% detailed message recall. Be Safe reported a 62% recall. Overall, there was a high recall rate from the campaigns, indicating that FASD education can increase awareness and understanding of the condition.

In the UK, public awareness of alcohol guidelines during pregnancy is inconsistent. A Health Needs Assessment carried out by Trathen (2021) found that confusion may stem from conflicting advice between the Chief Medical Officers and NICE guidelines. A NOFAS (2019) poll found that 76% believed abstaining from alcohol in pregnancy is safest, with awareness levels varying by age, gender, and region. Women and older respondents scored the highest. A Greater Manchester #Drymester campaign ran between 2018 and 2021, focusing on the motif "No safe time, no safe amount" (Reynolds et al., 2021). It received 1.4 million views, with 80% of views from expectant mothers. A follow-up survey found 80% of those exposed to the campaign correctly believed that drinking during pregnancy is unsafe, compared to 53% who had not seen it. Thus, the campaign demonstrated that exposure to FASD education significantly improved the awareness of safe drinking practices.

Moreover, the UK Seashell Trust and the National Organisation for FASD (2020) developed a language guide to reduce stigma and promote respectful, accurate terminology (e.g., "person with FASD" rather than "FASD kids"). This guide could help to reduce stigma in the community and ensure future campaigns targeting at-risk individuals reach their target audience. Similarly, in the US, the Centers for Disease Control and Prevention (CDC) created a Let's Talk toolkit (CDC, 2025a). It offered free, accessible materials for professionals and the public on FASD. However, while their content has been useful, their effectiveness was not measured. Thus, it is crucial to develop FASD educational materials that improve awareness about the condition and how to prevent it; it is also crucial to ensure their effectiveness is assessed.

The U.S. has launched several FASD awareness campaigns, including those led by NativeAIR under the National Institute on Alcohol Abuse and Alcoholism (NIH). One such initiative, the Changing High-risk Alcohol Use and Increasing Contraception Effectiveness Study (CHOICES), used posters, radio ads, t-shirts, brochures, and follow-up phone calls targeting non-pregnant Native women to raise awareness (Hanson et al., 2012, 2013). The intervention led to a significant reduction in pregnancies at risk of alcohol exposure. However, participant numbers dropped from 231 to just 51 over 12 months, highlighting the challenge of retaining engagement. While the campaign shows that FASD awareness efforts can be effective, sustaining participation remains critical for long-term impact.

Over 7000 members of the Irish public took part in the Healthy Ireland survey (Department of Health, 2021) and found that 84% of participants were aware that alcohol should not be consumed during pregnancy. Similarly, a poll with 1001 Irish adults found that 78% of adults agreed pregnant women should not drink (Sheehan, 2025). While these figures are encouraging, there is little information available about public awareness of the shared responsibility of both parents to abstain from alcohol and the consequences of prenatal alcohol exposure or knowledge of FASD. At the time of writing this report, the HSE has published no data assessing public awareness of the condition. This represents a significant gap in the literature, as such data is essential for designing effective prevention campaigns. Understanding which demographics are at higher risk and evaluating the impact of current education efforts is crucial, especially given that Ireland is estimated to have one of the highest prevalence rates of FASD globally. Greater public education about FASD is clearly needed.

A HSE (2022b) position document on FASD prevention outlines several campaigns promoting the message that “no amount of alcohol at any stage of pregnancy is safe for your baby.” The HSE argues that such messaging can significantly reduce harmful drinking behaviours, citing the success of similar campaigns in Canada (Burgoyne, 2006). Although the Public Health Act (2018) introduced mandatory pregnancy warnings on alcoholic beverages, implementation is still pending. The HSE maintains that these labels will help reduce alcohol consumption and associated harm. The ‘Ask About Alcohol’ campaign also revealed that many women lack clear guidance on alcohol use during pregnancy. The document further highlights a national gap in understanding whether women know or follow recommended alcohol guidelines.

To address this, two key initiatives have been developed: Making Every Contact Count (MECC) encourages healthcare professionals to deliver brief behavioural interventions on issues like smoking, diet, and alcohol use (Meade et al., 2022). While still ongoing, its effectiveness has yet to be evaluated. Another programme, Support, Ask and Assess, Offer Assistance, Refer (SAOR), provides online training to equip professionals with intervention skills (SAOR, n.d.). The HSE intends to implement both MECC and SAOR nationally. If delivered effectively, these initiatives could play a vital role in disseminating FASD-related education. Given the evidence of the positive impact of public awareness campaigns elsewhere, they could significantly impact the prevention of FASD in Ireland. It is worth noting that neither of the HSE programs raise awareness of the responsibility that men have in preventing FASD, and this is a significant oversight. In addition to this, despite being a member of the United Nations on the Rights of Persons with Disabilities (UNCRPD), an international treaty to protect human rights of disabled people (National Disability Authority, n.d), Ireland still does not recognise FASD as a disability. Such campaigns cannot be truly impactful if FASD is not attributed the resources and acknowledgement that the UNCRPD recognises it needs.

The HSE provides online resources to raise awareness about safe drinking during pregnancy. The My Child website (HSE, 2023) includes accessible information on how alcohol can cause FASD and what its signs look like, supporting both prevention and early recognition. Similarly, the My Pregnancy Book (HSE, 2020) offers detailed guidance on pregnancy and childbirth, including FASD-related content. These freely available materials are valuable tools for expectant parents in Ireland. Despite these efforts, a significant gap remains in Ireland, whereby there is no data on public awareness of FASD or the effectiveness of current prevention initiatives. While general knowledge of safe drinking practices is encouraging, a deeper understanding of FASD is lacking. International research shows that confusion, especially about whether “small amounts” of alcohol are safe, can lead to increased FASD risk. Rich, detailed public education is essential to dispel this uncertainty.

Both Canada and the UK have identified lower awareness among men, suggesting a need for targeted interventions. Adopting stigma-free language, such as that recommended by the Seashell Trust, could also improve outreach. Although Irish surveys show widespread recognition that drinking during pregnancy is unsafe, it remains unclear how much the public understands about FASD itself. Given Ireland’s high estimated prevalence, this is a critical gap. The introduction of initiatives such as MECC and SAOR, if widely implemented by healthcare professionals, offers promising channels for improving public education. However, without data to measure impact, it will be difficult to evaluate their success. Internationally, awareness campaigns using diverse media formats have demonstrated strong message recall. Ireland's new initiatives are a positive step, but further research and evaluation are needed to ensure meaningful progress in FASD prevention.

PREVALENCE AND DIAGNOSIS

Estimating the prevalence of FASD is consistently difficult across countries, largely due to limited diagnostic options and inadequate training among healthcare professionals. While several diagnostic guidelines exist, there is no globally accepted standard. Most countries rely on the Canadian guidelines, with the UK adapting them for local use. Irish caregivers have also expressed frustration with the current lack of a diagnostic pathway, citing delays and a lack of interest or support.

It is estimated that in 2018, 6–17% of children in the UK may have FASD, particularly those from unplanned pregnancies (McQuire et al., 2019). This estimate was based on a large sample of participants (n = 13,495), though incomplete data may have affected the accuracy. In Canada, a national health survey identified that only 0.1% of children were diagnosed with FASD, rising to 1.2% among Indigenous children (Palmeter et al., 2021). However, among the children in high-risk populations, such as those on First Nations reserves or in foster care, were not included, thus the true rate is likely underestimated (Bower et al., 2018; Popova et al., 2017). The CDC estimates that 1 in 20 children in the US may be affected by FASD (Fox et al., 2015), though this estimation is based on data from children aged 7–9 and excludes diagnoses that were made later in life. Ireland's FASDCare report cites a prevalence estimate of 2.8–7.4% (Lange et al., 2017), but similarly lacks robust national data. Despite different estimates, all countries acknowledge the serious public health concern FASD presents and the limitations in tracking it accurately.

For diagnosis, Canada's 2016 guidelines (Cook et al., 2016) take a multidisciplinary approach, including neurodevelopmental assessments, physical exams, and parental alcohol use screening. Diagnosis can be made even without confirmed alcohol exposure if neurodevelopmental impairments are evident. Scotland's SIGN group has adapted these for the UK, but does not yet include treatment guidance. The 4-Digit Diagnostic Code (Astley, 2004) is widely used, assessing four features—growth deficiency, facial features, brain abnormalities, and prenatal exposure—on a severity scale. This method has been used by multidisciplinary teams and resulted in training over 2,000 professionals in 38 countries in how to diagnose FASD (FAS DPN, 2024). It is now freely available online, and when implemented widely, it can potentially improve diagnostic access globally and result in more accurate prevalence rates worldwide.

Ireland has not adopted a formal diagnostic standard. According to the FASDCare report (Tobin et al., n.d.), caregivers face long waits and multiple referrals, with some told a diagnosis is "assumed" but not confirmed. Of the 70 caregivers surveyed, 51 had received a diagnosis, but 89% reported dissatisfaction with the current healthcare services. Many stated their children were denied treatment due to resource constraints or disbelief from professionals. These gaps in diagnosis can have devastating long-term consequences. Delays in identification and support increase the risk of disrupted education, mental illness, and involvement with the justice system (Streissguth et al., 2004). Ireland lags behind other countries that, while still lacking a global standard, are making efforts to improve diagnostic consistency.

Overall, there is a lack of a universal diagnostic framework for FASD, which hinders the assessment of accurate prevalence rates and providing young people with early intervention. While Canada, the UK, and the US rely on structured diagnostic models, gaps in access to it and training for professionals persist. Ireland's situation is especially critical. The caregivers of people living with FASD report extreme dissatisfaction with the lack of resources and the systemic neglect from the government (Tobin et al., n.d). Existing tools, such as the Canadian guidelines and the 4-Digit Code, offer promising frameworks that can be applied in Ireland. However, unless they are adopted nationally, across the entire HSE, Ireland's healthcare system will remain unequipped to diagnose or support FASD adequately.

COST

There's little research on the economic cost of FASD, partly because reliable prevalence data is also lacking. Still, existing estimates suggest significant financial strain across multiple sectors, healthcare, education, and criminal justice in particular. Annual direct costs range from CA$762 million to $10.5 billion across Canada, the US, and New Zealand, with justice system expenses alone making up the largest share (Andersson & Elliott, 2018). Indirect costs add billions more. Expulsions from school and criminal justice involvement are common among those with FASD, which are both costly outcomes that early intervention could help prevent (Streissguth et al., 2004).

Workforce productivity is another area of concern. In Canada, FASD-related health and behavioural issues reduce labour output by an estimated 0.03%, costing up to CA$1.08 billion annually (Easton et al., 2014). People with FASD earn significantly less, and caregivers often lose income too. A CDC estimate puts the cost of FAS alone at $2 million per person, amounting to over $4 billion per year (CDC, 2024b). A UK estimate places the national burden at £2 billion, though it's based on US data (Moore & Riley, 2015). A Canadian cost-benefit analysis showed that if FASD services prevented just 28% of related disabilities, the programmes would pay for themselves (Thanh et al., 2013).

Ireland currently lacks any national economic data on FASD. The FASDCare report (Tobin et al., n.d.) calls this a significant oversight and recommends partnering with agencies in countries such as Canada, which already have solid models. However, given Ireland's higher estimated prevalence, the actual financial toll may be even greater.

CURRENT DRINKING GUIDELINES

Drinking guidelines are widely available on government health websites such as the CDC (USA), NHS (UK), HSE (Ireland), and the Canadian Centre on Substance Use and Addiction. These guidelines outline what's considered 'low-risk' alcohol use, amounts that reduce, but don't eliminate, the chance of harm (see Table 2). Each country defines a "standard" drink differently:

- UK: Measures in units—1 unit equals 8g of pure alcohol. A 125ml glass of wine is about 1.5 units, and a pint of 3.6% beer is roughly 2 (NHS, 2022).
- US: A standard drink is 14g of alcohol—roughly one beer or a shot of spirits (CDC, 2024a).
- Canada: Uses 13.45g per standard drink—one beer or small glass of wine (Canada, 2021).
- Ireland: Defines a standard drink as 10g of alcohol—a half pint of beer or a small glass of wine (HSE, 2022).

Canada recommends no more than 27g of alcohol per week, effectively two drinks. This is far lower than the US, UK, or Ireland, where the HSE advises 110g for women and 170g for men per week. These differences may help explain the disparity in FASD rates: between 2% to 3% in Canada (Chudley et al., 2005; Popova et al., 2019) versus an estimated 2.8–7.4% in Ireland.

All four countries advise against drinking during pregnancy, but only the CDC links directly from its drinking guidelines to information on FASD. The NHS provides a separate page on FASD, but it's not prominently linked. Most guidelines warn against prenatal alcohol use but stop short of explaining the risks or consequences, leaving a critical gap in public education.

Recommending higher levels of drinking for men over women raises questions about the appropriateness of this guidance, given that men are statistically more prone to alcohol misuse (Ritchie & Roser, 2024). While drinking guidelines alone don't determine FASD rates, Ireland's high prevalence suggests a need for clearer public messaging. Aligning with the CDC's example, linking alcohol guidelines directly to FASD information, could be a small but important step toward better awareness.

Table 2
Low-Risk Drinking Guidelines by Country

<table>
<tr><th>Country</th><th>Recommends Teetotalism</th><th>Low Risk Drinking for Women</th><th>Low Risk Drinking for Men</th><th>Drinking and Pregnancy</th></tr>
<tr><td>Canada (Canadian Centre on Substance Use and Addiction, 2023)</td><td>“Not drinking has benefits, such as better health, and better sleep”</td><td colspan="2">27g (2 standard drinks) or less per week</td><td>“When pregnant or trying to get pregnant, there is no known safe amount of alcohol use”</td></tr>
<tr><td>UK (NHS, 2021, 2023)</td><td>“There's no completely safe level of drinking”</td><td colspan="2">112g a week (14 units) over the course of three or more days.</td><td>“It's recommended that if you're pregnant or planning to become pregnant you should not drink alcohol”</td></tr>
<tr><td>United States (CDC, 2025b)</td><td>“If you don’t currently drink, don’t start for any reason”</td><td>14g (1 standard drink) per day</td><td>28g (2 standard drinks) per day</td><td>“You shouldn’t drink at all, even in moderation if you are pregnant or might be pregnant”</td></tr>
<tr><td>Ireland (HSE, 2022b)</td><td>“The less you drink the lower your risk of developing alcohol-related health issues”</td><td>110g (11 standard drinks) per week, to be spread out over the week, with at least 2-3 alcohol free days</td><td>170g (17 standard drinks) per week.</td><td>“It is not safe to drink if you’re pregnant or thinking about becoming pregnant”</td></tr>
</table>

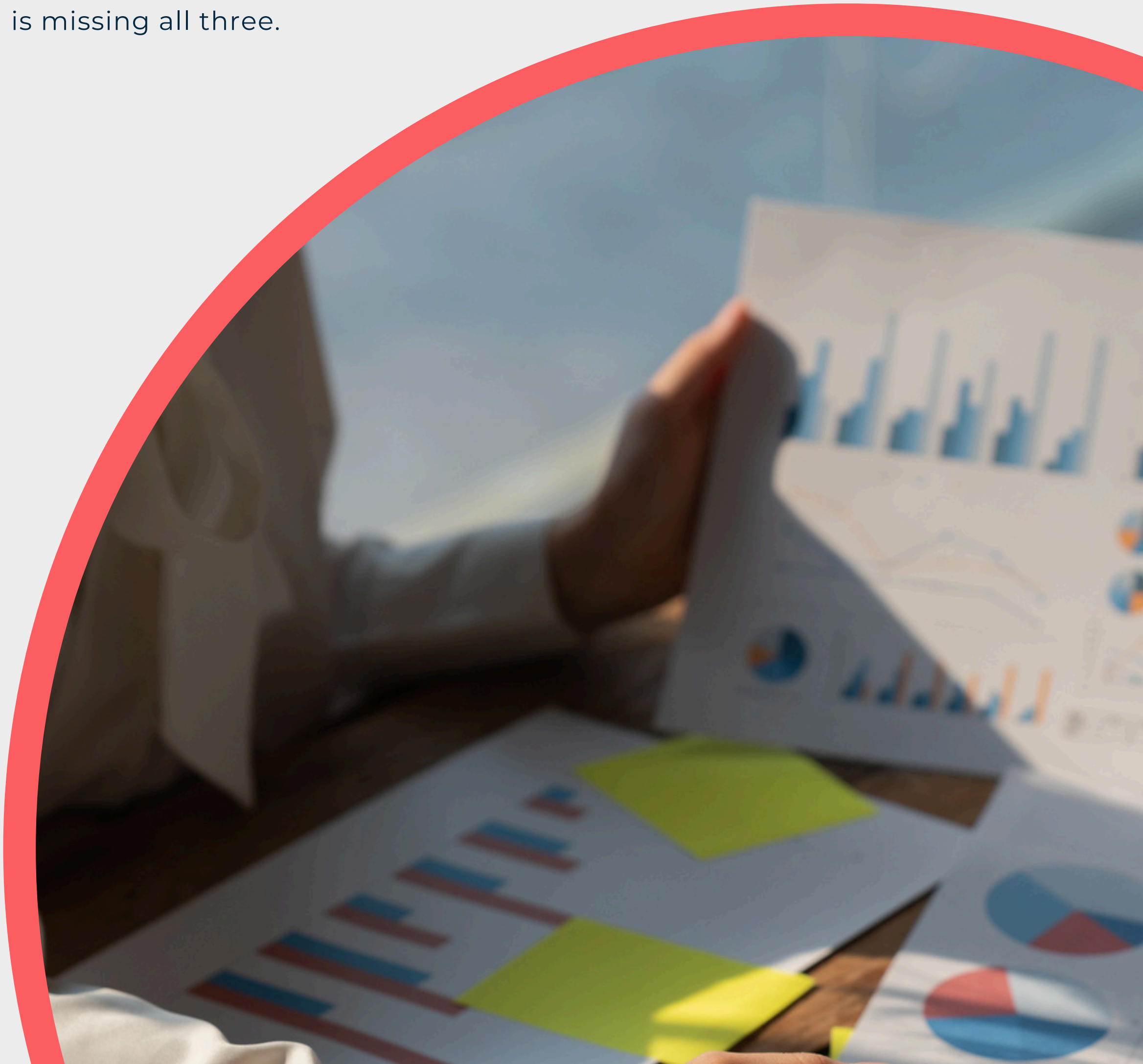
CONCLUSION

Of the four countries reviewed, Canada reports the lowest estimated prevalence of FASD and leads in both research and policy development. Its diagnostic guidelines have influenced other systems, including the UK's SIGN framework. Canada recommends the most conservative drinking limits, backed by current medical evidence, and also displays mandatory warning signs at the point of purchase of alcohol, advising of the harm that can be caused by alcohol to a developing baby.

Meanwhile, the US has developed the 4-Digit Diagnostic Code, which stands out for its scientific rigour and global accessibility. This tool is supported by free training available to medical professionals. The UK's needs assessment offers a detailed synthesis of existing FASD research and highlights major gaps in prevalence data, diagnostic clarity, and public understanding. These issues are not limited to the UK alone.

Ireland, in contrast, shows little research output on FASD. HSE documents lack any real insight into public knowledge or national prevalence. Caregivers have voiced frustration over the absence of diagnostic pathways and inadequate support services. Without trained professionals or standardised tools, individuals with FASD are left without proper care, which may be causing significant harm and long-term costs to families and public systems alike.

At the same time, there is potential for progress. The roll-out of MECC and SAOR in Ireland may help increase awareness and improve early intervention. Ireland could also draw from international examples, adopting Canada's evidence-based drinking guidelines or the UK's inclusive campaign language. Ultimately, prevalence data, public education, and diagnostic access remain the three pillars of effective FASD response. Right now, Ireland is missing all three.



Needs Analysis

A needs analysis was conducted to gauge the levels of awareness and understanding of FASD amongst various populations, and to assess the current institutional procedures in place, to identify next steps in research, clinical and social practice, and policy to bring standards up to an appropriate level.

This analysis consisted of two elements: a three-question poll to assess general awareness of the condition, and interviews with those impacted by FASD.

Public Poll

Two three-question polls were distributed; one was administered online to individuals following various medical social media accounts, and the other was administered face-to-face with individuals stopped randomly in Dublin city centre. They were given multiple-choice questions:

Q1: Have you heard of FASD? (yes-no)
Q2: How much is safe for a woman to drink whilst pregnant? (none, once or twice, only during the third trimester)
Q3: Do you think men can drink when trying for a baby? (yes-no)

The online poll was delivered on JISC, a secure survey software. A link to the questions was posted on various social media accounts, including the Centre for Positive Heath Sciences (CPHS) Instagram. Because of this, the poll was accessible to people from all over the world and received a total of 109 responses. Question 2 responses were aggregated into correct (no) or incorrect (yes). Interestingly, 82% had said they had heard of FASD before. There was also a general consensus that women should not drink whilst pregnant (92%). The final question regarding men's drinking, however, proved to be the most controversial, with 39% thinking that men's drinking habits do not influence the development of FASD (see Figure 3).

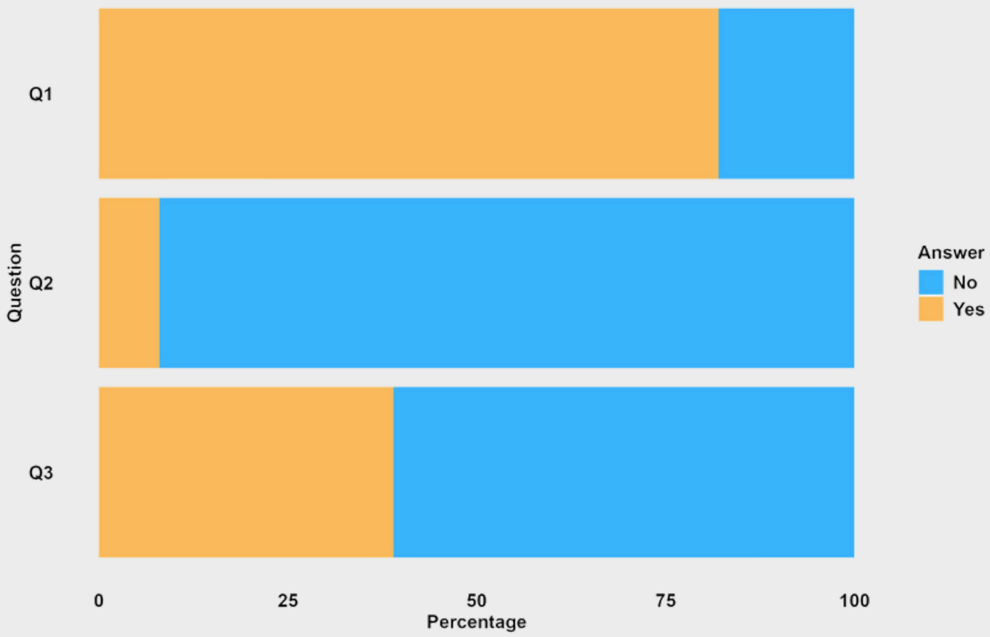


Figure 3. Stacked bar chart to show frequency (%) of yes or no answers to an online poll (n = 109)

The results indicate a relatively good awareness of the condition, but a more mixed understanding of it. Whilst administering the poll online meant a greater number of responses, the sample population does not represent the general public. Given that most responses came from the CPHS post, many participants may have a medical/ scientific background or at least an interest in it; this could contribute towards the high number of those who had heard of FASD.

For this reason, an in-person poll was also conducted. Two research assistants asked random people in the streets of Dublin City Centre the same three questions. Given that there may be regional differences in FASD education, it is worth noting that the poll was conducted in Grafton Street and St. Stephen's Green; these areas are in South Dublin, which may differ from other regions across the city. A tally chart was used to record responses. A total of 50 people took part. Interestingly, answers to questions one and two were very different from the online responses (see Figure 4). Most people had not heard of FASD (82%), and many mistook it for the stroke recognition mnemonic, 'FAST'. Whilst it was still agreed that women should not drink whilst pregnant (98%), the majority of respondents thought that men could continue drinking whilst trying for a baby (72%).

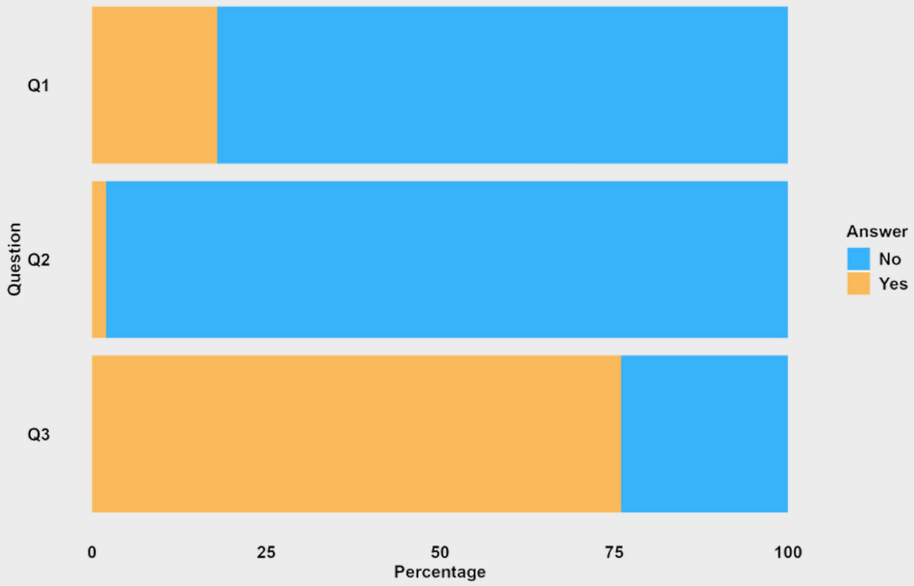


Figure 4. Stacked bar chart to show frequency (%) of yes or no answers to an im-person poll in Dublin city centre (n = 50)

There are many possible explanations for the difference in responses. The most marked being that the online respondents likely had a medical background. The differences in the polls indicate that a population with greater FASD awareness is more likely to have a better understanding of safe drinking practices, as they were less likely to say men could continue to drink when trying for a baby. Whilst there is a considerable number of those who know women should avoid drinking, the most marked finding is the role of men's drinking. Both groups demonstrated much less understanding of how men's drinking can impact a foetus. This highlights the importance of delivering more effective FASD education, especially for men.

Interviews

Volunteers who had been impacted by FASD took part in interviews as part of a needs analysis. A total of 8 people were interviewed, who were either carers of children living with FASD, or those working with them in educational institutions. The interviews followed a Design Thinking process and took place online through Microsoft Teams. The researcher took notes throughout the call, following a Needs Statement structure document to assess the following:

- Stakeholder – the individual, i.e., parent, carer, educator
- Challenges – the key issues or barriers identified
- Root Cause – the underlying factors contributing to the challenges
- Strategies – approaches taken to overcome challenges

This information was then analysed using MAXQDA for a content analysis. This analysis identified a variety of challenges faced by these caregivers, including behavioural difficulties and mental illness. Often, those living with FASD were reported to experience poor emotional regulation, mental illness, learning difficulties, and hyperactive behaviour. There was an overwhelming report of a lack of knowledge and resources for support, but also optimism that interventions have made significant improvements in emotional regulation and wellbeing. This highlights the severe need for carers and teachers to receive better support and to be given more education around FASD. People living with FASD who have access to educated professionals or carers will be able to receive greater support, but currently, there is not enough information available.

Challenges

Parents, carers, and educators have identified a range of challenges experienced by young people living with FASD. The most frequent challenges related to impulsivity, hyperactivity, and difficulties with self-regulation. Many of these young people also experienced learning difficulties, mental illness, and, in some cases, aggressive behaviour (See Figure 5).

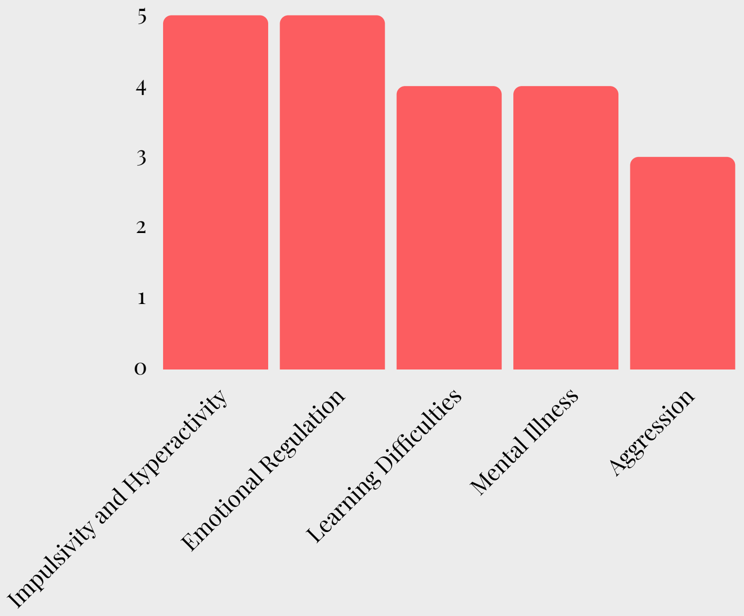


Figure 5. Bar chart to show reported challenges parents or teachers of children living with FASD have experienced (n = 8)

Root Causes

The root causes of the young people's struggles stemmed from a lack of research in the area, a severe shortage of resources specialising in FASD, persistent stigma surrounding their condition, and the absence of wellbeing supports that not only help them manage their mental health but also promote prevention of further conditions (see Figure 6).

Strategies Used

The most effective strategies for supporting young people included engaging them in therapy, teaching and practising breathing exercises, introducing structured reward systems, and incorporating regular movement breaks (see Figure 7).

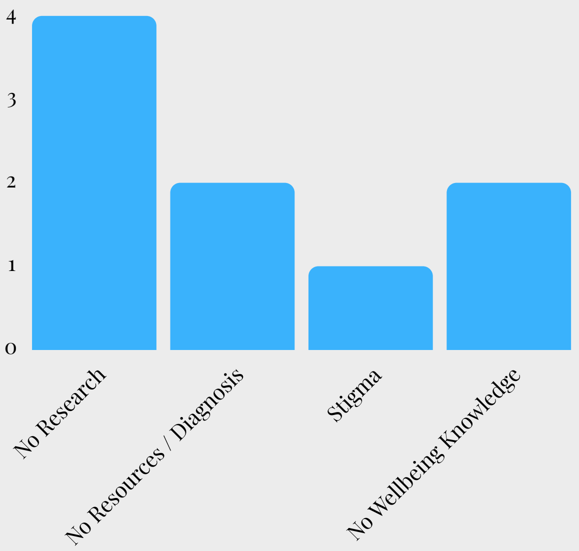


Figure 6. Bar chart to show reported root causes parents or teachers of children living with FASD have identified (n = 8)

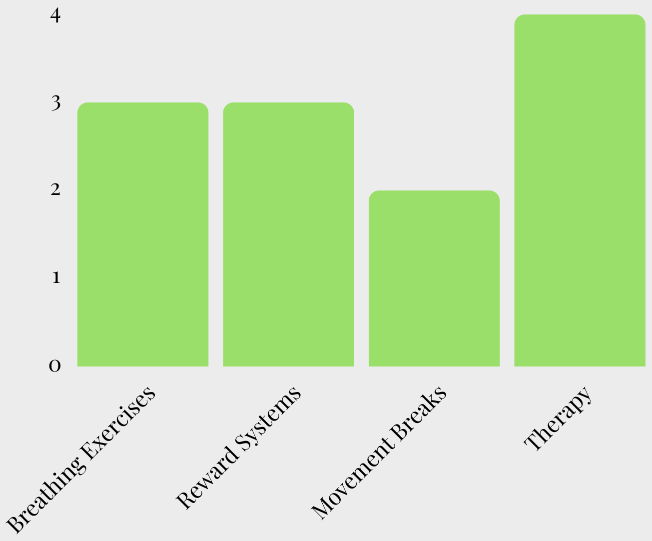


Figure 7. Bar chart to show the strategies used by parents or teachers of children living with FASD (n = 8)

Needs Analysis Statement

Four needs have been identified from the interviews. We need to find a way:

1. To provide young people with FASD access to mental health and wellbeing resources, skill-building opportunities, and supportive environments that promote self-regulation, learning, and social inclusion, empowering them to reach their full potential.
2. To ensure parents and carers of young people with FASD have coordinated access to resources, evidence-based parenting strategies, emotional support, and respite services, enabling them to better manage day-to-day challenges and enhance family wellbeing.
3. To provide educators with targeted training, practical strategies, and access to specialist support so they can effectively address the behavioural, emotional, and learning needs of students living with FASD, while creating inclusive and supportive classroom environments.
4. For government and service systems to implement a coordinated, cross-sector approach to FASD that prioritises research, prevention, diagnosis, resource allocation, and public awareness, reducing stigma and improving long-term outcomes for individuals and families.

Part Two: Research

This section will describe the research conducted by the Centre for Positive Health Sciences, RCSI. This research consisted of narrative interviews of carers and those living with FASD to gain personal insight into how living with FASD has impacted their wellbeing.

Narrative Interviews

METHODOLOGY

Participants were recruited through social media posts and printed posters, which were distributed in public spaces and at conferences. A total of 12 participants took part, with 2 male and 10 female, and an average age of 47 (SD = 14.44). Nine of them were guardians of those living with FASD, and 3 of them either had a diagnosis or suspected diagnosis of FASD. The inclusion criteria were: adults 18 or over, carers of those living with FASD, or adults with a diagnosis or suspected diagnosis. Those without a diagnosis were included due to the challenges many face with receiving a diagnosis in Ireland.

Measures - Interviews included two demographic questions to measure age and gender, followed by questions regarding their life experiences with FASD, with support networks such as healthcare and education, and how this experience has impacted their lives and wellbeing. The research aimed to explore the impact of living with FASD and parenting a person living with FASD on wellbeing.

Procedure - Participants who expressed interest in taking part would sign up on JISC, a secure survey platform, to provide their contact details. Researchers then reached out to them via email, where they were provided with a copy of the information sheet and the opportunity to ask additional questions. After participants consented, an online 30-60-minute interview took place on Microsoft Teams. Interviews were recorded for transcription purposes and were deleted shortly afterwards. Each participant was given an ID, and the transcripts were pseudonymised.

RESULTS

Four emerging themes were identified, encompassing educational wellbeing, social wellbeing, family wellbeing, and identity creation. These themes flowed between each other, often with one linking to another (see Figure 8). All names and personal information in this report have been changed to protect participants' identities.

Figure 8. Themes Identified from narrative analysis of carers and those living with FASD (n=12)

Family Wellbeing

Parenting a child with FASD

Parents and carers of those living with FASD were met with many challenges, including difficulties getting acknowledgement from healthcare services and the mental or sometimes physical toll of caring for someone living with FASD. They also expressed resilience in the face of these challenges, as they constantly advocated for their children. Such experiences have led to significant personal growth and strengthened familial bonds.

Caring for a child with FASD can be challenging; many of these children experience sensory issues, difficulties regulating their emotions, and more. This can have a significant impact on the health and wellbeing of carers. Ellis describes how, from day one, they knew something was different about their son:

"So I went home then and looked because I was always looking at the middle of his face like as a baby thinking, what is that? What is that beautiful angelic little piece here in the middle? Because everyone's bridge is very defined. Everybody has, you know, the bridge is genetic. You can see some of their family always in their nose, which you couldn't see. And then when I went home and looked up FASD features, his little face was sitting there beaming out at me."

Their son's mood can switch suddenly, "just out of nowhere, he'll turn and he'll stay for hours just stuck in this terrible personality", causing arguments to break out at home:
"when he turns, he's so cruel and so manipulative and crazy. Like when he turns it's like a whole other person. It just starts."

These changes in mood and sensory challenges can impact his relationship with his siblings:

"He's mad about them and he hates them. He can't stand being around them because they're too noisy and then he bounces off the house and torments them every 10 minutes. He starts at them, they rise, then he hits them. Then he comes up starts and rises, and so then he feels everybody hates him."

Ellis has been fighting for better support for their son, trying medications, professional help, and even looking at residential homes. This learning experience has helped Ellis discover ways to help their son. For example, Ellis discovered that their son can better articulate himself through emails:

"And then by e-mail, his brain is unbelievable. It's like talking to an adult. It's really, really weird. He was going to my brother's for the weekend, so I was like, 'I want to go there early. So we spent a whole day arranging it, drove to his house, and got him there. All good. 'See you later, love you. ' That night I get an e-mail. 'Hi, mum. For further notice, if asked to go to your brother's for a day, please say no. I am bored. Night. Love you'."

They also reflect on the growth they have made throughout their parenting journey:

"I think we're a lot quieter than we were. We're trying to react a lot less so that he has time to head off and have a little think himself, which he does often come back up with a 'sorry', but it'll be the same behaviour 'I'm sorry again'. But at the moment, we're just doing a lot less of everything we used to do. The house had become very reactionary. And now when he started, if I can feel it starting instead of giving out or talking, I'll just take one of the others' hands and walk away."

Ellis's story is a testament to the learning process and resilience involved in parenting a child living with FASD.

Resilience and Advocacy

Similarly, Sasha recounts their experiences learning how to help their son. Throughout his life, he has dealt with "losing his temper", anxiety, and being exploited by friends because "he's just very vulnerable". Sasha learnt to be patient and understanding of their son's difficulties. In particular, they learnt to offer wisdom, explaining things "slowly" so that he may understand in time:

"so I'll just make him very aware of different things, but rather I'm not ramming it down his throat he has to think it slowly, slowly"

They acknowledge that this learning curve has been beneficial for their parenting but feels regret at the cost of this learning experience:

"This is fantastic, but I regret that sometimes it came a number of years too late for me. I could have done without knowing all this because dealing with this had a very emotional and psychological effect on me. And what I didn't realise this was normal behaviour, and I didn't know how to ask for help. In a sense, I knew to ask for the schools, but I didn't know to ask for help for me. So I was blaming myself for an awful lot."

Sasha emphasises the impact on their own wellbeing, particularly when faced with judgment from those around them, who accused them of "spoiling him" and claiming "he's old enough" to do things on his own. This demonstrates the importance of FASD-related support and education to help carers look after not only their children but themselves also.

When facing these challenges, a consistent theme of resilience and dedication runs throughout. Robin describes their journey advocating for their children, how "nobody really understands anything about it". Robin took matters into their own hands to push to just for someone to see their children. They had been told, "any child coming in with FASD, they will refuse them".

"And I said to the woman at the assessment, I said, 'You do realise a pile of kids in there with all these diagnoses and you're seeing them and the real problem is FAS?' and she says 'probably'. I remember ringing a couple of hospitals, trying to get a secretary for a consultant paediatric neurologist to see would they take the youngest in case I needed medication later on. I said, 'Does she do FAS?', 'No. Just no.' I said 'why?' to the secretary, 'we don't know, but I know that she refuses them'."

After constant advocacy, Robin was able to find a speech therapist "that got it" and that "it's very rare you get somebody that gets it". Robin's resilience and persistence eventually led to a diagnosis for one of their children:

"I think these children will do well if they have a continuous advocate support. Left in a house trying to survive, they will not do well."

In summary, parenting a child with FASD is both a challenging and meaningful journey. The demands of caring are constant, as young people navigate their sensory sensitivities, accept their emotional volatility, and learn to live with strained sibling relationships. Young people often face inadequate healthcare support, stigma, self-stigma, and a lack of professional understanding. These pressures can take a toll on the psychological, emotional, and physical wellbeing of their carers. Despite these challenges, many parents develop many skills, such as resilience, adaptability, and advocacy. They learn new ways to communicate with their children, practice patience, and strengthen family bonds. For many, this experience is a basis for their personal growth and a deeper connection with their child. All this happens as they continue to push against systemic barriers to secure the support that their children deserve.

Educational Wellbeing

School Experience

Participants revealed a mixed experience within the education system, some more positive than others. In particular, many children living with FASD experienced social or academic challenges within school, but many also felt well supported by teachers, even if their awareness of FASD was lacking. In particular, those who sought FASD training were described as more understanding and empathetic towards parents and children. For example, Rowan felt as though the school did not want their son and did not know how to manage his needs:

"So we were at a school meeting and the teacher said, 'Look, it is absolutely your decision. This is his work." And he showed me, like, stuff that he just destroyed. And she basically said, even though she didn't say it with her words, she said, 'Get him out of here. ' We were wearing masks, but the tears streamed down."

Rowan felt they received "no guidance" from the school. They felt "utterly on my own". The prospect that their child may need to go to a special school was upsetting; their "heart collapsed" because:

"to me, I always saw potential in him, and then for somebody to say 'no, he has an intellectual disability', I couldn't see that. For me, he was bright."

When the special school was proposed, it felt very "clinical" and "black and white". However, Rowan recognised that their child "wasn't enjoying school" and was falling behind academically. Once he transferred to a special school, it was "the best decision we've ever made, he's happy". The special needs school was able to provide "specialised teachers and SNAs" and had a better "ratio SNA to the pupils".

Rowan was also able to encourage staff to take FASD training because "this is a unique disability, and the more people know, the better". One of the teachers took the class and said, "your son is not the only child I've ever taught with this condition". Rowan found the mainstream system inappropriate for their son, who was not receiving the support he needed. The special needs school was accommodating of their son's needs, and went out of their way to better educate themselves.

Abilities, Skills, and Talents

Those living with FASD have exceptional skills and special interests such as being "musical", "a super dancer", being a "human SATNAV", good at sports, "an expert at Google Maps", and many more. These skills and interests can offer a respite when stressed, and can be tools for emotional regulation. For example. Robin describes how their daughter experienced severe meltdowns and difficulties regulating her emotions. To help her with this, "one of the best things I ever bought was an in-ground trampoline". When their daughter was in a "really bad" mood, it would "regulate her". Additionally, Taran tells their story of their love for music and how this has helped ground them throughout their life. It started when they were young:

"I just love listening to classical music because I always would listen to classical music when I was very young. So whenever I was going to bed or something, my mum would always put it on for me."

One day, Taran "heard the cello" and decided to learn how to play. They "absolutely love it. It just makes my soul so happy". They talk about how vital the cello has been in their life, grounding them when things have been hard:

"It just calms me down in a way which I actually love. It's definitely gotten me through the harder times. Definitely, when COVID hit, it definitely got me through that. I don't think I could be without the cello in my life. Because I don't know where I'd be. I think I'd be extremely lost if I didn't have the cello to ground me a little bit."

The cello has served not only as a source of great enjoyment and emotional regulation, but also aids their social life. Attending the local orchestra allows them to "just share the experience with other musicians like which I really love, and it's me out socialising as well".

Growth and Progress

Participants have demonstrated the significant growth and progress they themselves, or their children, have gone through. Such as Reese, who recounted how their daughter's teacher was instrumental in her developing confidence. Reese's daughter found going on school trips difficult because of her anxiety. Her anxiety often got in the way of things; she would "worry herself to death". When the opportunity came to visit a concert hall, Reese was concerned for their daughter:

"But the teacher insisted and said 'No'. And I said, as the typical overprotective parent, I said, 'Well, I'll wait outside'... And she said 'No, you won't- I don't want you anywhere near the place'. Because she's right... So I gave in, I said, 'Right, OK'. She said, 'I'll sit beside her on the bus. I'll take care of her'. And she's brilliant. She loved it."

This teacher "just knew exactly how far to push her and when to pull back". Reese's daughter was able to start going out of her comfort zone. She was able to manage her anxiety and have a good time at the concert, and could go on other school trips like the "cinema". Reese and their daughter now live by the mantra that "if you spend your whole time worrying," you will "miss the fun".

Casey's son also demonstrates significant growth when faced with challenges in making friends. He "hated school" and was "bullied" by his peers:

"He screamed every morning getting on the school bus. It was torture, torture sending him to school."

However, after moving school, "for the first time ever, he made friends":

"And he discovered a different way of communicating because he could draw. And he started doing technical graphics and engineering, and he just loved them, really excelled at them, you know. So it kind of carried him through the other stuff."

Casey reflects on his drawing, how this newfound form of communication opened up his self-confidence and self-worth.

"when you are excelling at something, your self-worth improves, and I think for the first time he felt he was worthy to have a friend. I think you know that that's me thinking that but. And he met a fella who shared a lot of his interests, and they had great fun together."

In summary, young people living with FASD often face significant educational challenges. These include difficulties with social connection, academic struggles, and inadequate support within mainstream settings. While some young people are lucky to encounter empathic educators willing to adapt their teaching and eager to learn about FASD, others experience exclusion and misunderstanding due to educators' lack of FASD awareness. Transferring to schools with trained staff and more meaningful resources targeting FASD transforms the educational experiences of young people living with FASD. This allows them to improve their wellbeing and foster a sense of belonging. Beyond formal learning, many young people's unique skills, such as music, sports, or technical drawing, become crucial for their self-expression, emotional regulation, and building their confidence amid their challenges, thus improving their educational wellbeing. Positive connections, meaningful school relationships, and tailored approaches to education are important to facilitate students' personal growth, resilience, and wellbeing. It allows them to balance the positive with the negative impacts of FASD stigma and a range of unmet needs associated with their neurodiversity.

Social Wellbeing

Peer Connection

Unfortunately, it was a common experience for children with FASD to experience bullying or exclusion despite their pro-social nature. Ellis describes how their son “wants friends so badly” but finds friendships “really difficult to maintain” because he plays too rough with his peers. Despite this, outside of school and in the context of his special interests, his social skills flourish. Ellis describes how, at a farming fair, their son was highly social and curious:

“He'll talk to people, he'll talk to adults with animals. Full on have the chats with them like a normal fecking person and then come back and not be able to talk to us at all. Head in the air. Can't have a conversation. At chicken fairs, people will stop us, you know? They’ll say, ‘Come over and see this coop,’ and he’ll talk to the person that built it. And they're like ‘He's asked, every single question that an engineer would ask as to how it's built and how it works’. ‘Is it good enough?’ you know, amazing.”

Ellis’s son demonstrates a highly pro-social and curious nature when in the right environment, highlighting how contextual factors can shape his social engagement with others.

Despite bullying and social challenges being rife experiences amongst the FASD community, there was an overwhelming pattern of desire for connection and compassionate behaviour. Finley describes how their daughter had difficulties with her peers in school. Despite wanting to make friends, she was bullied. Often, Finley’s daughter would not understand that the other children were being mean, so her teacher devised a plan to help:

“So she took her aside and she gave her 4 bodyguards, 4 little classmates, 4 little boys from her class. And they were to look after her. They were to be her bodyguards outside in the playroom, in the playground, in the gym, and when they go off on a trip. They'd mind her and make sure that nobody was bullying her or doing anything that they shouldn't be doing to her. She was included in things you know.”

This intervention enabled Finley’s daughter to feel included with her peers and made school a safer environment.

Relationships

Children living with FASD have also been described as incredibly kind and compassionate, having a positive impact on those around them. Ellis’s son is kind and protective of his siblings:

“Oh, kindness, safety, security. All the things that are his weakest are his greatest. His heart is huge. He's so good, like celebrations, birthdays, anything like that. He's so in charge. His attention to detail is unbelievable.”

His situational awareness and compassion make him “really protective” of his siblings. When his younger sibling woke up in the middle of the night, it was him she turned to for help because she knew she could depend on him when it mattered the most:

“’You were the one she knew would get up and respond to her, and you did, ’ I said, ‘If that was John, what would you have done?’ He said ‘He'd went back to sleep’, I said ‘But you got up naturally’. And he's so kind in those moments.”

Community

FASD faces a lot of stigma in Ireland; many parents feel judged by others when advocating for their children, and acknowledge the challenges biological mothers face. Feelings of isolation were common, highlighting the importance of finding a community that can support and understand.

Biological mothers are often stigmatised. Casey explains how difficult it is for biological parents "to come forward to say their child has it because that would mean that they were responsible". But having worked with many women and pregnant women, Casey recognised that many of these women "didn't know":

"I don't think people can be blamed for not knowing, and if a child has foetal alcohol, I think that no blame culture needs to be reinforced."

Casey had their own experiences of facing stigma, they were told they "need to go on a parenting course" and that "mothers are blamed but they're not supported". It wasn't until Casey discovered an FASD group that they were met with acceptance:

"And they said 'it's not your fault'. And I cried and I said 'I can't believe you just said that', you know, that is the single most important thing anybody's ever said to me about the child."

Joss describes their journey of seeking educational and therapeutic services. Their constant advocacy was viewed as overbearing or overprotective:

"Nobody said a word to us, and at that stage you begin to be deemed over-anxious parents... You nearly see their eyes rolling when we walk into the room. So you learn very quickly to pull it back, to not tell the outside world, not share with the outside world with your intimate circle."

Constantly fighting battles on their own and facing judgment from those they were seeking help from, both Joss and their son lived "a lonely life":

However, Joss came across an FASD community. There, Joss was able to meet others who had gone through similar experiences, "It was like a great white light and then the rest is history". Their son attended an FASD gathering, where he finally felt comfortable opening up about his experiences:

"I said, Do you realise, son? I said, 'You said things that you haven't even said to us, and I think we've known', I said 'we've known. But you weren't able to share. You weren't able to use the words'. And he said, 'Mum, because I never felt so safe in all my life'."

Finding others living with FASD allowed parents and those impacted by the condition to find a like-minded and empathetic community. Similarly, Taran expresses the importance of the FASD community for them:

"Which it's kind of I think very important for someone living with FASD because if you are suspected living with this but you don't have any support out there, it can feel very lonely and isolating. So I think having that kind of social outlet is really like just really, hugely important."

Such community social events can also help parents, such as Robin, who just wanted "somebody that gets how you're feeling".

In conclusion, young people living with FASD often face significant social challenges. These include bullying, exclusion, and difficulty maintaining friendships, even though they express a strong desire for connection, pro-sociality, and have a reportedly compassionate nature. Many thrive socially in contexts aligned with their interests, where their curiosity and skills are valued, highlighting the importance of supportive environments within formal education. Acts of kindness, empathy, and protectiveness toward siblings and peers are common among the young people living with FASD, yet stigma, especially toward biological mothers, can deepen their feelings of isolation. Finding a community, whether through FASD-specific groups, supportive professionals, or peers, can result in an enhanced sense of safety, feelings of acceptance, and opportunities for genuine connection, which ultimately enhances their social wellbeing.

Identity Creation

Meaning of FASD

People living with FASD face many challenges in their day-to-day lives, which is why diagnosis and support are a necessity. Shay describes how they grew up not knowing they had already been diagnosed with FASD:

“So, I grew up not knowing, whereas the people around me knew, but at the same time, back then, they didn't really know what FASD was and so, you know, it was very much trial and error. I was very much the Guinea pig for a lot of things.”

Growing up, Shay was “having meltdowns and struggling academically” but did not know why. Shay blamed themselves for the difficulties they faced:

“but I remember up until that point I thought I was this demon child. Like I would be like, ‘Why did you foster me? Why don't you just put me on the streets?’ I'm this awful person who doesn't learn from their mistakes and has meltdowns and hurts people and says things I don’t mean because I can't control it. And I remember going to my foster parents. Being like, ‘why? Why do you love me? Because I'm an unlovable kid, because I keep having meltdowns or struggling, and I'm not like your other kids’.”

After Shay’s parents told them about their FASD diagnosis, “it was like a weight lifted off my shoulder”. They felt relieved that they were not to blame, and they finally had an explanation. However, they also felt that they still did not fully understand what it meant to live with FASD. This is something they had to learn on their own.

“Like, wait, it's not my fault that I struggle. Oh, wait a minute. I'm not this awful, terrible, unlovable child. And so for me, it was a relief. Looking back now, I wish it had been explained to me a little bit better because a lot of this I've had to discover things like triggering on my own.”

For some time, Shay felt upset at this diagnosis, feeling that “this isn't fair. I didn't ask for this. Why me?”. However, thanks to their parental support, they were encouraged to speak at a community event. Here, they were able to speak to parents of children living with FASD. They met parents who expressed gratitude for Shay sharing their experiences. It was this moment when Shay learnt to accept their diagnosis, and to fiercely advocate for others affected by the condition:

“And yeah, and I think for me that was the changing point where I was like, OK, I have FASD for the rest of my life, it's not going anywhere. I can stay in this ‘This isn't fair. My life is over, or I can do something good with it. And that's where, I guess, my advocacy journey started, where I started speaking out”

Shay’s story is a testament not only to their resilience but their forgiveness and acceptance. They were able to transform their challenges and shame into something inspiring for themselves and those in the FASD community. They have been able to grow, and are no longer “ashamed when I need help”.

Strength Development: Overcoming Aversity

Denial and acceptance of FASD is a common experience amongst those living with it. Taran felt anger about their birth mother’s drinking, and it has taken them time to come to terms with this:

“I think what I found out about it was when I was reading through my kind of adoption notes that I knew my birth mother was drinking and all this and now kind of looking back on it, I'm kind of angry about it. And just I've never been really happy with it, and now I'm only kind of come to terms with it.”

As is the case with Shay, Taran found solace and forgiveness amongst the FASD community. After attending an FASD community event, they were able to meet others like them and realise that they are not alone:

“So I think it was really helpful that I just don't feel alone anymore, that I know there's other people out there living with this and everything. So they must have more challenges. You know, living with it on all this.”

For both of them, receiving a diagnosis can elicit mixed feelings. Anger and frustration, and a sense of unfairness, but also relief that they now better understand themselves. Finding a connection to others who understand them has been instrumental in this process.

However, for many parents, a diagnosis is not only hard to come by but not particularly helpful. Ellis describes how after fighting for healthcare providers to assess their son, a diagnosis of FASD did not open avenues for support:

“Because he didn’t have autism, he wasn’t given any help until he was 10. He was diagnosed with autism at 10. And that's when his services, because there's no services here, one of his OTs had said, you know, ‘unless it's ADHD or autism’, she said, ‘I could have a child here with just a head in a wheelchair and they'll get no services without a mental disability’.”

It was only after receiving an autism diagnosis that their son was eligible for support. Robin also felt that a FASD diagnosis was pointless, stating:

“I'm never going to get an FASD assessment on the older two now because one is aged out, and the way I look at it, and you'll understand this, that it's so badly looked after in Ireland that there's no point. Like, what's the benefits?”

A diagnosis of FASD can mean a lot at an individual level; it can offer an explanation, and relieve feelings of shame, self-hatred, begin a process of forgiveness and can help people accept and love themselves. However, on a wider systematic level, a diagnosis means very little. Children and young adults are not getting the support they need unless they are able to get diagnosed with an alternative condition.

Emerging Adult

Many parents felt “deeply concerned” for the future of their children. In a world with little support and understanding of FASD, the responsibility of care rests on the parents, who worry that their children will never be completely independent. Rowan laments how FASD changed their expectations of the future:

“So at the start, like it was, yeah, your life is crumbling. Your dreams and your hopes that you had for your child and for yourself, for your own life, you know, moving out, have your own life, have your own family, have a job. This is what you think will happen. It most likely will not happen that way.”

Ash expresses concern for the future of their daughter within the education system, they face uncertainty about what resources the school will be able to provide, and how their daughter will manage the “big jump” into the next school year:

“But I don't know where we're kind of at the mercy of... we hope. And then if we have this conversation in six months time, I might have a completely different response here and go ‘Yeah, it's terrible. There's nothing there they can't resource it’.”

Whilst Ash faces these worries, they feel a strong sense of hope that their daughter will manage these challenges. They have faith in her as a person, and her kind nature:

“She's socially comfortable and she's kind; she's very kind with other kids. She's very aware of their feelings and stuff. And I think that will stand to her. And we've always said to her that all of her reports have always been really good in that space. So we said, ‘Don't worry about the learning piece. The being a nice piece is more important, and that will help you’.”

Ash accepts the difficulties but feels optimism for the progress their daughter has already gone through, and will continue to go through:

“It hasn't been easy all the time, but she makes it easier every time she moves forward.”

Yet among these concerns shared, there were also powerful accounts from individuals living with FASD who are forging their own paths. Kit found school “very challenging”. They found it “hard to keep up in class” and felt that “no one acknowledged I was there. They walked right past me, and they’d only use me for fun”. After it “clicked” that their friends were “using” them. Kit decided to make a change in their life. They “stopped trying to be accepted” and eventually decided to drop out of school to do an apprenticeship.

“I've always kind of had a passion to work with my hands and you know, because also I find that I started working with my cousin when I was 10 or so going down to him at the weekends, helping him out and ever since then, I was like, ‘this is what I want to do’. I want to be you know, practical job like and working with my hands. So that's always been my dream. So I kind of hopped on the bandwagon and went for it.”

Kit’s authenticity and bravery led them down a route better suited to their skills and interests. They were supported by their family but still given the space to figure things out on their own:

“I can say that he really helped me, and he kind of lined everything up for me. And he said, ‘I've done so much. You have to do the rest yourself’.”

Kit is hopeful for their future and looking forward to what the world has to offer them once their apprenticeship finishes:

“I find it’ll then be the world is just going to open up so much for me then… I look forward to challenging myself, and you know, taking thought that one day I would be like my cousin and then hopefully make it happen.”

In summary, for many individuals, an FASD diagnosis or realisation that they may have this condition became a turning point in shaping their sense of self. Before learning about FASD, when they experienced academic struggle, emotional dysregulation, and social rejection, they often internalised their experiences as personal failings, and reported feeling shame and self-blame. However, learning about FASD resulted in feelings of profound relief. They perceived their challenges not as moral or personal flaws, but began reframing them as part of a recognised condition. This, in turn, allowed them to practice more self-acceptance and paved their way towards developing FASD advocacy. They did not experience the same relief when misdiagnosed as having ASD or ADHD, as the diagnosis didn’t feel right for them. At the same time, participants emphasised that the process of integrating their FASD diagnosis into identity was complex. They often experienced grief, anger, and a sense of unfairness before being able to accept their diagnosis and forgive their biological parents. While systemic shortcomings meant that diagnosis rarely resulted in accurate support, it empowered them to embrace their strengths, pursue paths aligned with their skills and values, and redefine success on their terms. In this way, identity creation for those with FASD emerged through resilience, self-advocacy, and the reclaiming of personal narratives.

DISCUSSION

This report provides the first integrated account of the lived experience of individuals with FASD in Ireland, framed within a review of national and international policy, public awareness, and diagnostic practice. The findings highlight a stark mismatch between the potentially high prevalence of FASD in Ireland and the absence of coordinated policy, standardised diagnostic pathways, and targeted education for carers, teachers, and healthcare professionals. The estimated prevalence of FASD in Ireland (2.8–7.4%, Lange et al., 2017) is among the highest globally, yet no surveillance system, registry, or epidemiological study exists to confirm these figures. While the HSE (2022a) acknowledges the condition, the lack of comprehensive national data obscures its full impact. International evidence suggests that prevalence is often underestimated due to diagnostic barriers, limited professional training, and the stigma surrounding prenatal alcohol exposure (Chasnoff et al., 2015; Ergun et al., 2021).

Participants in this study reported long delays in obtaining a diagnosis, often after ADHD or ASD misdiagnoses, and encountered professionals who lacked FASD knowledge or declined assessment. Such delays increase the risk of poor outcomes, including educational disruption, substance misuse, criminal justice involvement, and mental health problems (Streissguth et al., 2004). Participants described instances where stimulant medications prescribed under an ADHD diagnosis exacerbated anxiety or sleep disturbances, consistent with O'Connor and Paley's (2006) caution that ADHD pharmacotherapy can have unpredictable effects in FASD. Ireland lags behind countries such as the United States, where tools like the 4-Digit Diagnostic Code (Astley & Clarren, 2000) are standard practice. Misdiagnosis risks both ineffective intervention and the loss of opportunity for early, targeted, and multidisciplinary support. Participants also suggest that many mainstream schools in Ireland do not have the knowledge or resources needed to support students with FASD effectively. Some parents described being encouraged, directly or indirectly, to move their children out of mainstream education. When teachers had received targeted training on FASD, families reported significant improvements in educators' empathy, their understanding of children's behaviour, and flexibility of approach.

Importantly, several carers highlighted the strengths and talents of their children in such areas as music, sport, navigation, or art, thus echoing international findings showing that individuals with FASD often develop distinctive abilities that can support emotional regulation and social connection (Flannigan et al., 2021). In the Irish setting, structured school support that nurtures these strengths among young people living with FASD is sporadic at best. Thus, providing educational resources that help teachers, carers, and students tap into their unique strengths is essential. It can become a powerful pathway for helping them cope with challenges and overcome the obstacles they face every day. Educators and carers can achieve this by engaging in strength spotting, strength discussions, and enhancing greater strength awareness, as well as regular strength use. The regular use of strengths can boost self-esteem (Matsuguma et al., 2019), facilitate psychological flourishing (Hone et al., 2015), and has the potential to improve the quality of life of young people living with FASD and their families.

This study underscores the urgency of coordinated government action. Parents and carers called for a national diagnostic clinic, mandatory professional training, and a cross-sector strategy linking health, education, and social services. Without such measures, families must navigate a fragmented system, often at considerable personal and financial cost. Despite these challenges, many individuals demonstrate resilience and valuable strengths. Supporting wellbeing requires an integrated approach that combines early diagnosis, tailored interventions, and the cultivation of strong social networks. Recognising and building on strengths can help prevent mental health problems and foster long-term psychological flourishing.

Part Three: Recommendations

This section will offer recommendations to improve the supports, health, and wellbeing of those impacted by FASD. This section will use research findings to offer recommendations to improve FASD services in Ireland. It will offer recommendations at three levels:

- Micro – actions of individuals
- Meso – groups and organisations within society
- Macro – society as a whole

MICRO LEVEL

PEOPLE LIVING WITH FASD

Stigma is a powerful inhibitor for both social wellbeing and FASD support; stigma prevents biological mothers from receiving unjudgmental advice, and prevents those expressing FASD symptomology from being taken seriously. On a micro level, the individual can make a huge difference in changing these attitudes. So what can an individual do to help those living with FASD?

1. Education – use online resources to further educate themselves on FASD. A greater understanding of the condition can improve both empathy and recognition of the condition.
2. Training – seek out FASD-related training courses and encourage others, especially aspiring parents, teachers, and doctors to do the same.
3. Parenting a child living with FASD – if a parent suspects their child could have FASD, they can seek help from FASD-focused organisations, online community groups, and healthcare professionals.
4. Practice – those who are planning to have a child, or are already pregnant, should cease drinking any amount of alcohol immediately if it is safe for them to do so.
5. Breaking Stigma – communities who support each other create thriving environments. Children who have public dysregulation (meltdowns) are not ‘bad’, and parents who have children living with FASD are not ‘bad’ either. Removing these negative labels can improve their wellbeing, and ensure they receive the support and empathy they deserve.

PROFESSIONALS

Front-line professionals in healthcare, education, and the legal system who work with people with FASD or their families should proactively engage in training from such organisations as:

- FAS DPN - free online diagnostic and screening training, University of Washington
- FASD Ireland – CPD accredited Introduction to FASD
- National FASD – UK organisation, several online courses for practitioners

PARENTS/CARERS

Parents who suspect their child may have FASD should seek support through FASD-focused organisations, online community groups, and healthcare providers. Anyone planning a pregnancy or already pregnant should refrain from alcohol consumption entirely.

RESEARCH

Research should design and evaluate interventions developed specifically to address the needs of people living with FASD and their families. Studies should explore the impact of effectiveness of family/carer-led support programmes and the long-term impact of early diagnosis and interventions on wellbeing. The aim of such research should be to identify best practices for improvingthe quality of life of people living with FASD.

MESO LEVEL

EDUCATION

1. Training - Schools should implement mandatory FASD training for all staff.
2. Resources - until FASD diagnosis becomes accessible, schools need to provide additional educational needs assistance even in the absence of a diagnosis.
3. Communication – regular and open communication with parents.
4. Pathway supports – schools need to offer parents support and advice on their options for the future. For example, should a child be recommended for a special needs school, the parents should be supported in finding a school and talked through the application process.
5. Appreciate the Positives - strengths-based practices can boost self-esteem and wellbeing.

HEALTHCARE

1. Training – all healthcare institutions, particularly those working with children or parents, should have mandatory FASD training.
2. Education – healthcare professionals must spread FASD awareness to patients (including men), identify and support those who are at high risk of drinking during pregnancy.
3. Mandatory FASD leaflets or posters should be accessible in clinics.
4. Alcohol-related support for high-risk individuals needs to be accessible without judgment
5. Dedicated FASD Clinics or Pathways – GPs and paediatricians need dedicated and clear pathways for FASD diagnosis and support; they need to be able to accurately refer patients along this pathway.

THE COMMUNITY/ FASD SPECIFIC

1. Community Awareness Talks and Resource Days – events in town halls, libraries, and other shared public spaces where FASD can be discussed, and awareness can be spread.
2. Cross-Service Collaboration – child protection, adoption services, disability services, mental health, education, and healthcare need to develop collaborative protocols.
3. FASD Service Dogs – other countries offer service dogs that have been trained specifically for FASD. Irish service dog charities should implement the same training.
4. Adult Support Services - the need for support does not cease at the age of 18

WORKPLACE

1. Structured Routine - predictable schedules and clear deadlines can relieve a lot of stress for those living with FASD.
2. Wellbeing Resources - access to a quiet room, or sensory accommodations such as noise-cancelling headphones, dim lights, or fidget toys.
3. Communication - it can take up to 22 seconds to process an instruction. In addition, more complex instructions may need to be repeated or broken down into sections
4. Adequate breaks - short breaks throughout the day or an alternating work schedule (working Monday-Wednesday-Friday).
5. Strengths-Based - strengths-based leadership ensures employees are flourishing at work, identify their strengths, and promote tasks that use these strengths.
6. Empathy - making it more approachable for the employee to share their concerns and worries in the workplace.

RESEARCH

Research should explore how schools, healthcare services, legal representatives, and community organisations can implement FASD-informed practices effectively. This includes evaluating teacher training programmes, school inclusion strategies, and multidisciplinary healthcare approaches. Community-based studies should assess the impact of FASD stigma reduction campaigns, accessibility of services supporting people living with FASD, and the efficacy of social support networks in promoting healthcare, psychological, and educational outcomes.

MACRO LEVEL

The Irish government needs to implement a national strategy to ensure FASD support is implemented across the meso and mirco levels.

PUBLIC AWARENESS CAMPAIGNS

Ireland has a rich, ingrained drinking culture, so educating the public on the risks of drinking alcohol is essential. This could look like:

- TV adverts – public safety announcements
- Posters / Billboards
- School educational campaigns
- Clearer labelling on bottles (see Figure 8) – the Public Health Act (2018) and the HSE (2022) Position Paper initiated mandatory labelling on alcohol products (postponed from 2026 to 2028)
- Mandatory leaflets in clinics for all aspiring parents

Figure 9. Pregnancy warning symbol for alcoholic drink packaging, advising against consumption during pregnancy.

DEDICATED FUNDING AND CLINICS

With the third-highest prevalence in the world, Ireland needs dedicated funding and departments for FASD to better prevent this epidemic. Research conducted in a province in Canada discovered that FASD-associated secondary disabilities cost $22.85 million per year. However, when spending just $6.12 million per year on 12 FASD-specific services, they would break even if these clinics were only 28% effective (Thanh et al., 2013). Essentially, spending money on FASD supports would save money in the long term. Establishing a FASD service network, alongside its own department with funding, is vital.

- Ireland needs dedicated funding for diagnosis, support, and research
- Develop a National FASD Policy: Recognise FASD as a neurodevelopmental disability with lifelong implications.
- Define Referral Pathways: Ensure clear referral processes involving GPs, paediatricians, CAMHS, disability services, and educational supports.
- Provide Pathways for Adults: clinics and groups which can support adults living with FASD
- Appoint a National FASD Clinical Lead: Establish oversight within the HSE or Department of Health to guide implementation and planning.
- Establish a National Diagnostic Clinic: Leverage the cost-effective 4-Digit Diagnostic Code system. Training, tools, and software are freely available through the University of Washington's FASDPN platform, with no licensing or intellectual property barriers.

ADHERING TO HSE RECOMMENDATIONS

The 2022 HSE Position Paper on FASD outlines 14 key action points, including training healthcare professionals to enable timely diagnosis and care (HSE, 2022)

RESEARCH

At a national level, research should aim to gather accurate data on the prevalence of FASD, using tools like surveillance systems, epidemiological studies, and registries. Research should also examine how national FASD strategies, diagnostic pathways, awareness campaigns, and legal system measures affect health, education, and social outcomes. Comparative research with international FASD models in countries such as Canada, the UK, and the USA should be conducted to help guide effective, evidence-based policies in Ireland. Research should also focus on creating and testing wellbeing programmes for children, young people, and adults living with FASD, as well as their families, to reduce the challenges they face and give them a real chance to thrive emotionally, psychologically, and socially.

Conclusion

This report identifies the current challenges in Ireland; a lack of support, diagnosis, and awareness of the condition results in significant stress on those impacted. Ireland's current policy on FASD is severely lacking, with research on prevalence and public awareness in desperate need. This has put a huge strain on wellbeing, as those living with FASD go largely ignored in the healthcare and educational systems. Despite this, carers and those living with FASD have demonstrated inspirational resilience and constant advocacy in the face of these challenges. It is vital for Ireland to open its eyes to this issue, to educate its people, and to implement nationwide support systems for a community of people who have suffered in silence for long enough.

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