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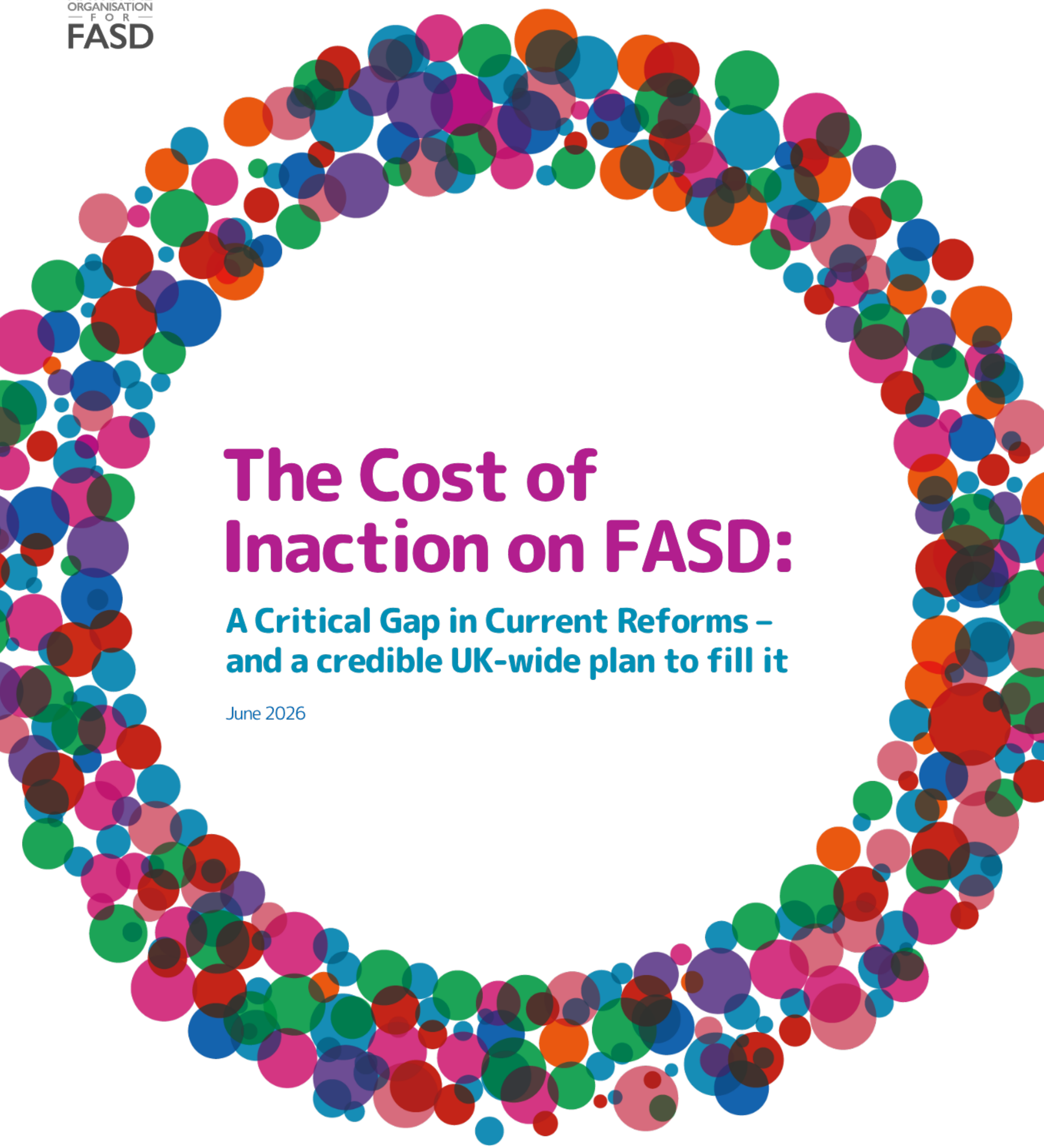

The Cost of Inaction on FASD:

A Critical Gap in Current Reforms – and a credible UK-wide plan to fill it

June 2026

About this report

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This report was written by Sandra Butcher, Chief Executive, with input from Joanna Buckard, Director of Innovation, and Katie Liddle, Senior Programme and Engagement Lead. We'd like to thank Zac H R Mukherjee, Parliamentary Intern, for research and content for Section 2 on the underrepresentation of FASD in Parliament.

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Language note

This report uses person-first, non-stigmatising language in line with the *FASD: Preferred UK Language Guide*. FASD is described as a lifelong neurodevelopmental condition caused by alcohol-exposed pregnancies, with each person affected differently and each person having strengths as well as support needs.

- Use **FASD** as the umbrella diagnostic term, rather than older labels or shorthand such as "foetal alcohol."
- Say **"FASD is caused by alcohol-exposed pregnancies"** or **"FASD results from prenatal alcohol exposure"**, not language that blames birth mothers.
- Use **person-first language** such as "person with FASD", "people with FASD", "young people with FASD" and "adults with FASD."
- Do not use stigmatising terms such as **"sufferer"**, **"suffers with FASD"** or **"victim."**
- Avoid language that frames difficulties as wilful misbehaviour; FASD is a **brain-based**, lifelong neurodevelopmental condition, not simply a behavioural problem.
- Recognise that **each person with FASD is affected differently** and early diagnosis and appropriate FASD –informed support especially for executive function, optimizes life chances.
- **Support is available across the UK** via independent FASD UK Alliance groups. Please see www.FASDUKAlliance.info

Acronyms used in this report

ADHD – Attention Deficit Hyperactivity Disorder

AI – Artificial Intelligence

ARND – Alcohol-Related Neurodevelopmental Disorder

AUDIT C – Alcohol Use Disorders Identification Test – Consumption

BCR – Benefit–Cost Ratio

BMA – British Medical Association

CAMHS – Child and Adolescent Mental Health Services

CMO(s) – Chief Medical Officer(s)

CPD – Continuing Professional Development

DHSC – Department of Health and Social Care

DfE – Department for Education

EHCP – Education, Health and Care Plan

EHRC – Equality and Human Rights Commission

FAS – Fetal Alcohol Syndrome / Foetal Alcohol Syndrome

FASD – Fetal Alcohol Spectrum Disorder / Foetal Alcohol Spectrum Disorder

FASD PRP – FASD Prevention and Response Programme

GB – Green Book (HM Treasury Green Book – use only if “GB” appears as shorthand)

GP – General Practitioner

HM Treasury – His Majesty’s Treasury

ICB(s) – Integrated Care Board(s)

LAC – Looked-After Children[1]

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[1] The term Looked after children (LAC) came from the children act 1989 and therefore is used in peer reviewed literature. We acknowledge that some care experienced people may prefer the term 'Children in Care’ or ‘care experienced’. This report uses both.

MBE – Member of the Order of the British Empire

NHS – National Health Service

NHS England – National Health Service England

NIHR – National Institute for Health and Care Research

NICE – National Institute for Health and Care Excellence

NICE QS204 / QS204 – NICE Quality Standard 204 (FASD)

OHID – Office for Health Improvement and Disparities

ONS – Office for National Statistics

PHE – Public Health England

PIP – Personal Independence Payment

PPP – Purchasing Power Parity

PRP – Prevention and Response Programme

QALY – Quality-Adjusted Life Year

QS – Quality Standard

SEND – Special Educational Needs and Disabilities

SIGN – Scottish Intercollegiate Guidelines Network

SNOMED CT – Systematized Nomenclature of Medicine – Clinical Terms

UK – United Kingdom

US – United States

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The purpose of this report

This report is presented as a proof of concept – it is not meant to be proscriptive. We want to contribute to the UK-wide dialogue and after publication we will organise roundtables to flesh out details.

This report's main purpose is to show that it is possible to fund a truly comprehensive UK-wide FASD Prevention and Response Programme (PRP) and that is needed on many different levels.

It shows that this is needed if the four nations want to meet their own goals on current reforms and avoid risk. It shows that people with FASD and their families are paying the price for cost of current inaction. It calls for synchronous national consultations to sort out the details.

The National Organisation for FASD is a small charity. We have used some advanced AI to show that it IS possible to fund a UK-wide FASD Prevention and Response Programme – and that such a programme can include more than just diagnostics.

To prove our concept we have modelled what an FASD PRP programme might look like, but please know that is not really the point of this publication. How that programme unfolds should be debated and discussed via national consultation processes engaging people with FASD, their families, experts, commissioners, policy makers and others. How this unfolds in each nation will be unique.

We ask as you read this that you not get bogged down by the details.

We ask that you see the big picture: With what is a rounding error on the alcohol duty, a national response could be made to prevent and respond to FASD. As we have said before, the Time is Now.

All that is lacking is political will.

FOREWORD

A Message from Our Chief Executive

A personal challenge to policymakers: can you live with the cost of your inaction?

Foreword

National FASD is a small charity with a big mission focused on prevention and wellbeing around FASD (Fetal Alcohol Spectrum Disorder). We provide evidence-based resources, policy work and raise the voices of those with lived experience. Since our founding in 2003, we have worked hard to help build a UK where FASD is understood, diagnosed early and properly supported, and alcohol-exposed pregnancies are reduced. We are dedicated to supporting people with FASD, their families and communities, promoting education and networking for professionals and public awareness about the risks of alcohol consumption during pregnancy.

Time and time again on this journey we have been told by policy makers, commissioners and others that there is not enough evidence, not enough money and not enough resources to address the needs properly. This report shows excuses for failing to implement policy on FASD are simply not valid. Not only that – it shows the costs of this inaction.

We show a way forward in a structure developed with the help of some powerful AI tools. It shows, using accepted methods and with figures that are a fraction of one percent of the alcohol duty income, how a solid system can be put in place to meet the needs of some of our society's most vulnerable. We are advocates, supported by university researchers and professionals. We KNOW the cost of the current inaction. We KNOW it rings true that improved prevention, diagnosis and post-diagnostic support for FASD will have profound impact on our society. We stand ready to help change things.

If we as a small charity can use technology to help show that a four-nation FASD Prevention and Response Programme is possible, imagine what Governments could do if they put their resources to the task.

Some may say that it's not realistic to take 0.25% of the alcohol duty for this purpose. We say those whose lives have forever been impacted by alcohol harm before they took their first breath should be the very first to get access to the roughly one billion pounds that comes into Government coffers each month from the sale of alcohol. We show that in fact, allocating these funds to an FASD Prevention and Response Fund will save money in the long-term.

Our challenge to every policy maker and commissioner who reads this is this – can you live with the cost of your inaction? What would you be doing if it were your own loved one's future at risk? More than 50 years after the first FASD diagnoses, decades behind some similar countries, it is time to step up and have lasting generational impact by implementing the guidance from NICE, DHSC, SIGN, PHE and invest to save.

I'm mum to a young adult with FASD who once was in crisis and whose life has changed completely due to the insights and knowledge that diagnosis and FASD-informed support provided him. I know what a diagnosis can mean. I know all too well how precarious his future is without needed systemic understanding of FASD. I also know, as every person with FASD and their families know, policy makers have the power to change their trajectories.

What will YOU do? Thank you for reading this report and for taking the next step. It is a time of great change across the NHS and nationally. That also means it is a time of great opportunity.

Sandra Butcher
Chief Executive

EXECUTIVE SUMMARY

Why This Matters Now

The case for action, the headline numbers, and what we are asking for.

Executive Summary & Policy Action Points

This report argues that the UK can no longer afford to ignore Fetal Alcohol Spectrum Disorder (FASD): the human cost is profound, the policy gap is clear, and the economic case for action is now strong. It sets out a proof-of-concept for a four-nation FASD Prevention and Response Programme funded through an amount equivalent to 0.25% of alcohol duty receipts, showing that a comprehensive response is both affordable and likely to save money over time.

FASD is a lifelong neurodevelopmental condition caused by alcohol-exposed pregnancies, yet it remains under-recognised, under-diagnosed and under-supported across the UK. The report's central case is that inaction is already generating large avoidable costs for individuals, families, public services and the wider economy, while existing policy reforms in health, education, social care and justice will continue to miss their objectives unless FASD is explicitly included.

Why this report matters

The report is intended as a proof of concept rather than a final blueprint. Its purpose is to show that a genuinely comprehensive UK-wide response to FASD could be funded, and that such a response must go beyond diagnostics to include prevention, post-diagnostic support, workforce training, public awareness, research, data infrastructure and lived-experience leadership.

At its heart is a simple proposition: with what the report describes as a rounding error on alcohol duty receipts, governments across the four nations could build a meaningful national response to prevent alcohol-exposed pregnancies, identify FASD earlier, and support people already living with the condition. The detail should be refined through national consultation, but the report contends that lack ofso-called lack of evidence or affordability can no longer credibly be used as a reason for delay.

Section 1: Stakeholders are calling for action

The first section shows that the case for investment is not only epidemiological or fiscal; it is also grounded in repeated testimony from people with FASD, families, carers and professionals. Across the draft's surveys and cited lived-experience evidence, a common pattern emerges: people describe being misunderstood, blamed, misdiagnosed, or left without meaningful support after diagnosis.

This section argues that the current system fails at three connected stages: prevention, timely diagnosis and post-diagnostic support. Families report long waits, absent pathways, poor professional understanding, and services that either do not recognise FASD or stop helping once diagnosis is obtained.

The report therefore presents the proposed 0.25% funding mechanism not as an optional enhancement but as a proportionate response to longstanding unmet need. It also highlights support from more than 100 UK experts and aligns these calls with the UK FASD Manifesto, concluding that implementation failure—not merely lack of awareness—is now the core policy problem.

Section 2: The scale and cost of inaction

The second section quantifies the scale of FASD and its economic burden in the UK. Drawing on the Salford active case ascertainment study, the report states that 2–4% of children in mainstream primary schools met criteria for FASD or possible FASD, with none previously identified, suggesting that between 1.4 and 2.8 million people in the UK may be affected and that most remain undiagnosed.

Using a purchasing power parity adaptation of a widely cited US cost model, the report estimates a lifetime cost of about £359,835 per diagnosed case and £431,802 per undiagnosed case, with an annual UK societal cost of around £9.2 billion and a 30-year cumulative present-value burden of around £160 billion.

The report is careful to acknowledge the limitations of using US source data and AI-assisted modelling, and it calls for UK-native administrative and linked-data research as a priority. Even so, it argues that the model is robust enough to establish the policy direction: under almost any plausible scenario, FASD imposes costs far above the price of earlier diagnosis, prevention and coordinated support.

A particularly important contribution in this section is the argument about the “hidden majority.” The report says current identification efforts are concentrated on children in care, adopted children and justice-involved groups. While acknowledging the importance of addressing FASD in those groups, the report states the overwhelming majority of people with FASD are likely to be living with birth families, in mainstream schools and ordinary communities, without recognition or support. It argues that universal services such as maternity care, health visiting, primary care, Children and Family Hubs, schools and CAMHS must therefore become core parts of the response.

Section 3: FASD is a policy blind spot

The third section argues that FASD is severely underrepresented in UK legislative discussion relative to autism and ADHD, despite its prevalence and complexity. Using Hansard-based analysis, the report states that among 8,565 neurodevelopment-related entries, autism accounts for 6,148 mentions, ADHD for 1,953 and FASD for only 464, showing a major visibility gap in parliamentary discourse.

The report contends that this lack of visibility has practical consequences. Because FASD is not routinely considered in policy debates, reforms in SEND, benefits, mental health, maternity care, justice, homelessness and more risk being designed around incomplete assumptions about need, behaviour, disability and service failure.

This section also maps the four-nation policy landscape and argues that current legal and policy duties already create grounds for stronger action. The report shows that failure to implement existing guidance and to make reasonable adjustments increases both systemic risk and potential legal liability, while integrating FASD more explicitly into current reforms would reduce that risk and improve outcomes.

The central policy conclusion is that current reform agendas will fall short unless they recognise prenatal alcohol exposure and FASD as material factors across multiple systems. In other words, FASD is not a niche issue to bolt on later; it is a cross-cutting condition that must be built into mainstream policy now.

Section 4: The invest-to-save case

The report's core funding proposition is set out in the section on investment. It argues that the UK is not currently funding FASD at the scale required, and contrasts this with more structured investment in other areas such as smoking in pregnancy prevention.

The proposed solution is to benchmark a stable, recurring funding stream at around 0.25% of UK alcohol duty receipts, worth roughly £31–32 million per year and producing a five-year funding envelope of about £157.5 million. Against that, the draft models a five-year programme costing £106 million undiscounted, leaving headroom within the envelope and producing a lifetime benefit-cost ratio of 3.56:1 through avoided downstream costs.

The proposed FASD Prevention and Response Programme is not limited to diagnostic clinics. It combines four national centres and twenty regional centres with five evidence-led components: a national linked database or registry, a UK prevalence study, a standing research fund, sentinel surveillance and data linkage, and implementation/evaluation functions, alongside prevention, lived-experience support, workforce development and innovation.

The report argues that this is the difference between funding a service and funding system change. It also sets out an implementation route that would not require primary legislation, suggesting that the allocation could be made through existing budgetary mechanisms, with devolved funding flowing through Barnett consequentials.

Section 5: What should happen next

The conclusion is clear that a four-nation response is both possible and overdue. The report presents priority next steps sequenced by feasibility, cost and likely return, and identifies actions for key stakeholders including UK and devolved governments, the NHS, researchers, commissioners and the voluntary sector.

Its practical message is that the UK already has enough policy guidance, enough indicative evidence and enough service learning to begin. What is missing, in the report's view, is political will, implementation discipline and dedicated funding that connects prevention, diagnosis, support, research and accountability.

What the appendices add

The appendices strengthen the report's credibility by showing how the main argument works in methodological, policy and practical terms. They are not peripheral; together they supply the technical and comparative scaffolding for the main proposal.

- **Appendix A** summarises the cost model methodology and explains why a simple foreign exchange conversion from US cost estimates would be misleading. It sets out the two-step purchasing power parity and healthcare price adjustment used to derive UK estimates, reinforcing that the economic figures are intended as a reasoned starting point rather than a claim of false precision.
- **Appendix B** argues that failure to include FASD in the Independent Review into Mental Health, ADHD and autism creates a serious analytical and equity gap. The appendix says FASD overlaps conceptually and clinically with the review's scope, that non-diagnosis increases

mental health risk, and that omission of FASD means the review cannot fully understand the needs of a significant affected group.

- **Appendix C** uses US research funding as a case study to show what sustained dedicated investment can support. It contrasts a substantial multi-year US research portfolio, including translational and therapeutic work, with the UK's near-absence of dedicated FASD research funding, and uses that comparison to support the report's 0.25% proposal.

- **Appendix D** presents the Soft Drinks Industry Levy as the clearest fiscal precedent for the proposed FASD Prevention and Response Fund. Its argument is that clearly directed or even hypothecated receipts can be used to address preventable health harms, making a modest allocation from alcohol duty both administratively and politically plausible.

- **Appendix E** sets out an illustrative four-nation programme model in greater operational detail. It describes how national and regional centres could work in hub-and-spoke or specialist-network forms across the UK, the functions they would perform, and the five evidence-led components that would enable the programme to operate as a full prevention-and-response system rather than a narrow clinical service.

Conclusion

This report's overall conclusion is that the UK faces a stark choice: continue absorbing the escalating human and financial cost of fragmented, under-commissioned FASD provision, or make a modest, structured and evidence-informed investment in prevention, diagnosis, support and research. The report finds that a four-nation FASD Prevention and Response Programme funded at the equivalent of 0.25% of alcohol duty is feasible, aligned with wider policy goals, and likely to deliver substantial long-term returns; the real barrier is no longer affordability, but whether decision-makers are prepared to act.

SECTION 1

FASD Stakeholders Call for Action

Lived experience shows the human cost of inaction
and the case for funding.

AT A GLANCE · SECTION 1

FASD stakeholders call for action

People with FASD, their families and the professionals who support them are not asking for more leaflets — they are asking for diagnosis, support and dignity.

100
UK experts called for **policymakers to act**

60+
people with FASD shaped **the UK FASD Manifesto**

5 yrs
typical wait for **an FASD diagnosis**

0.25%
of alcohol duty is **the proportionate ask**

Voices from the FASD community

Direct testimony from the FASD UK Alliance survey, UK FASD Manifesto and National FASD education survey.

Refused diagnosis
“Refused assessments — no trained staff in area.”
FASD UK Alliance survey (2023)

Waiting years
“We know he has FASD but are waiting for diagnosis (5 years).”
FASD UK Alliance survey (2023)

Closed doors
“We cry for help and meet a series of closed doors.”
FASD UK Alliance survey (2023)

Be believed
“We are not naughty. Understand why things are harder for us.”
UK FASD Manifesto (2023)

What the evidence from lived experience tells policymakers

Six consistent themes across FASD UK Alliance surveys, the Manifesto and the Not Commissioned report.

Inaction has immediate consequences

Disability misread as poor behaviour, unwillingness or parental failure — every day a challenge for families.

Delayed diagnosis intensifies harm

Five-year waits, refused assessments, escalating crises and burnout. Delay is itself a clinical and social harm.

Families want support, not just information

Practical advocacy, case coordination, school and transition support — not more leaflets. Visibility matters.

Lived experience aligns with the Manifesto

60+ people with FASD: understand us, respect us, never give up on us. Just because you can't see it doesn't mean it's not there.

‘Not Commissioned’ makes the gap explicit

Two years after NICE QS204, NHS response is too slow and uncoordinated. The implementation gap is the policy problem.

0.25% of alcohol duty is proportionate

Modest, evidence-led correction — funds prevention, diagnostic capacity and post-diagnostic support together.

Lived experience can't be ignored

People with FASD ask to be believed, diagnosed in time and supported — not blamed for an unrecognised disability.
The Manifesto and Not Commissioned report align with the epidemiology, the economics and the legal duties.
0.25% of alcohol duty funds prevention, diagnostic capacity and post-diagnostic support — together, not as competing priorities.
Embedding people with FASD, families and professionals as partners is what makes policy work.

Sources: FASD UK Alliance survey (2023, March 2023); National FASD education survey (2026); UK FASD Manifesto (National FASD, 2023); National FASD, Not Commissioned (2024); NICE Quality Standard QS204; SIGN 156; DHSC FASD Health Needs Assessment (2021).
From: The Cost of Inaction on FASD (June 2026), Section 1.

Section 1: FASD stakeholders call for action

The voices of people with FASD, their families and the professionals who support them need to be heard when determining policy.

Lived experience, urgency, and the case for dedicated FASD funding

We want to say clearly, up front. The case for dedicated investment in FASD (Fetal Alcohol Spectrum Disorder) is not only epidemiological or economic; it is also grounded in a clear and repeated message from people with FASD, their families, and the professionals who support them. This section is based on direct feedback from people with FASD, their families and the professionals that support them. The current system is failing to prevent avoidable harm, failing to diagnose in a timely way, and failing to provide meaningful support after diagnosis. The proposal that follows in this report to allocate the equivalent of 0.25% of the alcohol duty to fund an FASD Prevention and Response Programme is therefore best understood not as a discretionary enhancement, but as a proportionate, affordable response to longstanding, documented unmet need. The case for 0.25% is laid out in further sections.

Lived experience shows that inaction has immediate consequences

People with FASD consistently describe being misunderstood in education, health, and social care settings, with their disability misread as poor behaviour, unwillingness, or parental failure.

> *“Each day is a challenge,” Special guardian (FASD UK Alliance survey, March 2023).*

Diagnosis is often unavailable. One person said, “Refused assessments as no trained staff in area” (FASD UK Alliance survey, 2023). Another explained the educational impact in stark terms: “FASD is a life long disability and severe impairment of short term memory. This makes revision and exams extremely challenging. Please see the child that can’t rather than the child that is not willing” (National FASD education survey, 2026). One carer wrote that “FASD is still NOT understood by the education system and is being misdiagnosed as attachment …and would be overlooked” (National FASD education survey, 2026). Another said, “As FASD has a blame culture it tends to be ignored rather than supported” (National FASD education survey, 2026). This sense of blame, invisibility, and systemic misunderstanding is repeated across datasets. In an earlier survey, one respondent said, “If they haven’t a clue how the heck can they help anybody or understand the insurmountable difficulties we face. They think we make everything up” (National FASD, improving quality of care survey, 2019). These accounts show that the costs of inaction are not abstract. They are experienced as worsened outcomes due to systemic ignorance, preventable school failure, and deep personal distress. Such testimony provides a direct rationale for dedicated investment in multi-agency workforce development and public awareness as part of a four-nation FASD Prevention and Response Programme.

Delayed or absent diagnosis intensifies harm

The evidence from lived experience also shows that delay in diagnosis is itself harmful. Families repeatedly link the absence of diagnosis to escalating crises, misdirected interventions, and burnout. One respondent wrote, “Because the longer it takes to diagnose the child and family are suffering and needs early intervention” (National FASD, improving quality of care survey, 2019). Another explained, “Early diagnosis helps shape ongoing care and educational support. That can make a vast difference to the total outcome for that young person" (National FASD, improving quality of care survey, 2019). It also can impact longer-term outcomes for example with adoption permanence.

A person with FASD called for "better understanding" and described "being bullied," saying it was the "reason why I bunked off school due to bad behaviour of others. Found it difficult to concentrate and do homework" (National FASD education survey, 2026).

The structural nature of these delays is particularly clear. One parent reported: "We know he has FASD but are waiting for diagnosis (5 years)" (FASD UK Alliance survey, 2023). A birth mum described being told not to seek diagnosis because "nothing can [be done]', and there's nothing they have done. No loop back into Local Offer, no understanding in school. No Disability Team accepting him until … too late," she said she's now facing court proceedings that could result in the loss of her child (FASD UK Alliance, FASD care management plans survey, 2023). A retired doctor similarly reported recognising FASD in her adopted daughter for a decade without being able to secure assessment (FASD UK Alliance, FASD care management plans survey, 2023). One family member talked about the need for a, "Clear pathway on the NHS including CAMHS - we have no where to get help and paediatrician keeps trying to discharge my daughter. Need CAMHS too and can't even get on the waiting list. It's an utter disgrace" (National FASD, improving quality of care survey, 2019)

These testimonies support investment not only in the FASD Prevention and Response Programme model with diagnostic clinics but also in regional and local pathways that ensure diagnosis leads somewhere. This is precisely why a 0.25% funding proposal should cover both diagnostic capacity and post-diagnostic support rather than treat diagnosis as an endpoint.

People with FASD and their families are calling for support, not just information

People with FASD and their families do not simply want more leaflets or better rhetoric. They want practical, accessible, sustained support – they want FASD to be more visible. One adult with FASD said, "Why isn't FASD made more public? I just can't believe how many people don't know about it it's like it's being swept under the carpet" (National FASD 2024 impact survey, 2025). Another adult with FASD emphasised the need to "Support older adults with FASD" (National FASD trustee survey, 2026).

> "We don't have any care management, plan, strategies. In fact we have no help at all with our little one…[W]e cry for help and meet a series of closed doors" (FASD UK Alliance survey, 2023)

One person said, "What parents need is practical support not sheets of paper. We need support groups, physical advocates to support us all in challenging professionals… living with and catering for FASD children is a lonely challenging sometimes violent place and there is nothing out there to physically and emotionally support us parents" (National FASD, 2024 impact survey, 2025). Others explained the importance of knowing they are "not alone" (National FASD, 2024 impact survey, 2025). One person described FASD as "a very very lonely disability as so few ppl know what it even is" (National FASD, trustees survey, 2026).

This evidence matters because it highlights an important policy design point. A prevention-only approach would not meet the needs described by families, nor would diagnosis without funded follow-on services. People are asking for advocacy, case coordination, school support, transition support, adult pathways, and research into what works. They are also asking for professionals who understand what FASD is. One person put it simply: “Education!! For diagnostics, providers, parents, schools (especially schools!)… so important” (National FASD, trustees survey, 2026). A stable, recurring, dedicated 0.25% funding stream would create the conditions for this broader response by supporting training, management plans, navigation, and multidisciplinary provision alongside prevention and assessment.

100 UK experts call for policymakers to take action

> “We the undersigned call upon national, regional and local decision makers to ensure that people with FASD (Fetal Alcohol Spectrum Disorder) are actively considered in the reforms underway to health, social care and education. National leadership is needed. Research shows that improvements in quality of care that are called for in the DHSC FASD Health Needs Assessment and the NICE Quality Standard 204 are not being implemented.
>
> Rather than introducing improvements in quality of care, planned changes to benefits and education mean that people with FASD are now facing a more uncertain and risky future than ever.
>
> Proposed changes include: changes to the Personal Independence Payment (PIP) assessments, cut backs to the Adoption Support and Special Guardianship Fund, rolling back legal guarantees for children with special educational needs and disabilities (SEND), including putting more with SEND into mainstream settings and eliminating Education, Health and Care Plans (EHCPs) for all but those attending specialist provision. Coming at time of deep cuts and upheaval in the health and social structures, these changes could have dire impact on some of the most vulnerable.
>
> This can change. We call upon policy makers at all levels to meet with people with FASD and their families, researchers, practitioners and other experts. We ask for funding via an FASD Prevention and Response fund. With £13 billion expected to enter the government coffers in 2025-26 via alcohol duty, we do not accept there is no funding as just 0.2% of that would put the UK spending on FASD prevention and support on par with other countries like Canada, Australia and the US and this would save money. We ask you, in the words of the UK FASD Manifesto written by more than 60 people with FASD, to ‘never give up’ on people with FASD. Together we can bring about change.”
>
> --100 UK experts call for action (University of Salford, June 2025)

UK FASD MANIFESTO

HOW WE WANT YOU TO TREAT US BY PEOPLE WITH FASD

LISTEN TO US

SPEAK SLOWLY AND CALMLY

BE KIND

KEEP THINGS SIMPLE

BE PATIENT

GIVE US TIME TO RELAX

KNOW OUR BRAINS ARE DIFFERENT AND SOMETIMES WE DON'T GET IT

UNDERSTAND WHY THINGS ARE HARDER FOR US

TREAT US WITH THE SAME RESPECT AS OTHERS

HELP US TO SHINE BRIGHTER

KEEP THINGS UPBEAT

REMEMBER OUR DIFFICULTIES ARE LIFELONG

DO!
DON'T TRY - DO

LEARN MORE ABOUT FASD

NEVER GIVE UP ON US

ME & MY FASD

SCAN ME

#HearOurVoices
@nationalfasd

SCAN ME

NATIONAL ORGANISATION FOR FASD

Lived experience aligns with the UK FASD Manifesto

The UK FASD Manifesto, developed with direct input from more than 60 people with FASD, reinforces the same message in concise, powerful form (National FASD, 2023).

The manifesto says, “Understand why things are harder for us.” “Remember our difficulties are lifelong.” “Treat us with the same respect as others.” “Never give us on us.” It adds, “Remember, just because you can’t see our disability doesn’t mean we don’t have one”. Most strikingly, it says: “We are sick of people saying they understand, or that they are trying to help, but they do nothing … just because you can’t see our disability doesn’t mean we don’t have one.”

That final statement captures the core policy challenge. The problem is no longer solely one of awareness in the abstract. As we detail further below, national guidance exists in varying degrees across the four nations. The DHSC health needs assessment exists. NICE Quality Standard 204 exists. SIGN 156 exists. Yet lived experience still describes inaction, fragmentation, long waits, disbelief, and the absence of meaningful post-diagnostic help (DHSC, 2021; National Institute for Health and Care Excellence [NICE], 2022; Scottish Intercollegiate Guidelines Network [SIGN], 2019). The case for earmarked funding is therefore also a case for implementation. Dedicated investment would signal that FASD is not a rhetorical priority but a practical commissioning priority.

The “Not Commissioned” evidence strengthens the case for urgent investment

National FASD’s *Not Commissioned* report (2024) makes this implementation gap explicit. It argues that two years after NICE QS204, the NHS response remained too slow and too uncoordinated, describing a “golden opportunity to protect baby’s brains and futures” as being missed through “slow, non-strategic and uncoordinated responses”. The report calls for strong leadership, clear local accountability, better data systems, greater diagnostic capacity, funded post-diagnostic pathways, and better tracking of indicators for improvement in quality of care (NICE, 2022). It also explicitly recommends establishment of an FASD Prevention and Response fund and links that recommendation to international comparisons in public spending on alcohol-related harm.

The testimonies from families and professionals provide the human explanation for why those recommendations matter. When one person said in 2019 (before NICE Quality Standard 2024, “Nothing else will happen if it isn’t commissioned. FASD needs to be kept on the agenda and highlighted in all relevant commissioning processes” (National FASD, improving quality of care survey, 2019), they are describing the same systemic failure identified in *Not Commissioned* in 2024. When another said in 2019, “Because when you have a diagnosis there is no one to help you and no support” (National FASD, improving quality of care survey, 2019), they are exposing the cost of a pathway that stops at diagnosis that was evident in 2024 research – two years after NICE Quality Standard 204. The proposal for 0.25% funding directly addresses this gap by resourcing the three linked stages that lived experience says must not be separated: prevention, diagnosis, and post-diagnostic support.

Why a sum equivalent to 0.25% of the alcohol duty is proportionate

The argument for allocating 0.25% of funding to FASD prevention, diagnosis, and post-diagnostic support is strengthened by the breadth and consistency of these lived-experience accounts. Families are not describing isolated failures. They are describing a pattern: poor prevention messaging, low professional knowledge, under-recording of prenatal alcohol exposure, lack of diagnostic routes, weak education plans, little ongoing support, and the transfer of costs onto families through stress, burnout, isolation, and crisis. These findings align with the DHSC health needs assessment, which characterises FASD as an under-recognised, multi-faceted public health problem requiring coordinated primary, secondary, and tertiary prevention (DHSC, 2021). They also align with guidance from the National Institute of Health and Care Excellence (which is in effect across England and Wales - NICE QS204) and SIGN 156 (diagnostic guidelines for children and young people prenatally exposed to alcohol developed by the Scottish Intercollegiate Guidelines Network – which have been adopted by NICE and are in effect across Scotland, England and Wales). These two important documents assume that systems will have enough capacity to identify, assess, and support those affected (NICE, 2022; SIGN, 2019).

Against that background, a 0.25% allocation is not excessive as this report shows below. It is a modest but meaningful mechanism for correcting a systemic imbalance in which families currently bear the burden of service gaps. Such funding could support public health messaging on alcohol in pregnancy, improved recording and digital prompts in maternity care, research, clinician training, diagnostic models, local care-management plans, school support, family navigation, and adult transition pathways. In other words, it would fund exactly the areas where lived experience has identified the consequences of inaction most clearly.

Lived experience can’t be ignored

The evidence from people with FASD, their families, and supportive professionals is direct, urgent, and morally difficult to ignore. They are asking to be believed, diagnosed in time, supported properly, and no longer blamed for the consequences of an unrecognised brain-based disability. As the UK FASD Manifesto puts it, “We are sick of people saying they understand… but they do nothing” (National FASD, 2023). A proposal to allocate 0.25% of funding to FASD prevention, diagnosis, and post-diagnostic support is therefore not simply a budgetary proposition. It is a response to sustained lived-experience testimony that the current level of provision is inadequate and that delay is causing avoidable harm. If policy is serious about prevention, equity, and reducing long-term costs, then lived experience itself points to the same conclusion: action is needed now.

As Prof Raja Mukherjee MBE, Consultant Psychiatrist and FASD service lead said about the Manifesto (2023), “It’s critical that we listen to the voices and experiences of people with FASD as we begin to ramp up services across the UK following on from the NICE Quality Standard on FASD.”

SECTION 2

The Scale & Economic Cost of FASD in the UK

1.4–2.8 million people in the UK may have FASD, mostly undiagnosed — a hidden ~£9.2 billion annual cost to society.

AT A GLANCE · SECTION 2

The scale and economic cost of FASD in the UK

FASD is the UK's most common preventable neurodevelopmental condition — and its most under-recognised. Most cases go undiagnosed, and the cost of that inaction falls quietly across health, education, social care and justice.

2–4%
of UK schoolchildren met FASD criteria **(Salford study)**

1.4–2.8m
people in the UK may have FASD, **most undiagnosed**

~£9.2bn
recurring **annual societal cost** to the UK

~£160bn
cumulative **30-year cost** (present value, 3.5%)

The lifetime cost of a single UK case

Anchored on the most-cited US estimate, converted to UK pounds using standard purchasing power parity methodology.

£359,835	Lifetime societal cost per **diagnosed** UK case	**£431,802**	Lifetime societal cost per **undiagnosed** UK case
~10%	Estimated **UK diagnosis rate** — most cases never identified	**~92%**	Share of the annual cost borne by the **undiagnosed** group

Why the diagnosis gap dominates the bill

Most of the population-level cost is driven by people who are never identified or supported.

Missed early intervention

Undiagnosed children miss tailored education plans and FASD-informed support, when intervention would be most effective and least costly.

School exclusion & SEND

2–4% of pupils meet FASD criteria, yet almost none are identified — driving exclusions and unmet special educational needs.

Care & adoption

27% of children in care in one Peterborough study had FASD; 75% of adoption reports indicated prenatal alcohol exposure.

Justice & welfare

Undiagnosed adults have repeated, costly contact with the justice and welfare systems — the least visible part of the bill.

Productivity loss

Lost lifetime productivity is the single largest cost component for each UK case in the model.

Robust to assumptions

Even at 1% prevalence and a 5% discount rate, the 30-year cost still exceeds £40bn. The diagnosis rate drives the figure higher, not lower.

Investment in identification is not a cost — it is a saving

More than 90% of FASD's ~£9.2bn annual cost falls on the undiagnosed. Earlier identification, NHS diagnostic pathways and SEND support shift the spending from reactive crisis to upstream prevention. UK-specific research replicating this analysis on national data should be a priority.

Sources: McCarthy et al. (2021) Salford prevalence study; Greenmyer et al. (2018) US lifetime cost estimate; Shemilt et al. (2010) PPP cost-transfer methodology; DHSC FASD Health Needs Assessment (2021); NICE QS204; SIGN 156; Peterborough Looked-After Children FASD study; OECD Health at a Glance (2025); HM Treasury Green Book.
From: The Cost of Inaction on FASD (June 2026), Section 2. Figures are illustrative proof-of-concept estimates; UK-specific research is needed.

NATIONAL ORGANISATION FOR FASD · nationalfasd.org.uk

Section 2: The scale and economic cost of FASD in the UK

This section explores the scale and societal cost-of-illness estimate for diagnosed and undiagnosed Fetal Alcohol Spectrum Disorder based on estimated costs from widely cited, peer-reviewed research from the USA. UK- specific research is needed.

Prevalence and misdiagnosis

FASD results from prenatal alcohol exposure affecting fetal development. It has lifelong impact. It presents across a wide spectrum, frequently overlapping with — and being misidentified as — ADHD, autism, trauma, attachment disorder, or conduct disorder. The Salford active case ascertainment study (McCarthy et al., 2021) found 2-4% of children in mainstream primary schools met FASD criteria, and none had been previously identified.

FASD is a brain- and body-based disability associated with a wide range of neurodevelopmental, behavioural, cognitive, emotional, communication, adaptive and, at times, physical differences. In utero alcohol exposure damages developing cells and alters later development, producing diverse presentations that frequently can co-exist with other conditions.

To have a diagnosis of FASD, someone must have “severe impairment” (SIGN 156, 2019) in three or more neurodevelopmental areas. Each person is affected differently. This diversity in presentation is important for policy because it partly explains why FASD is so often missed. Just like autism, FASD does not present as a single uniform profile. Instead, it can include executive functioning difficulties, poor adaptive functioning, attention problems, impulsivity, memory problems, emotional dysregulation, sensory differences, social communication difficulties, challenges in understanding consequences, and struggles with daily living. In practice, these features may be interpreted separately rather than understood as part of a coherent neurodevelopmental disability. The result is repeated relabelling rather than recognition.

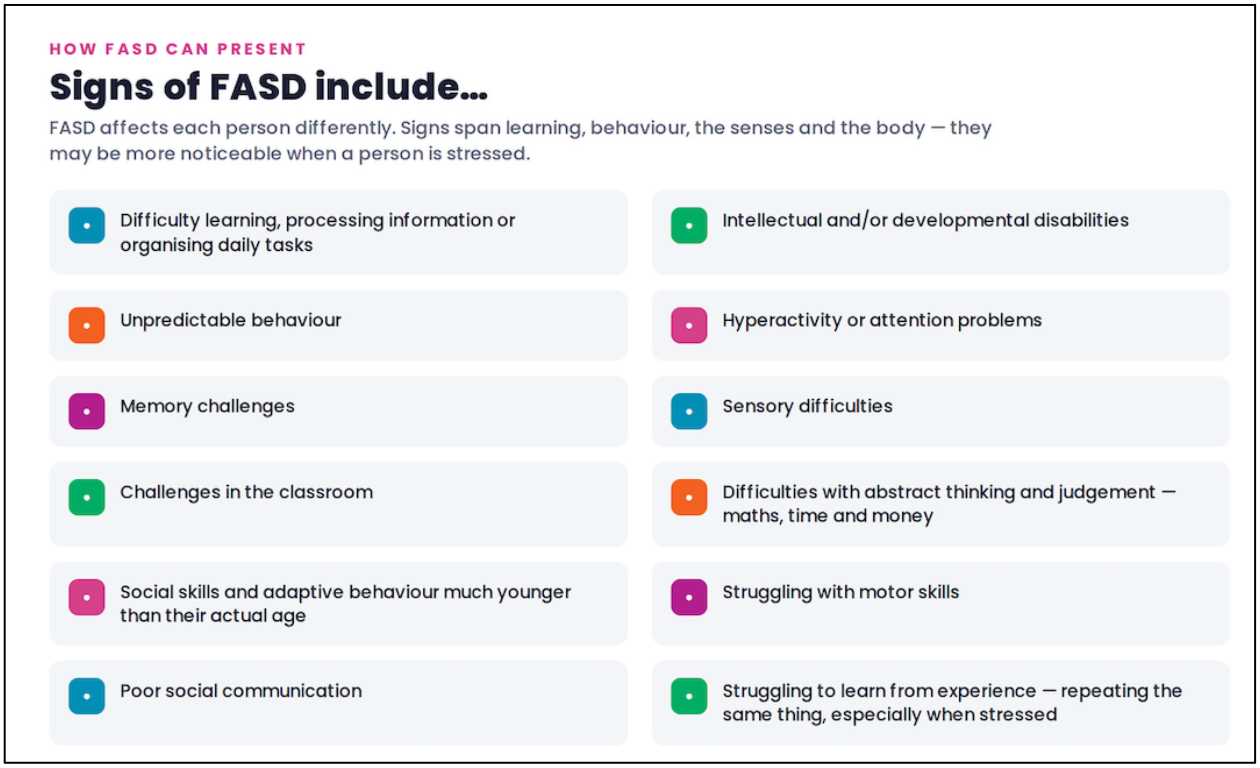
The prevalence data show why this matters at population level. McCarthy et al. (2021) found that 2-4% of children in mainstream Greater Manchester primary schools met criteria for FASD or possible FASD. A 2% to 4% range means that 1.4 to 2.8 million people in the UK may have FASD, with most undiagnosed. The DHSC FASD health needs assessment quotes 3.2% of the population may be affected.

FASD is preventable, but preventability does not lessen the need for disability-informed support once it is present. The DHSC health needs assessment frames FASD as an issue that requires both prevention and a life-course response, including better awareness, training, diagnosis, and support pathways (DHSC, 2021). A policy approach that focuses only on prevention while neglecting people already living with FASD misses the central social justice issue identified throughout this report.

FASD is disproportionately concentrated in high-cost, high-need populations. Research shows 27% of children in care in one Peterborough study had FASD, and 75% of adoption reports indicated prenatal alcohol exposure. (It also has a high impact on those affected by kinship arrangements, though this research has not been done.) FASD appears to explain a significant portion of the complexity, service failure, and high downstream cost seen across children's social care, CAMHS, SEND, and criminal justice systems.

Reforms to mental health services, ADHD and autism pathways, SEND policy, education support for medical conditions, adoption and special guardianship support, justice, homelessness, workforce, benefits, and responses to the early deaths and severe harms experienced by care leavers will remain incomplete and less effective unless they explicitly incorporate FASD. The reason is not simply that FASD is another diagnosis to add to a list. It is that FASD explains a substantial part of the complexity, poorer outcomes, repeated service failure, and high downstream public cost seen across these systems.

> Fetal Alcohol Spectrum Disorder is recognised in the Department of Health and Social Care (DHSC) health needs assessment, NICE Quality Standard 204, and SIGN 656 as a high-need condition that requires prevention, recognition, diagnosis, and coordinated lifelong support. *This diagnostic failure is not marginal — it is structural.*



HOW FASD CAN PRESENT

Signs of FASD include...

FASD affects each person differently. Signs span learning, behaviour, the senses and the body — they may be more noticeable when a person is stressed.

- Difficulty learning, processing information or organising daily tasks
- Intellectual and/or developmental disabilities
- Unpredictable behaviour
- Hyperactivity or attention problems
- Memory challenges
- Sensory difficulties
- Challenges in the classroom
- Difficulties with abstract thinking and judgement — maths, time and money
- Social skills and adaptive behaviour much younger than their actual age
- Struggling with motor skills
- Poor social communication
- Struggling to learn from experience — repeating the same thing, especially when stressed

What is FASD?

Fetal Alcohol Spectrum Disorder is a lifelong, whole-body neurodevelopmental condition caused by prenatal alcohol exposure — and it should be actively considered, not overlooked.

COMMON DESCRIPTION — PREFERRED UK LANGUAGE GUIDE

> "FASD results when prenatal alcohol exposure affects the developing brain and body. FASD is a spectrum. Each person with FASD is affected differently. While more than 400 conditions can co-occur, FASD is at its core a **lifelong neurodevelopmental condition**. All people with FASD have many strengths. Early diagnosis and appropriate support are essential, especially for executive functioning."
>
> *National Organisation for FASD, FASD: Preferred UK Language Guide*

A whole-body diagnosis

Alcohol can affect any organ or system. More than 400 conditions can co-occur, and the brain is affected in everyone with FASD.

A spectrum, often invisible

Each person is affected differently. Fewer than 10% have facial features, so most people show no outward signs.

Strengths and support

All people with FASD have many strengths. Early diagnosis and the right support — especially for executive functioning — build brighter futures.

LIFELONG

FASD is not something a child grows out of. It is a permanent condition — needs change across the lifespan, from childhood into adulthood.

> **There is no 'mild' FASD.**
>
> Department of Health & Social Care, FASD Health Needs Assessment for England (2021)

There is no proven safe amount, type or time for alcohol in pregnancy

No safe AMOUNT **No safe TYPE** **No safe TIME**

Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay (SIGN 156). The UK Chief Medical Officers advise that if you are pregnant or could become pregnant, the safest approach is not to drink alcohol at all.

Sources: National Organisation for FASD, FASD: Preferred UK Language Guide; DHSC, FASD Health Needs Assessment for England (2021); SIGN 156, Children and Young People Exposed Prenatally to Alcohol (2019); NICE Quality Standard QS204; UK Chief Medical Officers' alcohol guidelines (2016).

From: The Cost of Inaction on FASD (June 2026).

The Economic Burden

Fetal Alcohol Spectrum Disorder (FASD) is the most common preventable neurodevelopmental condition in the UK, yet it remains the most under-recognised. New analysis using Perplexity AI and based on the most widely cited US lifetime cost analysis, figures from the Salford prevalence study and an internationally standard purchasing power parity (PPP) cost-transfer methodology indicates that the lifetime cost to UK society of a single FASD case is approximately £359,800 when diagnosed and £431,800 when undiagnosed. Applied to the estimated 18,000 affected children born each year, the recurring annual societal cost is on the order of £9.2 billion, and the 30-year cumulative present-value burden is around £160 billion under HM Treasury Green Book discounting.

Crucially, the analysis indicates that more than 90% of this cost is concentrated in the undiagnosed population, where missed early intervention, school exclusion and contact with the justice system drive the highest lifetime expenditure. Investment in earlier identification, NHS diagnostic pathways and SEND support is therefore not a cost — it is a saving.

This section sets out the figures, the methodology behind them.

Metric	**Figure**
Lifetime cost per diagnosed UK case	£359,835
Lifetime cost per undiagnosed UK case	£431,802
Annual UK societal cost	£9.2 billion
30-year cumulative cost (PV at 3.5%)	£160 billion
Estimated UK diagnosis rate	~10%
Share of annual cost borne by undiagnosed group	~92%

Source: PPP (Purchasing Power Parity) - adjusted from Greenmyer et al., 2018 via Shemilt et al., 2010 methodology. Even on the most conservative sensitivity assumptions (1% prevalence, 5% discount rate), the 30-year cumulative cost exceeds £40 billion. The dominant source of uncertainty is not prevalence but the diagnosis rate: a lower true diagnosis rate than the assumed 10% drives costs higher.

The scale of the problem

FASD describes a spectrum of lifelong cognitive, behavioural and physical impairments caused by prenatal alcohol exposure. As previously mentioned, the most rigorous active-ascertainment UK study — the Salford / McCarthy et al. 2021 study — found a prevalence of 2-4% among Greater Manchester schoolchildren, comparable to the higher end of international estimates and substantially higher than rates in published clinical registers. Salford also found that none of the affected children had been previously identified — a finding that anchors the diagnosis-rate assumption used here.

The lifetime cost of a UK case is built up from six components, anchored on the most widely cited US estimate (Greenmyer et al., 2018: $596,000 per case) and converted to UK pounds using the two-step PPP method described below. The breakdown of costs is shown below.

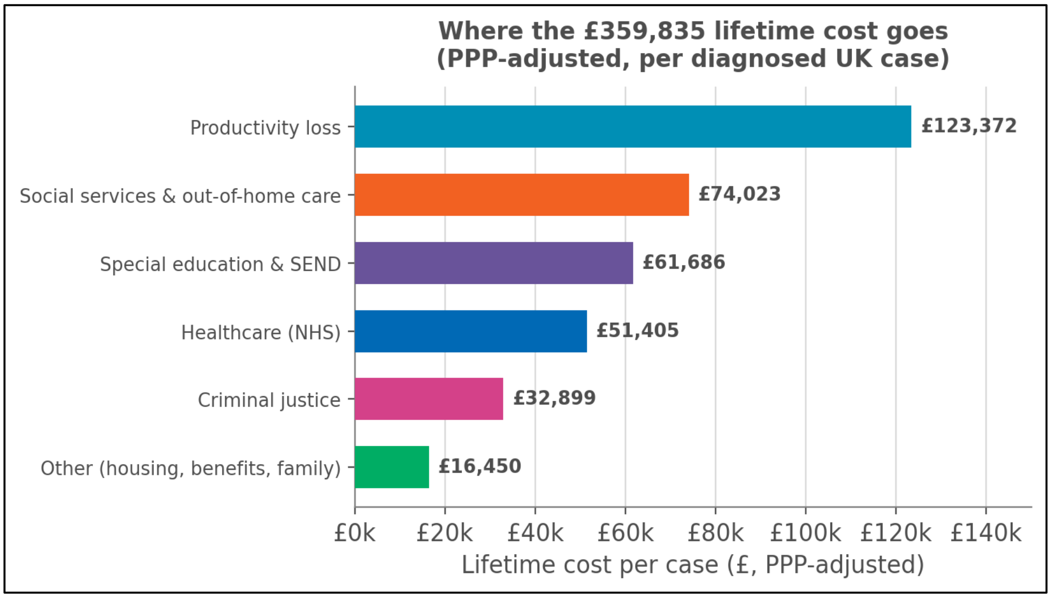


Figure: Lifetime societal cost of one diagnosed UK FASD case (£359,835), by component. Productivity loss is the single largest driver. Source: National FASD UK Cost Model, June 2026.

We are a small charity with limited resources. Our analysis is admittedly limited and relies on AI and some non-UK research findings. Nevertheless, we put it out there as a thought exercise. We call on our national Governments, in cooperation with leading universities, to examine the issues we raise here.

Replicating the Greenmyer et al. analysis on UK administrative data should be a research priority. This report suggests a way to fund such research, and on a scale commensurate with the need.

The diagnosis gap dominates the bill

Because so few UK cases are formally identified, the bulk of the population-level cost is borne by undiagnosed individuals — children who do not receive tailored education plans, adolescents who fall out of mainstream schooling, and adults whose contact with the justice and welfare systems is repeatedly costly. The model assumes a 20% lifetime cost premium for undiagnosed cases, reflecting missed early intervention, and applies a 10% diagnosis rate consistent with the Salford finding.

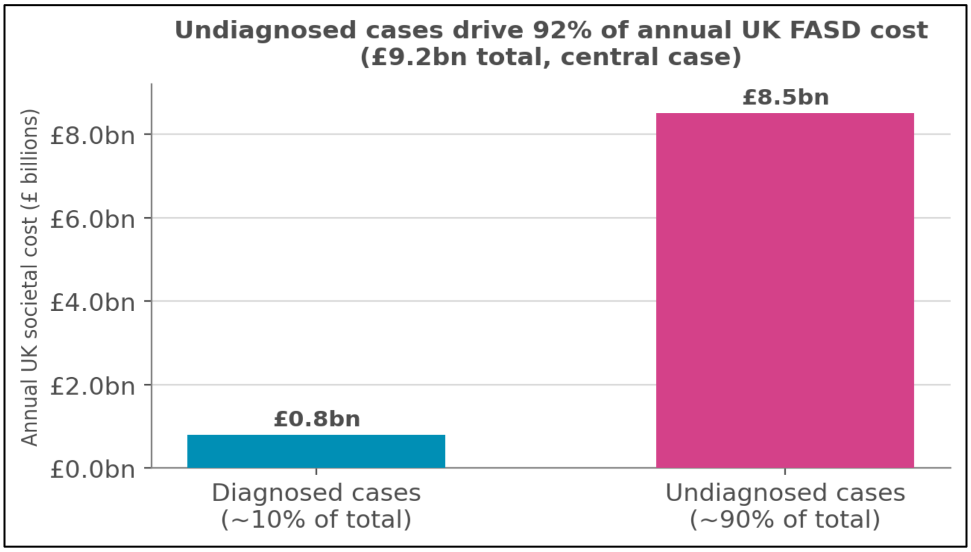


Figure: Annual UK societal cost split between diagnosed and undiagnosed cases. Approximately 92% of the £9.2 billion annual cost falls on the undiagnosed group.

The 30-year burden

Discounted at HM Treasury Green Book rate of 3.5%, the cumulative present-value cost of FASD to UK society over the next 30 years is approximately £160 billion under the central case (2.7% prevalence midpoint). Even under conservative assumptions the figure exceeds £100 billion — a scale that warrants the same level of cross-departmental coordination as comparable public-health priorities.

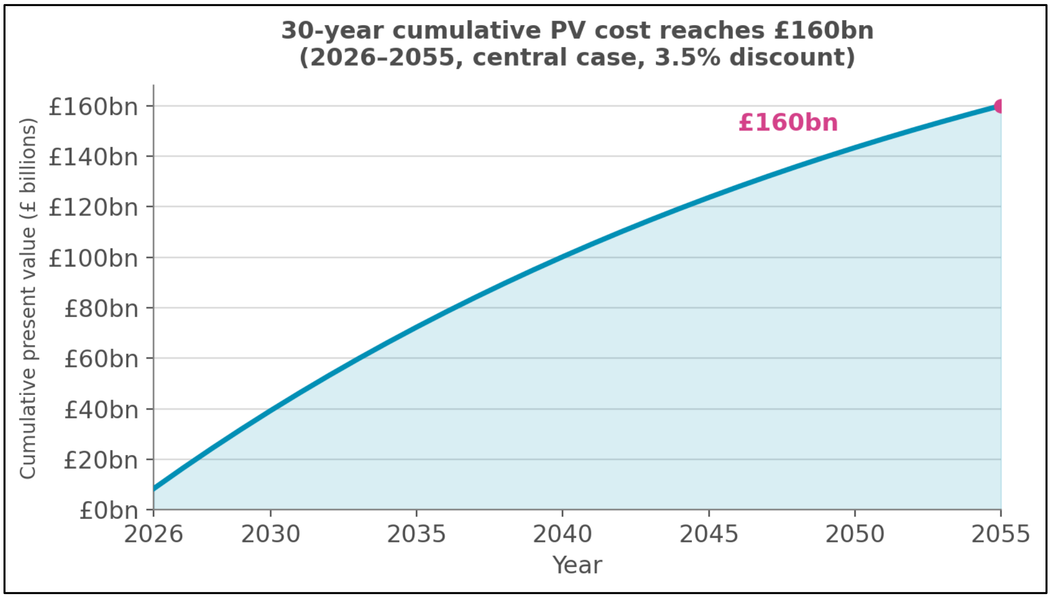


Figure: Cumulative present-value cost of UK FASD over 30 years, assuming each annual birth cohort accrues lifetime costs that begin discounting in their year of birth.

Methodology in brief

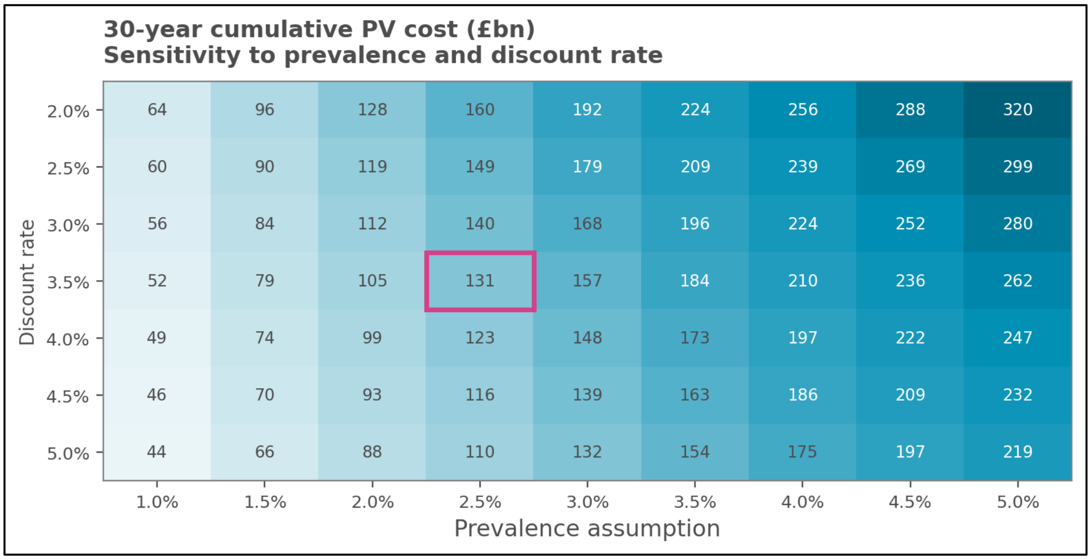
The model transfers the US lifetime cost estimate to the UK using the two-step approach recommended by Shemilt et al. (BMJ, 2010) and standard NICE/HTA practice:

> Step 1 — GDP Purchasing Power Parity. Convert $596,000 to GBP using the OECD/World Bank GDP PPP factor of 0.69 GBP per international dollar, giving £411,240 — the price-level-adjusted UK equivalent.
>
> Step 2 — Healthcare price ratio. Apply a 0.50 healthcare-specific ratio to the medical-care slice (25% of cost) to reflect the fact that US healthcare prices are roughly twice UK NHS prices for clinically equivalent services (OECD Health at a Glance 2025). Productivity, education, social-services, criminal-justice and housing/benefits costs retain only the GDP PPP conversion, because these sectors do not exhibit the same UK/US price gap.

Combining the two steps yields a final lifetime cost of £359,835 per diagnosed UK case — 16.1% lower than a naive market-FX conversion would produce. See Appendix A for further information on methodology.

Sensitivity and robustness

Two assumptions drive most of the variability in the headline number: the underlying prevalence rate, and the discount rate applied to future costs. The heatmap below shows 30-year cumulative present-value cost under all combinations of prevalence (1.0–5.0%) and discount rate (2.0–5.0%). The Green Book central case (3.5% discount, 2.5% prevalence) is highlighted at £131 billion; the headline £160 billion figure used elsewhere in this brief reflects the higher 2.7% midpoint of the Salford range.



30-year cumulative PV cost (£bn)
Sensitivity to prevalence and discount rate

Discount rate \ Prevalence assumption	1.0%	1.5%	2.0%	2.5%	3.0%	3.5%	4.0%	4.5%	5.0%
2.0%	64	96	128	160	192	224	256	288	320
2.5%	60	90	119	149	179	209	239	269	299
3.0%	56	84	112	140	168	196	224	252	280
3.5%	52	79	105	131	157	184	210	236	262
4.0%	49	74	99	123	148	173	197	222	247
4.5%	46	70	93	116	139	163	186	209	232
5.0%	44	66	88	110	132	154	175	197	219

Figure: 30-year cumulative present-value cost (£bn) sensitivity to prevalence and discount rate. Even the lowest plausible cell (1% prevalence, 5% discount) exceeds £40 billion.

What the sensitivity tells us

Robust to discount rate. Halving or doubling the discount rate from 3.5% does not change the policy conclusion — the cost remains an order of magnitude above the cost of any plausible early-diagnosis or prevention programme.

Robust to prevalence. Even at the bottom of the Salford range (1.8%), the 30-year cost exceeds £100 billion. The case for action does not depend on the upper-bound prevalence figure.

The dominant uncertainty is the diagnosis rate, not the prevalence. If the true rate of formal UK FASD identification is materially below 10%, the undiagnosed-case premium drives the bill higher, not lower.

Limitations

Cost transfer relies on US base data; no UK-native lifetime cost study of comparable scope exists.

The 20% premium for undiagnosed cases is a conservative judgement, not an empirical estimate; UK linked-data research could refine it materially.

The model values mortality and quality-of-life losses only insofar as they show up in productivity. A full QALY-based valuation would yield a higher figure.

Costs are quoted in 2024 GBP; no adjustment is made for future medical-cost inflation above the discount rate.

Even on the most conservative assumptions in this analysis, FASD imposes a recurring societal cost in the low tens of billions of pounds per year. Comparable prevention and early-intervention programmes for autism, ADHD and developmental coordination disorder receive dedicated commissioning frameworks, NICE guidelines and SEND recognition. Treating FASD on the same footing is overdue, evidence-based, and — on the figures in this brief — fiscally compelling.

Costs borne by families and caregivers

The economic costs of FASD extend well beyond formal services to include lost productivity, foregone earnings and substantial financial strain for parents and other caregivers. Cost-of-illness studies and reviews show that FASD generates high annual costs per affected individual and explicitly identify caregiver productivity losses as part of the wider economic burden, alongside health, education, social care and justice costs (Greenmyer et al., 2018). A recent systematic review of caregiving and financial impacts found that families incur considerable out-of-pocket costs related to health care, education, social services and behaviour management, and that caregiving demands frequently disrupt employment, reduce working hours and limit career progression for parents and kinship carers (Darragh et al., 2025).

The effect on wellbeing is equally significant. Qualitative syntheses and caregiver studies describe high levels of stress, exhaustion, social isolation and adverse impacts on mental and physical health among those caring for children and young people with FASD, often compounded by difficulties navigating fragmented systems and securing appropriate support (Coons-Harding et al., 2020; Darragh et al., 2025; SIGN, n.d.). These hidden costs are rarely visible in routine budget lines but are central to the true cost of inaction: failure to prevent alcohol-exposed pregnancies does not only increase long-term expenditure for public services, it also erodes the income, productivity and wellbeing of the families who provide most day-to-day care.

These caregiver costs are not included in the current analysis, which means the estimates presented in this report are likely to understate the full economic and human burden of FASD.

The hidden majority: people with FASD living with their birth families

The UK's fragmented FASD identification landscape has, by default, concentrated what little diagnostic and support infrastructure exists on the groups that are easiest for services to find: children in care, adopted children, and young people in contact with the justice system. This is partially understandable. Research consistently shows that FASD prevalence in looked-after populations is between 10 and 40 times higher than in the general population (Popova et al., 2019), and the finding that 27% of looked-after children in one Peterborough study had FASD, compared with a general population estimate of 2–4%, has rightly drawn urgent attention to the needs of care-experienced children (Gregory et al., 2015; National FASD, 2025). Children in care possibly have an alcohol-exposure history on record; their cases come before assessors; their needs are visible in a way that is structurally easier for services to respond to. In addition, rates of prenatal alcohol exposure is high among adoptive children (Gregory et al., 2015).

But this concentration of attention carries a profound and largely unacknowledged cost. If FASD affects an estimated 2–4% of the UK population — between 1.4 and 2.8 million people — and if children in care, those adopted, and those in contact with justice services represent a small minority of all people with FASD, then the overwhelming majority of undiagnosed cases are not in those systems at all (McCarthy et al., 2021; National FASD, 2025). They are living with their birth families. They are sitting in mainstream classrooms. They are being assessed for ADHD, autism, or conduct disorder without prenatal alcohol exposure ever being considered as an explanatory factor. They are growing into adulthood without a diagnosis, without a framework, and without the support that a diagnosis could unlock.

This is the hidden majority of people with FASD — and current policy, commissioning, and service design has left them almost entirely unreached.

Why birth families are the largest unidentified group

Alcohol consumption during pregnancy occurs across all socioeconomic groups. It is not confined to households where alcohol dependence is present, to women in contact with social services, or to families known to child protection systems (Department of Health and Social Care [DHSC], 2021). Many women drink before they know they are pregnant; others do so at low to moderate levels without awareness of the risk; the Chief Medical Officers' no-alcohol-in-pregnancy guidance, in its current clear form, has only been in place since 2016, meaning that many parents of school-age and adult children were not given unambiguous advice during pregnancy. Some 45% of births are unplanned in England alone (Public Health England, 2018) and similar trends are likely across the UK. FASD is a public health condition affecting the whole population, not a condition confined to high-risk or high-harm households.

The most important single data point in the UK FASD evidence base makes this explicit. The Salford active case ascertainment study — the UK's most rigorous prevalence research — found FASD in 2-4% of children in mainstream Greater Manchester primary schools (McCarthy et al., 2021). These were not looked-after children. They were not children with alcohol exposure histories on record. They were children living with their families, attending ordinary schools (rates are higher in specialist educational provisions), and none of them had ever been identified.

The arithmetic is straightforward. If 2–4% have FASD, and children in care represent approximately 80,000 individuals nationally, then even if every looked-after child had FASD — which is not the case — they would account for fewer than 6% of the estimated total FASD population. The other 94% or more are living in the community, the majority with their birth families. The concentration of FASD identification efforts on looked-after children, adopted children, and justice-involved populations — however justified by the elevated prevalence in those groups — cannot on its own address the scale of the problem.

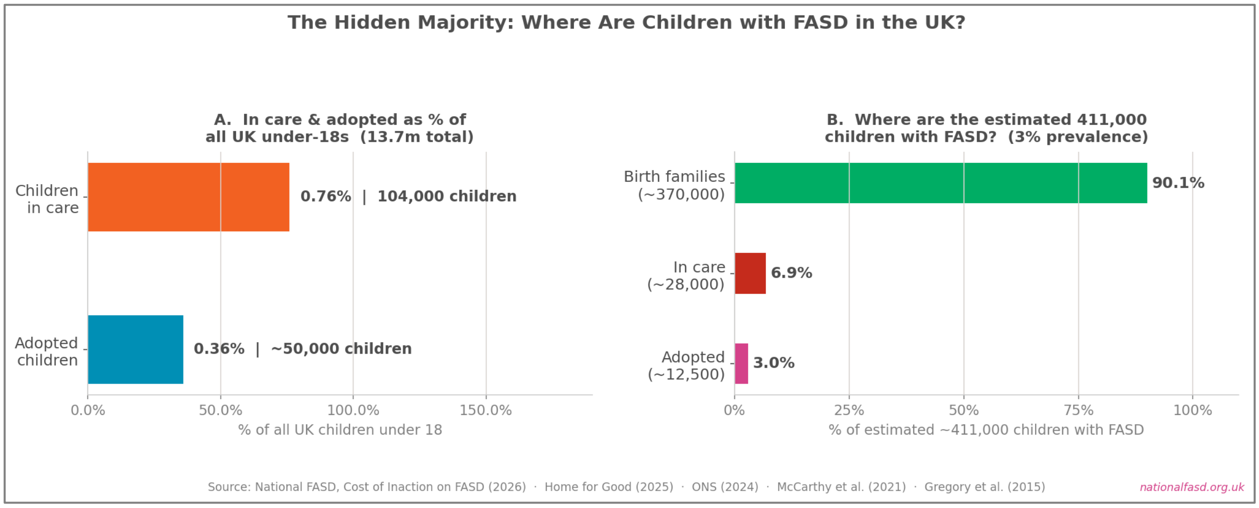


Figure: The Hidden Majority — children in care and adopted children together represent just over 1% of the UK under-18 population, yet these are the groups on whom FASD identification efforts are most concentrated. Applying prevalence estimates from McCarthy et al. (2021) and Gregory et al. (2015), approximately 90% of children with FASD are living with their birth families and largely unreached by current services. [2]

Put another way, the UK has an estimated 13.7 million children under 18 (ONS, 2024). Of these, approximately 104,000 are in care and ~50,000 are in adoptive families — together just over 1% of the child population. Applying the 3% prevalence midpoint from the UK's gold-standard active case ascertainment study (McCarthy et al., 2021), an estimated 411,000 children in the UK have FASD. Of these, around 90% (~370,000) are living with their birth families — the group least visible to, and least served by, current FASD identification and support systems.

> The implication is direct: the majority of children with FASD in the UK are invisible to the systems that might identify them, because those systems are not looking in the right places.

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[2] *Notes on the figures: Children in care: 104,368, all UK nations, Home for Good (2025); Adopted children under 18: ~50,000 conservative cumulative estimate (England ~3,000 adoptions/year; ~50,000 currently under 18 across UK); Number with FASD in care uses the 27% Peterborough prevalence figure (Gregory et al., 2015); Number with FASD who are adopted uses a conservative 25% estimate; the actual figure may be higher given that 75% of adoption reports show prenatal alcohol exposure.*

	Number	**Source**
Total UK population under 18	13,700,000	ONS, 2024
Children in care (all UK nations)	104,368 (0.76% of under-18s)	Home for Good, 2025
Adopted children under 18 (UK est.)	~50,000 (0.36% of under-18s)	CoramBAAF / Adoption England, 2025
Estimated children with FASD (3% midpoint)	~411,000	McCarthy et al., 2021
— of whom: living with birth families	~370,000 (~90% of children with FASD)	Derived from above
— of whom: in care	~28,000 (~27% children in care = ~7% of all children with FASD)	Gregory et al., 2015
— of whom: adopted	~12,500 (~25% of adopted children = ~3% of children with FASD)	Conservative est.; TACT, 2024

What keeps the birth family population hidden

Several intersecting factors maintain the invisibility of FASD in birth families, each of which requires a distinct policy and practice response.

The absence of a recorded exposure history is the most fundamental barrier. In looked-after children, a history of prenatal alcohol exposure may appear on a health assessment, adoption report, or court document. In birth families, no such record commonly exists. Routine antenatal alcohol enquiry — required by NICE Quality Standard 204 (National Institute for Health and Care Excellence [NICE], 2022) and SIGN 156 (Scottish Intercollegiate Guidelines Network [SIGN], 2019) but implemented patchily or not at all across most areas — is the single most important mechanism for creating a population-level exposure record that could trigger developmental monitoring and referral for assessment where needed. Without it, the prenatal history that is the essential starting point for FASD assessment is simply absent from the clinical record.

Stigma and blame culture compound the problem specifically in birth family contexts. A birth parent who drank during pregnancy — even unknowingly, even moderately, even before the pregnancy was confirmed — may face intense self-blame if FASD is raised as a possibility, and may encounter judgmental responses from professionals. National FASD's surveys consistently document this pattern: *"As FASD has a blame culture it tends to be ignored rather than supported"* (National FASD education survey, 2026). The consequence is that professionals who lack appropriate training on how to discuss these lifestyle questions avoid raising the possibility of FASD with birth families, birth parents do not disclose alcohol use in pregnancy, and children remain unidentified.

Misattribution of FASD-consistent presentations is endemic in education and primary care settings. Executive functioning difficulties, poor working memory, impulsivity, emotional dysregulation, and adaptive functioning deficits are FASD's most common features. In a birth family context — particularly where the family presents as stable and the child as otherwise well-supported — these features are routinely attributed to ADHD, autism, conduct disorder, anxiety, or attachment difficulties. The referral for neurodevelopmental assessment proceeds on the basis of the presenting label rather than the causal history. Without FASD being in the differential diagnosis, assessment processes designed for autism and ADHD will not identify it (Peadon & Elliott, 2010; McCarthy et al., 2021). The lack of adult identification routes means that the majority of adults with FASD living in birth family contexts — including those who are themselves parents — have no pathway to diagnosis. Without adult diagnostic pathways, the intergenerational dimension of FASD remains invisible to services designed to break that cycle (DHSC, 2021).

Jan and Rossi's Story: Hidden in Plain Sight

> Like many birth families, we did not know. Over the years Rossi accumulated multiple labels, diagnoses and difficulties, many of which are now recognised as commonly sitting beneath the FASD umbrella. Despite repeated contact with health, education and mental health services, nobody joined the dots. Eventually, my own search for answers led me to FASD. For the first time, I could see the connection between all the labels and, more importantly, I recognised my son. It was only when I began seeking support and recognition that I became aware of another challenge. I was often left with the impression that families like ours were not the families professionals expected to see affected by FASD.
>
> I was an educated, working mother in a stable family. At 36 I had a sudden cardiac arrest which induced an early menopause. When I became unexpectedly pregnant at 40, nobody warned me that FASD could happen to families like mine. The doctor told me to have sleeping tablets at first because I wasn't sleeping. I was horrified as I was pregnant and thought it would harm the baby so he literally said then start having a tot of brandy in the evening to help you relax as we know stress is not good for babies. In fact, the message I absorbed was that people like me did not have children with FASD.
> By the time we reached crisis point, Rossi was out of education, struggling with his mental health and questioning whether life was worth living. Once we understood his needs, everything changed. Today Rossi is a qualified makeup artist, author and advocate. He still needs daily support to succeed, but that support is an investment, not a cost. Given the right support, he is an asset to society, not a drain on the public purse. Our story is not unique. It reflects the experience of countless birth families hidden in plain sight. The true cost is not providing support; it is failing to recognise the need for it in the first place.

The critical role of the 0–19 workforce

The 0–19 Healthy Child Programme workforce — health visitors, school nurses, and the wider community health and early years offer including Children and Family Hubs — represents the UK's most significant and most underused asset for reaching the birth family population with FASD. These are the professionals who hold universal caseloads spanning all children from birth to 19, who conduct mandated developmental reviews, who are present in every community regardless of social care involvement, and who have repeated contact with families across the years in which FASD most commonly comes to clinical attention (National FASD, 2025a).

Health visitors hold caseloads covering all children aged 0–5, with mandated contact points at birth, 6–8 weeks, 9–12 months, 2–2.5 years, and school entry — contacts that occur precisely at the developmental stages when FASD-related differences in neurodevelopmental trajectory first become apparent. School nurses provide universal and targeted support from age 5–19. Children and Family Hubs, being developed across England as community-based early support settings, are an increasingly important additional tier — offering a non-stigmatising, universal access point for families with young children who may never present to social care but who would benefit from early FASD awareness, signposting, and support (National FASD, 2025a).

Yet current training provision for this workforce is wholly inadequate. Research by Howlett et al. (2019) found that only 20% of health visitors felt confident identifying signs and symptoms of FASD, and only 63.3% felt comfortable discussing FASD with a parent — despite 98% requesting more training (National FASD, 2025a). The existing e-learning content on the NHS E-Learning for Healthcare (eLfH) platform has been found to contain outdated terminology, inaccurate screening thresholds, and no meaningful FASD-specific content consistent with current NICE or SIGN standards. This systemic gap in professional education is not a minor oversight; it means that the practitioners with the greatest reach into birth families — health visitors in particular, who are far more likely than GPs or paediatricians to hold universal caseloads — are currently the least equipped to recognise and respond to FASD (National FASD, 2025a).

National FASD has submitted a proposal to NHS England's 0–19 workforce call for evidence, setting out a comprehensive training and resource package specifically designed to fill this gap (National FASD, 2025a). The package encompasses: an updated, expert-reviewed online training course on FASD identification aligned with NICE QS204; locally adaptable referral pathway guidance; communication frameworks and motivational interviewing principles to support non-judgmental conversations with birth families about prenatal alcohol exposure; prevention resources including alcohol-and-pregnancy leaflets, lanyard prompt cards, and tabletop quick-reference guides; and — critically — parent-facing resources designed to enable families themselves to ask the question that identification requires.

The theory of change is straightforward and well-supported: a trained and confident 0–19 workforce generates earlier and more accurate identification; earlier identification enables appropriate referral and tailored support; timely intervention reduces secondary harms including mental health crisis, school exclusion, and justice system contact; and prevention-focused conversations at universal contact points reduce the prevalence of prenatal alcohol exposure in future cohorts (National FASD, 2025a). Preventing even a single case of severe associated difficulties would likely offset the entire cost of programme development many times over. The intervention requires no new workforce, no new infrastructure, and no new legislation. It requires commissioning.

The importance of non-stigmatising, widely available public information

Alongside workforce training, there is an urgent and largely unmet need for accessible, non-blaming public information about FASD that is available in settings where birth families are likely to encounter it — GP surgeries, Children and Family Hubs, school waiting areas, pharmacies, children's centres, and community health settings. The majority of families affected by FASD are not accessing specialist services or advocacy organisations. They are raising children whose difficulties they cannot explain, cycling through appointments that do not converge on a diagnosis, and often concluding — after years of being met with scepticism or silence — that they must simply be failing as parents.

National FASD's *Ask About FASD* resources, developed for and with families, are framed for this challenge. The central message — *"Is your child struggling and you don't know why?"* — directly addresses the birth-family experience: a child with unexplained behavioural, attentional, or learning difficulties, whose parent has never encountered the words "fetal alcohol spectrum disorder" and has no reason to connect their child's presentation to alcohol exposure during pregnancy (National FASD, n.d.). The resources set out the signs of FASD in accessible language — memory difficulties, challenges with abstract thinking, unpredictable behaviour, social skills and adaptive behaviour challenges, struggling to learn from experience — without attributing blame, and direct families to their GP as a first port of call for assessment (National FASD, n.d.). Crucially, they carry the SIGN 156 standard directly to families: *"Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay"* (SIGN, 2019).

The case for wide distribution of these and equivalent materials in universal, community-based settings is strong. Unlike information targeted at people already in specialist or social care pathways, a leaflet in a GP waiting room or a poster in a Children and Family Hub reaches the parent of a child currently receiving no support, with no professional yet having considered FASD, in the setting where the first conversation about it is most likely to occur. Research shows that families consistently report that their own search for an explanation — prompted by encountering FASD in the media, online, or through materials in universal settings — was the catalyst for the eventual diagnostic journey (National FASD, 2025). Equipping families with the language to ask the right question is not a substitute for professional identification, but it is a complement to it, and for many families it will be the mechanism through which identification begins.

What the systems that serve birth families need to do differently

Universal maternity and health visiting services are the entry point to the majority of families with children, regardless of social care involvement. They are the setting in which prenatal alcohol exposure can most effectively be enquired about, recorded, and acted upon, and in which FASD prevention messaging can be delivered most consistently. The *Not Commissioned* report (National FASD, 2024) found that systematic alcohol enquiry in pregnancy was absent or inconsistent in most Integrated Care Boards in England and Health Boards in Wales, with limited reference to NICE QS204 in commissioning policies and no consistent provision of post-diagnostic management plans. Embedding routine enquiry, accurate recording, and brief intervention into universal maternity services is the primary mechanism for creating the clinical record that makes identification of affected children possible in birth-family contexts — for this and for future generations (DHSC, 2021; NICE, 2022).

Children and Family Hubs in England are a particularly important emerging setting for the birth-family population. They offer a non-stigmatising, community-based point of contact for families who would never present to social care, providing the kind of universal early support environment in which FASD awareness conversations can take place without the associations of surveillance or judgment that clinical and statutory settings can carry. FASD should be explicitly integrated into Hub staff training, resource libraries, and referral pathways. *Ask About FASD* leaflets and equivalent materials should be available in every Hub as a matter of routine (National FASD, 2025a).

Universal and mainstream primary school settings are where the Salford study found its 2-4% prevalence. Children with FASD in birth families are in those classrooms — attending ordinary schools, taught by mainstream teachers, assessed by SEND processes — and none of the identification pathways currently routinely in use will reach them unless FASD is in the professional vocabulary of those conducting them (McCarthy et al., 2021). FASD training for classroom teachers, educational psychologists, and SENCO staff — not as a specialist add-on but as part of routine neurodevelopmental continuing professional development — is the most scalable mechanism for reaching the birth-family population. The child struggling in Year 3 without explanation, whose parent has never been near a social worker, can only be reached through the universal education system.

General practice is the first port of call for the majority of birth families raising developmental concerns. Yet for the most part, GPs are not currently trained to take a prenatal alcohol history, are not equipped with FASD as part of their differential diagnostic vocabulary, and have no referral pathway to direct families toward even when they do consider it. (Scotland has an online ecourse for GPs that is not yet mandatory.) FASD training within GP continuing professional development, and the development of clear referral routes to services within the proposed FASD Prevention and Response (PRP) network, are prerequisites for general practice to fulfil its potential as an identification gateway for birth families (National FASD, 2024; NICE, 2022).

CAMHS and children's mental health services are frequently the destination of children with FASD who have not been identified — where emotional dysregulation, anxiety, depression, and suicidality are treated without the underlying causal framework being understood. Over 90% of individuals with FASD experience significant mental health difficulties (Streissguth et al., 2004; Pei et al., 2011), and many of those children are in birth families, accessing CAMHS without prenatal alcohol exposure ever having been considered. CAMHS practitioners who do not have FASD in their clinical vocabulary will deliver interventions calibrated to the wrong model — and children will continue to accumulate unmet need, secondary harm, and additional diagnoses as a result.

How to get better at finding the hidden majority

The following actions are needed to ensure that the majority population with FASD — those living with their birth families — is systematically reached:

- Commission the proposed National FASD 0–19 workforce training package through NHS England and OHID, hosted on the NHS eLfH platform and aligned with the Healthy Child Programme framework. This is the most scalable, cost-effective mechanism for reaching the birth-family population and requires no new workforce or infrastructure (National FASD, 2025a).
- Integrate FASD training and awareness into Children and Family Hub staff induction and ongoing CPD, alongside the provision of *Ask About FASD* and equivalent materials as standard resources available to all Hub visitors. Hubs represent a unique, low-stigma universal setting for early identification conversations with birth families.
- Make non-stigmatising FASD information resources — including National FASD's *Ask About FASD* leaflets and posters — universally available in GP waiting rooms, Children and Family

Hubs, school SEND information points, health visiting clinics, Children's Centres, pharmacies, and community health settings. These materials should be framed around the family's experience of unexplained difficulty — *"Is your child struggling and you don't know why?"* — rather than around risk or blame.

- Embed FASD as a mandatory topic in SENCO, educational psychology, and school nurse continuing professional development, ensuring that the professionals most likely to encounter FASD in mainstream schools have the vocabulary and referral knowledge to act on it (National FASD, 2022).
- Train GPs in taking a prenatal alcohol history as part of routine developmental assessment for any child presenting with behavioural, attentional, or adaptive functioning concerns, and provide them with clear referral routes to services within the commissioned FASD Prevention and Response Programme (PRP) network (NICE, 2022; DHSC, 2021).
- Design the FASD PRP services to be commissioned into community paediatric and primary care settings, not solely into specialist neurodevelopmental or looked-after children health pathways, so that birth-family referrals from GPs, health visitors, and school nurses reach an accessible assessment service (National FASD, 2024).
- Design the national FASD Linked Database/ Registry to capture birth-family cases, not only those arriving through care and justice pathways. Registry data derived primarily from LAC health reviews and court referrals will systematically undercount the birth-family population and perpetuate the false assumption that FASD is principally a condition of the care system (DHSC, 2021).

Address the intergenerational dimension by ensuring that alcohol and pregnancy prevention services and brief intervention training are designed to reach women across the socioeconomic spectrum — not only those in contact with alcohol treatment services or children's social care. The majority of alcohol-exposed pregnancies occur in households where alcohol dependence is not present; prevention targeted only at dependent drinkers will not prevent the majority of FASD cases (Proof Alliance, 2025).

The cost of continuing to look in the wrong places

This report's economic model estimates an annual UK societal cost of £9.2 billion, with the overwhelming majority of that cost falling on the undiagnosed population (National FASD, 2026). The undiagnosed population is not, as is sometimes assumed, a population that services have attempted and failed to reach. It is a population that services have never systematically sought — because the identification systems that exist are calibrated to the minority of people with FASD (important as they are to identify) who pass through care, adoption, or justice systems, not the majority who live with their birth families throughout childhood and into adulthood.

Every year that universal services — maternity, health visiting, Children and Family Hubs, primary care, education — continue to operate without FASD awareness, without routine enquiry, and without referral pathways to assessment, the birth-family population with FASD grows older without identification. Children become adolescents without support. Adolescents become adults without a diagnosis. Adults cycle through systems — mental health, employment, benefits, and sometimes justice — that cannot understand or accommodate them. The costs accumulate across decades and across services, invisible to any single commissioner, attributable in every budget line to something other than FASD.

Reaching the hidden majority requires a deliberate shift in where identification efforts are targeted, how services are designed and commissioned, how professionals are trained, and how public health messaging frames FASD — not as a condition only of the care system, but as a common, underdiagnosed, largely preventable neurodevelopmental condition that affects children and adults in every community and every family type across the United Kingdom. The infrastructure for that shift exists. The policy mandate exists. What is required is the commissioning decision to act.

SECTION 3

The FASD Policy Blindspot

In UK legislatures, autism is debated ~13x and ADHD ~4x more often than FASD — affecting current reforms.

AT A GLANCE · SECTION 3

The FASD policy blindspot

FASD is as common as — or more common than — autism and ADHD, yet it is almost invisible in UK legislative debate. New Hansard analysis shows this visibility gap is undermining the very reforms meant to improve neurodevelopmental, SEND and care outcomes.

~13x
more often **autism** is debated than FASD in UK legislatures

~4x
more often **ADHD** is debated than FASD

5.4%
FASD's share of **8,565** neurodevelopmental Hansard entries

2–4%
of the UK population has FASD — **a similar order of magnitude**

How often each condition is debated in Hansard

Analysis of 8,565 neurodevelopmental-related Hansard entries (They Work For You API).

Why reform agendas will fail without FASD

FASD is a cross-cutting explanation for poor outcomes — leaving it out makes each reform less effective.

Mental health reform

The interim review of mental health, ADHD and autism omits FASD — so its scope cannot capture a major driver of presentations.

SEND & education

FASD is frequently misread as ADHD, autism, trauma or behavioural difficulty, so SEND reform misses a key cause of unmet need.

Adoption & care

FASD is heavily over-represented among looked-after and adopted children, yet rarely named in care or guardianship reform.

Justice & welfare

Care-experienced and justice-involved young people are disproportionately affected, but FASD stays largely absent from these agendas.

An equity issue

Visibility is a postcode lottery — Scotland and NI debate FASD more than England or Wales (just 1 Welsh entry), reflecting interest, not need.

Stuck in ‘awareness’ mode

50+ years on, FASD is still framed as a data gap to “raise awareness” about — not a condition needing routine screening and pathways.

Visibility is not tracking need — and reforms pay the price

Strategies that focus only on autism and ADHD undermine their own goals on early identification, reducing inequalities and building coherent neurodevelopmental pathways. FASD must be explicitly written into mental health, SEND, adoption, care and justice reform across all four nations.

Sources: National FASD Hansard analysis using the They Work For You Hansard API (8,565 cleaned neurodevelopmental entries; see Appendix B); DHSC FASD Health Needs Assessment (2021); NICE QS204 (2022); SIGN 156; “Independent review into mental health conditions, ADHD and autism: interim report”.
From: The Cost of Inaction on FASD (June 2026), Section 3. Hansard is an imperfect measure — but the under-representation of FASD is clear.

Section 3: The FASD policy blind spot

This section concludes that FASD is massively underrepresented in UK legislative discussion compared to other conditions and highlights how current reforms across the four nations will fail to meet their goals if they do not take into account prenatal alcohol exposure and FASD.

FASD is under-represented in UK legislative discussions with grave impact

FASD is massively under-represented in UK-wide legislative discussions according to new research based on Hansard.

As mentioned in further detail in Appendix B, this research is specifically timely due to lack of inclusion of FASD in the recently published "Independent review into mental health conditions, ADHD and autism: interim report" and other ongoing consultations and reforms. This section is provided to show how the lack of attention to FASD compared to autism and ADHD is endemic in policy debates as demonstrated by Hansard.

FASD comprises 2-4% of the UK's general population (and is higher among looked after and adopted children, and other at-risk populations). Therefore, it is not possible to gain an accurate picture or to provide accurate recommendations of the independent review's attempted scope without analysis of FASD and its impact on mental health presentations, ADHD and Autism.

The data shows this to be not a singular example, but a trend of under-representation that must be ended to ensure legislation that includes all in need of support.

FASD must also be considered in other ongoing consultations into SEND, medical conditions in education and suicide rates for looked after children.

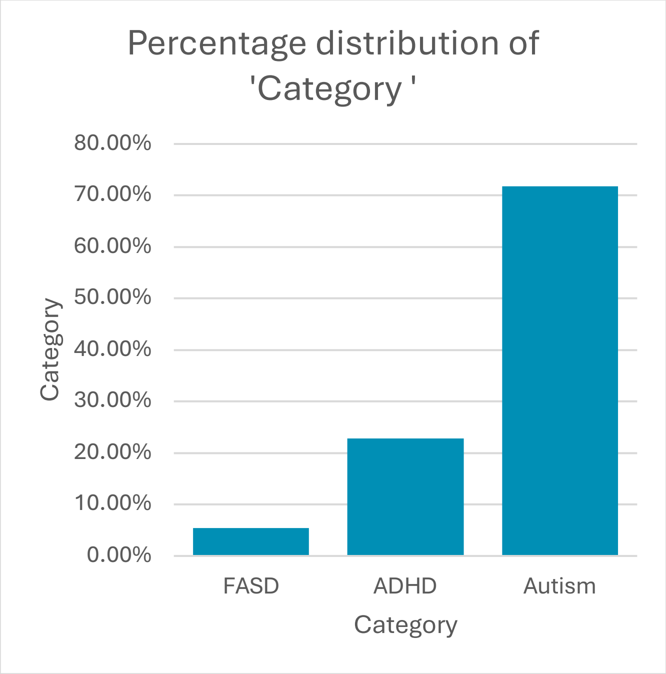
The data on visibility of FASD compared to autism and ADHD in Hansard

The data, while imperfect, shows an undeniable and concerning pattern.

Analysis of a Hansard dataset comprising 8,565 neurodevelopmental-related entries shows that autism (6,148 entries) and ADHD (1,953 entries) continue to dominate parliamentary discourse, while FASD is referenced only 464 times. Autism is therefore mentioned more than thirteen times as often as FASD and ADHD over four times as often, despite national policy documents (NICE QS 204, SIGN 156 and the DHSC FASD Health Needs Assessment) now framing FASD as a major neurodevelopmental condition requiring systematic identification and support. FASD-specific mentions increase from the late 2000s onwards and peak at 45 entries in 2018, but remain in the tens per year even after key FASD guidance is published, in contrast to the thousands of autism and ADHD entries accumulated over the same period. Across all UK nations, FASD is much less visible than autism or ADHD; Scotland and Northern Ireland contribute relatively more FASD debate, often linked to alcohol-harm strategies, but even there FASD is still framed as under-recorded and poorly understood.

This entrenched visibility gap in parliamentary debate is out of step with current policy expectations and helps explain why people with FASD and their families continue to experience fragmented pathways, misdiagnosis and a lack of coordinated support.

Category	Count of Category	Percentage
Autism	6148	71.78%
ADHD	1953	22.80%
FASD	464	5.42%
Total	**8565**	**100.00%**



Autism is mentioned about 13.3 times as often as FASD (6,148 ÷ 464).

ADHD is mentioned about 4.2 times as often as FASD (1,953 ÷ 464).

Term	Count of Category	Percentage
Autism	5129	59.88%
Autism Spectrum Disorder	669	7.81%
Asperger syndrome	60	0.70%
ASD	290	3.39%
ADHD	1062	12.40%
Attention Deficit Hyperactivity Disorder	891	10.40%
Foetal alcohol syndrome	138	1.61%
Foetal Alcohol Spectrum Disorder	129	1.51%
FASD	79	0.92%
Foetal Alcohol Spectrum Disorders	41	0.48%
Fetal Alcohol Spectrum Disorder	27	0.32%
FAS	26	0.30%
Fetal alcohol syndrome	23	0.27%
ARND	1	0.01%
Grand Total	**8565**	**100.00%**

Trends across nations

Country	Autism	ADHD	FASD
England	317	130	32
Scotland	660	269	63
Wales	309	81	1
Northern Ireland	409	70	10
UK-wide/unspecified	4,453	1,403	358

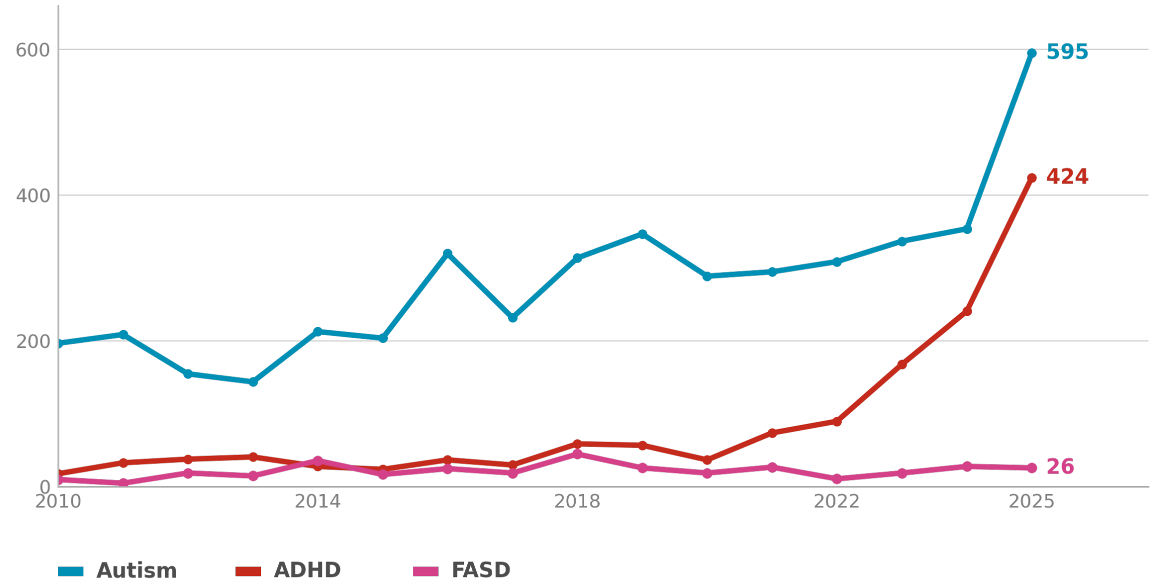
- Autism is the most frequently mentioned category in every nation and in UK-wide/unspecified business.
- ADHD appears consistently across the UK, with particularly high counts in UK-wide and Scottish business.
- FASD remains least visible everywhere: there is a meaningful cluster in Scotland and UK-wide/unspecified business, but only 32 FASD-labelled entries assigned to England, 10 to Northern Ireland and just 1 to Wales in the entire dataset.
- This pattern suggests that, even in devolved legislatures that are highly engaged on alcohol harm and children's policy, FASD has not yet reached the level of routine visibility that autism and ADHD enjoy.

Time trend for FASD mentions in Hansard

FASD-category entries by year (selected years):

- 2007–2012: fluctuating between low single digits and low 30s per year (for example, 23 in 2007, 32 in 2008, 19 in 2012).
- 2013–2016: steady but modest activity (10–36 mentions per year; 36 in 2014, 25 in 2016).
- 2017–2021: sustained presence with occasional peaks (e.g. 45 mentions in 2018, mid-teens to mid-20s in most other years).
- 2022–2025: continued but not escalating attention (11 mentions in 2022, 19 in 2023, 28 in 2024, 26 in 2025).
- Early 2026: only 2 FASD entries captured so far, as expected part-way through the year.

FASD-specific references are almost absent before the mid-2000s, then appear as small clusters in the later 2000s and 2010s, with a peak of 45 entries in 2018. Even after the publication of major policy documents such as the DHSC FASD Health Needs Assessment (2021) and NICE QS 204 (2022), the number of parliamentary mentions per year remains in the tens, not the hundreds. This is in stark contrast to autism and ADHD, which together account for more than 8,000 entries in the dataset.



The widening gap, 2010 – 2025

Hansard mentions per year. FASD has flatlined while autism and ADHD have surged.

Source: TheyWorkForYou / Hansard term search (1962–2026, n = 8,565). © National Organisation for FASD.

Rough overview of qualitative differences in discussion reveals a wider imbalance

Even in the most recent decade, AI analysis of the substance concludes that FASD debates are dominated by explanations of what FASD is and acknowledgements that it is under-recorded, whereas autism and ADHD debates assume mature service frameworks and focus on adequacy of provision. This shows that the parliamentary record has not yet caught up with the changed policy position. While national guidance now places FASD alongside other major neurodevelopmental conditions, parliamentary discourse as measured in Hansard still largely centres on autism and ADHD, treating FASD as a niche or emerging concern. Devolved legislatures, particularly Scotland, have played an important role in raising FASD within parliamentary business, but the absolute numbers remain small and FASD is far less present than autism or ADHD in every UK nation.

Methods used

Using the “They Work For You Hansard API” we collected data relating to the use of common terms for Autism, ADHD and FASD across Parliament and the UK’s devolved institutions. This has facilitated analysis of the frequency and context each are used, demonstrating substantially reduced focus and understanding of FASD in comparison to Autism and ADHD, despite its prevalence in the general population.

Using Anthropic's Claude Ai model, code was created to access the They Work For You Hansard API. An API (Application Programming Interface) is a tool that acts as a messenger between software applications, allowing the sharing of large amounts of information. They Work For You have compiled a complete picture of Hansard through scraping its data daily, allowing request to its API to provide broad, yet detailed, information regarding the data collected.

For the purposes of this analysis the API was asked to return information regarding a list of terms that broadly represent how Autism, ADHD and FASD are practically discussed. For each term the API was asked to fetch every reference made, along with its location, business, speaker, the link where this can be found within Hansard, and the immediate quote from which the term was used.

The terms searched were – ADHD, ARND, ASD, Asperger’s Syndrome, Attention Deficit Hyperactivity Disorder, Autism, Autism Spectrum Disorder, FAS, FASD, Fetal Alcohol syndrome, Foetal alcohol spectrum disorder and Foetal Alcohol Syndrome. These were grouped into ADHD, autism, or FASD. Effort was made to remove duplicate terms and clean the data provided, leaving 8749 entries since 1963.

These were drawn from: Written Answers, House of Commons, Scottish Parliament, House of Lords, Northern Ireland Assembly, Westminster Hall, Welsh Parliament, Public Bill Committees, Ministerial Statements, London Assembly.

Analysis of the frequency and context each are used, demonstrating substantially reduced focus and understanding of FASD in comparison to Autism and ADHD, despite its prevalence in the general population.

Limitations of this dataset

Using Hansard is an imperfect measure: it captures what is said in some formal proceedings but does not cover the full Parliamentary agenda, and it only records certain proceedings – for example select committees and all-party groups are not included. Government controls floor time, so Hansard does not necessarily show MPs’ interest in a topic. In addition delegated legislation, written statements and some committee procedures can be handled with little or no substantive debate. Some historic information may be missed due to changes in recording and digital systems.

Mentions do not equal meaningful attention - counts of speeches or questions do not necessarily mean deep scrutiny or policy impact. The data may also include multiple ‘hits’ for the same intervention.

Nevertheless, the data is clear that FASD is underrepresented in policy discussions.

Policy implications of the severely disproportionate attention to FASD in UK legislatures

International and UK estimates put FASD prevalence in the same order of magnitude as, or higher than, autism and ADHD in many populations, yet Hansard mentions show autism ~13x and ADHD ~6x as many references as FASD.

Strategies that only focus on ADHD and autism undermine goals on early identification, reducing inequalities and creating coherent neurodevelopmental pathways.

There is a visibility gap on FASD that does not reflect epidemiology and population need

International and UK estimates put FASD prevalence in the same order of magnitude as, or higher than, autism and ADHD in many populations, yet Hansard mentions show autism ~13x and ADHD ~6x as many references as FASD.

> This discrepancy implies that parliamentary and policy attention is not tracking actual population need for FASD.

More than 50 years after the first diagnosis, FASD remains stuck in “awareness and data-gap” mode

FASD is still often discussed as something government does not measure well and needs to “raise awareness” about. That makes it harder to achieve: routine screening and identification, clear diagnostic pathways, and embedded service expectations in education, CAMHS and social care.

FASD is becoming an equity issue across nations

The dataset suggests uneven FASD visibility across nations, with Scotland and Northern Ireland legislatures more likely to mention FASD than Wales or England, particularly in alcohol policy and child-protection contexts. Given high rates for alcohol-exposed pregnancies, alcohol-harm burdens and care-experienced populations across the UK, this likely reflects the personal interest of parliamentarians, not real differences in FASD prevalence. While Scotland has led the UK on FASD in terms of visibility and funding (though still limited), the same level of interest is not true in Northern Ireland. (It is also important to note it is an equity issue across different areas within each country as it is a postcode lottery with huge inequities between areas.)

Implications for the current national strategies and reforms

If national strategies focus only on autism and ADHD (as the Hansard ratios suggest) and do not deliberately bring FASD into scope, they will systematically overlook a major neurodevelopmental and mental-health need that is prevalent across the population and particularly concentrated among care-experienced, traumatised and justice-involved young people - one that is preventable.

Strategies that only focus on ADHD and autism undermine goals on early identification, reducing inequalities and creating coherent neurodevelopmental pathways.

Why current policy reform agendas will fail without including FASD

The current UK policy environment is characterised by multiple overlapping reform programmes. These include in varying degrees across the four nations:

- Mental health improvements;
- Special educational needs and disabilities reform;
- Pressures on adoption and special guardianship support;
- Growing concern about the poor outcomes, premature mortality and systemic neglect experienced by many care-experienced young people;
- Challenges facing the justice system;
- Attempts to engage more people with disabilities in the workforce;
- Attempts to address homelessness, NEETs and school exclusions;
- Alcohol harm reform, and more.

FASD is largely missing from this picture. Where it is absent, policy analysis becomes incomplete. That is because FASD is not just an individual diagnosis but a cross-cutting explanation for why some children, young people, and adults with apparently similar labels have much worse outcomes, need different support, and respond poorly to standard pathways.

Each of these agendas is concerned, in different ways, with rising demand, more complex need, delayed access to support, inequity, and repeated system failure. Each will be ineffective if FASD is not explicitly incorporated. Current UK reform agendas still tend to treat FASD as marginal, optional, or subsumed within other labels. National FASD analysis shows (see Appendix B) that this is a serious policy error. FASD is more common than autism, is heavily overrepresented among care-experienced and justice-involved groups, and is frequently misidentified as ADHD, autism, trauma, attachment disorder, behavioural difficulty, or generic mental ill health. Reforms to mental health services, ADHD and autism pathways, SEND policy, education support for medical conditions, adoption and special guardianship support, and responses to the early deaths and severe harms experienced by care leavers will remain incomplete and less effective unless they explicitly incorporate FASD. The reason is not simply that FASD is another diagnosis to add to a list. It is that

The Five Failures

In policy terms, the likely cost to the UK of inaction should be understood as the compounded cost of five failures:

1. Failure to prevent prenatal alcohol exposure;
2. Failure to identify FASD early;
3. Failure to provide tailored support;
4. Failure to protect high-risk groups such as looked after children; and
5. Failure to integrate FASD into mainstream reform.

Each failure creates downstream costs in education, health, social care, justice, welfare, and employment.

FASD explains a substantial part of the complexity, poorer outcomes, repeated service failure, and high downstream public cost seen across these systems.

The FASD policy landscape across the four nations

This section lays out what each nation has in place regarding FASD. Many of these are relatively new policies, and very welcome. However, the rest of the system has not yet caught up post-COVID. We point out in this report that there is a cost to this inaction.

UK-wide alcohol and pregnancy (FASD prevention) policy

- *UK Chief Medical Officers' Low Risk Drinking Guidelines (2016)*
  The UK CMOs from across the four nations revised the alcohol in pregnancy guidance to say that if you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.

England FASD-related policies

- *DHSC FASD Health Needs Assessment (2021)*
  England has a dedicated DHSC Fetal Alcohol Spectrum Disorder Health Needs Assessment, which recognises FASD as a significant public health issue requiring coordinated prevention, earlier diagnosis and long-term support for affected individuals and families. It highlights gaps in awareness, data, diagnostic capacity and post-diagnostic provision and calls for system-wide action across maternity, children's services, education and criminal justice.

- *NICE Quality Standard QS204 (FASD)*
  NICE QS204 sets out what high-quality care for FASD should look like in England and Wales, covering both prevention and management. It requires: consistent advice throughout pregnancy that the safest option is not to drink alcohol; routine enquiry and recording of alcohol use in pregnancy; referral for assessment where prenatal alcohol exposure and developmental/behavioural concerns are present; neurodevelopmental assessment where exposure or characteristic facial features are confirmed; and a management plan for every child or young person diagnosed with FASD. It includes measurable indicators of improvement of quality of care that are meant to be tracked over time.

- *NHS and public-facing guidance*
  NHS England information on FASD stresses that alcohol use in pregnancy can cause permanent mental and physical problems, that FASD is avoidable if alcohol is not consumed in pregnancy, and that early diagnosis with multi-disciplinary assessment and educational/behavioural support can significantly improve outcomes. This gives a clear prevention and early-intervention mandate for commissioners and providers.

- *Looked after children's medical guidance – assessment for FAS/FASD*
  National health guidance and LAC resource packs for England (jointly issued by DfE and DHSC) state that initial and review health assessments for looked after children must be holistic and should actively consider missed health problems and missed screening opportunities, with specific reference to prenatal alcohol exposure and potential Fetal Alcohol Syndrome (FAS) where relevant. While this was created before the change in diagnostic guidance and terminology to FASD, this creates an expectation that clinicians

assessing looked after children will consider FASD as part of statutory medicals when there is a history or suspicion of alcohol exposure in pregnancy.

- *Local Government and Social Care Ombudsman ruling on FASD*
  A Local Government and Social Care Ombudsman investigation (2021) into a council's handling of a family affected by FASD found the authority at fault for effectively gatekeeping access to assessments and respite, criticising the use of restrictive criteria that excluded children with significant neurodevelopmental and adaptive-functioning needs associated with FASD. The Ombudsman stated that applying such criteria placed unacceptable barriers in front of families seeking assessment and support, and required the council to change its practice, reinforcing that FASD-related needs must be properly assessed and provided for within social care systems.

- *Commissioning and service expectations*
  NICE makes explicit recommendations to commissioners (ICSs and NHS England) to commission maternity services that provide alcohol advice and support, services for pregnant women who continue to drink or are alcohol-dependent, neurodevelopmental assessment services that consider FASD, and services that provide management plans and support for those diagnosed. Specialist services such as the National FASD Clinic illustrate how national guidance (SIGN 156 and NICE) can be operationalised in an English context.

- *Public Health England "Maternity high impact area 4: Reducing the incidence of harms caused by alcohol in pregnancy"*
  This PHE document sets out a national prevention framework for Local Maternity Systems to reduce alcohol-related harms in pregnancy, including FASD, by embedding systematic approaches to: routine enquiry and accurate recording of alcohol use throughout pregnancy; consistent delivery of the CMOs' "no alcohol in pregnancy" message; training midwives, health visitors and other frontline staff in alcohol identification, brief intervention and FASD awareness; and ensuring clear referral pathways into specialist support for women who continue to drink or are alcohol-dependent.

- *Professional and voluntary-sector frameworks*
  National FASD's "The Time is Now" report (2022) draws on a series of 9 roundtables engaging practitioners, experts, researchers and people with lived experience and it builds on alignment between DHSC, PHE (now OHID), NICE and other bodies to argue for implementation of existing guidance on prevention, diagnosis and support. Voluntary-sector services provide FASD-informed post-diagnostic support and training, demonstrating demand and offering models that could be scaled through dedicated funding

- *Guidance in England and Wales is not being implemented*
  National FASD's *Not Commissioned: Systemic confusion in NHS services for alcohol, pregnancy and FASD report* (2024) uses Freedom of Information requests to ICBs and Trusts to show that, despite NICE Quality Standard 204 being in force, most areas have only a slow, non-strategic and uncoordinated response, with limited reference to QS204 in policies, little evidence of systematic alcohol enquiry in pregnancy, patchy or absent FASD diagnostic pathways and no consistent provision of post-diagnostic management plans; the report concludes there are only "pockets of hope but systemic confusion", and that services are currently missing a "golden opportunity to protect babies' brains".

Scotland – FASD-related policies

- Scotland has led the UK on FASD policy, including establishing the first dedicated national clinical guidance on FASD through SIGN 156, which sets out criteria, assessment processes and neurodevelopmental pathways for children and young people exposed prenatally to alcohol. (SIGN 156 was adopted by NICE and is also in effect across England and Wales).

- The Fetal Alcohol Advisory Support & Training (FAAST) Team is funded by Scottish Government with a national remit to provide and facilitate training, consultation and research in order to enhance the capacity, knowledge and confidence of Scotland's health and social care workforce in their work with people with FASD. The FAAST team works with FASD Hub Scotland (see below).

- The Scottish Government funds the FASD Hub Scotland (part of Adoption UK), a national tiered support service for all parents and carers of children and young people who have, or may have, been affected, by prenatal alcohol exposure.

- The new New Alcohol and Drug Policy mentions prenatal alcohol harm.

- Scotland's new Public Health Strategy includes prenatal alcohol harm prevention.

- SHAAP (Scottish Health Action on Alcohol Problems) is funded by RCPE with representation from all Medical Colleges and have been supportive in highlighting FASD and link with Alcohol Focus on issues.

- The Scottish Government has a Preconception Advisory group.

- The Scottish Government funds the National Autism Implementation Team (NAIT) to develop a Scotland-wide neurodevelopmental Pathway and develop resources for people with Neurodiversity, including FASD.

- The Scottish Government's FASD Awareness Toolkit and related professional resources (including neurodevelopmental pathway materials and educator guidance) embed FASD within wider children's services and education practice.

- Alcohol Focus Scotland and national public health messaging reinforce the UK Chief Medical Officers' advice that the safest approach is no alcohol in pregnancy, providing a clear prevention mandate alongside the clinical pathway.

- NICEQS 204 does not apply in Scotland, however it could be used as a reference framework in Scotland, with SIGN/HIS developing a Scottish quality standard for FASD in line with GIRFEC and Scottish law. This would then include measurable indicators of improvement in quality of care over time.

Wales – FASD-related policies

- NICE Quality Standard QS204 on FASD applies in England and Wales, setting out expectations on alcohol advice in pregnancy, routine enquiry and documentation of alcohol use, referral for specialist assessment, and management plans for all children and young people diagnosed with FASD.

- NHS 111 Wales public information reinforces that FASD is preventable if alcohol is avoided in pregnancy and that knowledge of prenatal alcohol exposure is essential for assessment and support.
- Together, QS204 and NHS Wales materials provide a nationally endorsed template for commissioning FASD prevention, diagnostic pathways and post-diagnostic support in Wales, highlighting a gap in implementation rather than policy.

Northern Ireland – FASD-related policies

- Northern Ireland follows the UK Chief Medical Officers' guidance that the safest option is to avoid alcohol completely during pregnancy, aligning its prevention message with other UK nations and could underpin investment in screening and brief interventions.
- The Alcohol and Drug Commissioning Framework for Northern Ireland provides a structure within which FASD-specific prevention and support activity can be prioritised as part of wider alcohol harm reduction and early-years work.
- NI has not indicated its adoption of SIGN156 nor NICEQS 204. Clinical practice can draw on SIGN 156 and NICE QS204 as transferable UK standards for FASD assessment and management, meaning additional spending can focus on adapting and implementing established models rather than creating new ones.

> Across all four nations, the same underlying question arises: whether governments and public bodies have taken reasonable, evidence-based steps to identify and meet the needs of a known vulnerable group.

Legal duties and systemic risk

Current NHS and education structures across the UK are not consistently configured to prevent, identify, diagnose or support fetal alcohol spectrum disorder (FASD), despite growing recognition that FASD is common, under-diagnosed and associated with substantial long-term impairment (Department of Health and Social Care [DHSC], 2021; NHS, 2024; McQuire et al., 2025). This creates not only clinical, social and economic harms, but also a growing risk that public authorities are failing to discharge established legal duties under equality, education and health legislation (Children and Families Act, 2014; Department for Education & Department of Health, 2015; Equality Act, 2010).

Legal risk and statutory compliance

In England, the legal position is clearest. The Equality Act 2010 protects people with disabilities from discrimination and requires reasonable adjustments where substantial, long-term impairments affect day-to-day functioning; many individuals with FASD fall within that definition, whether or not they have a formal diagnosis, because protection depends on functional impact rather than diagnostic label (Equality and Human Rights Commission [EHRC], 2020; NHS, 2024). Part 3 of the Children and Families Act 2014 and the SEND Code of Practice place duties on local authorities and partners to identify children and young people with SEND or disabilities, keep provision under review and jointly commission services across education, health and social care, with expectations further specified by NICE Quality Standard QS204 on FASD (Children and Families Act, 2014; Department for

Education [DfE], 2014; Department for Education & Department of Health, 2015; National Institute for Health and Care Excellence [NICE], 2022a).

Against that backdrop, current gaps in FASD prevention, diagnosis and support are increasingly difficult to reconcile with statutory requirements. A national health-needs assessment has already recognised FASD as prevalent and under-identified, and NICE has set out what improved practice should involve, including consistent advice on alcohol in pregnancy, appropriate assessment where concerns are present, and structured support following diagnosis (DHSC, 2021; NICE, 2022a). Yet in most areas there is no funded FASD pathway, leaving families without a clear route to referral or post-diagnostic support and making it harder for NHS bodies and local authorities to show that they have met their duties to identify need, make reasonable adjustments and jointly commission appropriate services (National FASD, 2022; NHS England, 2023).

Legal implications of inaction

The legal implications of continuing with the status quo can be summarised as follows:

- The risk that disabled people with FASD experience discrimination and lack of reasonable adjustments in health, education and justice settings, contrary to the Equality Act 2010 (EHRC, 2020).
- The risk that local authorities and partners are found to have failed to identify, assess and plan for a high-prevalence neurodevelopmental condition within their SEND or equivalent frameworks (Children and Families Act, 2014; Department for Education & Department of Health, 2015; DHSC, 2021).
- The risk that commissioning decisions which ignore FASD, despite national evidence and guidance, are challenged as irrational or as breaches of joint-commissioning and equality duties (DHSC, 2021; NICE, 2022a; NHS England, 2023).
- The risk that punitive or exclusionary responses to FASD-related behaviour in education and justice systems are found to be discriminatory and inconsistent with duties to make reasonable adjustments and to safeguard vulnerable children and adults (EHRC, 2020; Department for Education & Department of Health, 2015; McQuire et al., 2025).
- The risk of failing to inform the public of the teratogenic harm caused by prenatal alcohol exposure (DHSC, 2021; NICE, 2022; SIGN, 2019; UK Chief Medical Officers, 2016).

> In practice, this means that the costs of inaction are increasingly likely to include successful legal challenges, findings of unlawful discrimination and the need for remedial action under time pressure, rather than planned, cost-effective reform.

FASD, statutory duties and public sector compliance

The proposals in this *Cost of Inaction* report directly address these risks by translating existing statutory duties into operational practice. Measures such as routine and consistent alcohol-in-pregnancy prevention messaging, clearer referral criteria, multidisciplinary FASD diagnostic pathways, post-diagnostic management plans, FASD-specific training and systematic inclusion of FASD in local planning would enable public bodies to demonstrate that they have taken proportionate, evidence-based steps to meet the needs of this group (DHSC, 2021; NICE, 2022a).

To show how this could apply in each nation, the key legal duties are summarised below. This is an illustrative list to demonstrate a point. This is not legal advice.

Importantly, the proposals in this report do not create new legal duties; rather, they provide a realistic route for public authorities to comply with duties that already exist in law.

England – key relevant legal duties

Key duties engaged by FASD include:

- Equality Act 2010 duties not to discriminate against disabled people and to make reasonable adjustments in the way services, education and employment are provided (Equality Act, 2010; EHRC, 2020).
- Public sector equality duty to have due regard to the need to advance equality of opportunity for disabled people when making decisions and policies (Equality Act, 2010; EHRC, 2020).
- Children and Families Act 2014 Part 3 duties on local authorities and partners to identify children and young people with SEND or disabilities, keep provision under review, and jointly commission education, health and social care services to meet their needs (Children and Families Act, 2014; DfE, 2014).
- Duties under the SEND Code of Practice to ensure early identification, a graduated response in schools and integrated assessment and planning across education, health and care (Department for Education & Department of Health, 2015).
- Expectations in NICE QS204 that services should improve recognition, assessment, diagnosis and support for FASD, which provide a benchmark for what reasonable, good-quality practice looks like (NICE, 2022a).

Scotland – key relevant legal duties

Within Scotland, the relevant duties include:

- Equality Act 2010 duties on Scottish public authorities, including NHS boards, local authorities and justice bodies, not to discriminate and to make reasonable adjustments for disabled people, including those with FASD (Equality Act, 2010; EHRC, 2020).
- Duties under the Additional Support for Learning framework to identify, assess and make provision for children and young people who require additional support to benefit from education, which will include many with FASD-related impairments (Sen Policy Research Forum, 2018).
- National clinical guidance, including SIGN 156 and associated FASD diagnostic pathways, which set out expectations for referral, assessment and follow-up and provide an authoritative standard against which practice can be judged (SIGN, 2019).
- Wider children's rights and wellbeing duties, which require education and health services to take account of the best interests and views of children, particularly those with vulnerabilities or communication difficulties (Sen Policy Research Forum, 2018).

- The United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024, makes the UNCRC part of Scots law within devolved areas. It requires public authorities not to act incompatibly with UNCRC rights and allows children and their representatives to challenge breaches in the Scottish courts. Scottish Ministers (through the Health portfolio) and territorial health boards share responsibility for ensuring services and policies respect children's rights to the highest attainable standard of health and access to healthcare.

Wales – key relevant legal duties

In Wales, key duties and frameworks are:

- Equality Act 2010 duties on NHS Wales, local authorities, schools and justice bodies to avoid disability discrimination and to make reasonable adjustments (Equality Act, 2010; EHRC, 2020).
- The Additional Learning Needs and Education Tribunal (Wales) Act 2018, which creates a unified 0–25 additional learning needs (ALN) framework and statutory individual development plans for children and young people requiring additional learning support (Sen Policy Research Forum, 2018).
- The ALN Code and associated guidance, which expect early identification, planning and coordinated support across education and health for learners with ALN, including those with neurodevelopmental conditions such as FASD.
- NICE QS204, which applies in England and Wales and sets out expectations for FASD assessment and diagnosis, providing a shared benchmark for Welsh commissioners and providers (NICE, 2022a).

Northern Ireland – key relevant legal duties

In Northern Ireland, the principal duties and expectations include:

- Disability discrimination and reasonable-adjustment principles, which closely mirror those in Great Britain and require public authorities to accommodate disabled people in access to services, education and employment (British Medical Association, 2016).
- Special educational needs duties, including obligations on education authorities and schools to identify and make provision for children with SEN, under a framework that is currently being reformed to strengthen planning, annual review and learning-support coordination (Sen Policy Research Forum, 2018).
- Human rights and children's rights obligations, including those informed by the Human Rights Act and the UN Convention on the Rights of the Child, which require particular attention to the needs of vulnerable children and young people, such as those with FASD in contact with education, health and justice systems (British Medical Association, 2016; Sen Policy Research Forum, 2018).
- Policy expectations emerging from professional bodies, including recommendations from the British Medical Association on alcohol and pregnancy and FASD management across all UK health departments (British Medical Association, 2016).

Implementing the suggested proposals decreases the risk of legal liability

Taken together, these duties show that the absence of funded FASD prevention, diagnosis and support is not simply an unfortunate service gap; it is a growing legal liability that is not being addressed in most areas. By contrast, adopting the measures in this *Cost of Inaction* report would strengthen the ability of public bodies in each nation to demonstrate compliance with their legal duties, reduce the risk of successful litigation and complaints, and improve outcomes for some of society’s most vulnerable children and adults (EHRC, 2020; DHSC, 2021; NICE, 2022a; Rees et al., 2025).

Why current reform efforts will fail without considering FASD – some examples

Mental Health, ADHD and Autism

England’s independent review into mental health conditions, ADHD and autism was commissioned to address rising demand, inequity, and the complex needs of people falling through gaps. FASD is directly relevant to every one of those concerns, yet its interim findings contain no explicit reference to prenatal alcohol exposure as a driver of demand, a complicating factor in diagnosis, or an explanatory framework for why some people with ADHD and autism presentations respond poorly to standard interventions (National FASD, 2026). The evidence is unambiguous: ADHD is the most common co-occurring diagnosis in FASD and may be present in up to half of ADHD cases (Peadon & Elliott, 2010), while over 90% of individuals with FASD experience clinically significant mental health difficulties including anxiety, depression, suicidality, and psychosis (Streissguth et al., 2004; Pei et al., 2011).

The policy risk is structural, not marginal and it applies to all four nations. Within today's ADHD, autism, and mental health caseloads there is a high-need subgroup whose difficulties have a distinct causal pathway — prenatal alcohol exposure — and whose functional impairment is often more severe than the headline diagnosis suggests. If reform frameworks are built around generic ADHD and autism assumptions, this subgroup will remain invisible: excluded from services, cycling through crisis responses, and accumulating multiple labels without ever receiving a unifying explanation. Critically, non-recognition of FASD can itself worsen mental health outcomes — when a brain-based disability is interpreted as defiance, poor motivation, or bad parenting, the consequences include shame, fractured therapeutic relationships, school exclusion, and escalating crisis (National FASD, 2026). A review that does not name FASD will not fix the problems it has been asked to solve. (See Appendix B for National FASD’s policy brief on the impact of failing to include FASD in the Independent review into Mental Health Conditions, ADHD and autism.)

SEND, education and medical conditions in schools

Children with FASD are already present in education systems across all four nations; the problem is not their absence but their invisibility. Executive functioning difficulties, memory impairment, emotional dysregulation, sensory overload, and fatigue can all affect attendance, classroom behaviour, and attainment — yet without FASD recognition these are routinely framed as defiance, conduct disorder, poor parenting, or unmet mental health need rather than as disability-related differences requiring adaptation (National FASD, 2026). SEND reform proposals that narrow access to specialist provision, reduce legal protections, or push greater complexity into mainstream settings without corresponding workforce expertise will disproportionately harm this group, because the children most likely to be failed are precisely those whose needs are hardest to see (National FASD, 2022). The statutory frameworks in each nation — England's SEND Code of Practice and EHCP system, Scotland's Additional Support for Learning Act and GIRFEC framework, Wales's ALN Act and Individual Development Plans, and Northern Ireland's SEN framework — all contain sufficient legal architecture to accommodate FASD, but none currently names it explicitly. (In Scotland there is new legislation pending, the Learning Disabilities, Autism and Neurodivergence - LDAN Bill - which mentions FASD though the title shows it is still not on par with other conditions). The consequence is that children are assessed and supported under frameworks designed for autism and ADHD profiles that do not fully capture FASD's distinct neurodevelopmental presentation. Until FASD is named in guidance, training, and commissioning specifications across all four nations, the gap between policy intent and lived experience will persist — and the costs of exclusion, alternative provision, and crisis intervention will continue to fall on public budgets (Department of Health and Social Care [DHSC], 2021; National FASD, 2022).

Adoption, special guardianship and care-experienced children and young people

Looked after children, adopted children, and those in kinship or special guardianship arrangements represent the populations with high rates of FASD. Evidence from Peterborough found that 27% of children in care had FASD and that prenatal alcohol exposure was noted in 75% of adoption reports (Gregory et al., 2015). Despite this, support frameworks for children across all four nations are predominantly built around trauma and attachment formulations — which, while important, are often insufficient where FASD is also present. Prenatal alcohol exposure can create neurocognitive and adaptive impairments that persist regardless of the quality of the caregiving environment; where support systems assume that relational stability will resolve all difficulties, carers receive interventions that do not fit the child's actual profile, resulting in frustration, family stress, and breakdown (Price, 2017).

This is not a niche issue. Because FASD is likely overrepresented throughout care-experienced populations, adoption and special guardianship policy that does not explicitly address FASD is structurally under-supporting some of the children with the highest lifelong support needs. Missed diagnoses lead to late crisis responses; inappropriate support models lead to carer exhaustion and placement instability; and the absence of post-diagnosis planning leads to the loss of institutional knowledge at every transition. Government agencies across all four nations should be actively tracking how FASD affects outcomes within existing care, adoption, and kinship support programmes rather than leaving that monitoring to underfunded voluntary sector organisations like National FASD, Kinship and Adoption UK. It is also important to note that statistically the majority of people with FASD — diagnosed or not — are living with their birth families; policy focus on care-experienced populations, while warranted, must not come at the expense of this larger and often overlooked group.

Care leavers: early deaths, severe harm and justice involvement

The current policy and media focus on early deaths of care leavers, exploitation, criminalisation, homelessness, and acute mental health crisis maps directly onto the populations in which FASD is concentrated. Care-experienced young people with unrecognised FASD face elevated risk of school exclusion, substance misuse, suicidality, justice system contact, and severe mental health crisis; the literature links FASD with substantially higher rates of psychotic disorder and substance-related harm compared to the general population (Flannigan et al., 2022). The transition to adulthood is a point of particular risk: many young people with FASD lack the executive functioning, adaptive skills, and risk awareness to navigate adult systems independently, yet support packages are routinely calibrated on assumptions of adult autonomy. Even when care leavers are supported as adults by the families they lived with as children, there are still challenges as then there is no support for those adults as their former carers age, too often forcing the young adult into homelessness so the Councils will step in.

The policy implication is direct. Where services do not recognise that a young care leaver has an enduring neurodevelopmental disability affecting judgement, memory, vulnerability to exploitation, and ability to comply with complex processes, support will be miscalibrated — too short-term, too verbally complex, too reliant on self-advocacy, and too quick to attribute failure to motivation rather than impairment. Responses designed to reduce custody, homelessness, repeated crisis presentation, and early death among care-experienced young adults will not reach their stated objectives for a significant subgroup unless FASD is built into the explanatory framework and care planning from the outset. This is not an add-on to those agendas; for a meaningful proportion of the most high-risk care leavers, it is the core reason standard approaches have not worked (National FASD, 2022; Flannigan et al., 2022).

Justice

People with FASD are among the most heavily over-represented groups in the criminal justice system and among the least recognised within it. International evidence shows that individuals with FASD are between 19 and 40 times more likely to encounter the criminal justice system than those without the condition, and an estimated 35% will experience incarceration at some point in their lives — figures that reflect the foreseeable consequences of undiagnosed neurodevelopmental disability in systems never designed to accommodate it (Popova et al., 2015; Brown et al., 2024). The cognitive profile of FASD — impulsivity, suggestibility, poor working memory, difficulty understanding cause and effect, and an inability to translate verbal instruction into action — creates compounding vulnerabilities at every stage of criminal justice contact (Flannigan et al., 2022). Justice costs constitute one of the three largest components of FASD's societal burden, and represent a substantial element of the savings calculated in this report's 3.56:1 lifetime benefit-cost ratio.

Across all four nations, current reform processes are proceeding without FASD. The joint inspectorates' 2021 neurodiversity review made no FASD-specific recommendations (Criminal Justice Joint Inspectorate [CJJI], 2021); the Ministry of Justice's Neurodiversity Action Plan, updated as recently as February 2026, continues to make no reference to FASD across its 105 prison Neurodiversity Support Manager programmes (Ministry of Justice, 2026); and the Youth Justice White Paper *Cutting Youth Crime, Changing Young Lives* (May 2026) does not name FASD despite evidence that up to 36% of children in youth custodial settings internationally have the condition (Bower et al. 2018). The Michael Sieff Foundation Review (2025), which found that 80% of children cautioned or sentenced in the youth justice system have SEND or neurodivergence, makes recommendations — mandatory screening, specialist hearings, compulsory training — that directly align with FASD need, but does not name FASD explicitly (Michael Sieff Foundation, 2025). None of the changes required to address this gap need new primary legislation; all are achievable through existing commissioning, inspection, and workforce development mechanisms across all four nations.

It’s also important to note, people with FASD are over-represented among those who experience violence, exploitation and contact with the criminal justice system, in part because of their difficulties with impulse control, social judgement, susceptibility to coercion and trouble understanding consequences. These same neurodevelopmental differences mean they are often not appropriately supported as victims or witnesses due primarily to lack of training for professionals across the Justice system: they may struggle to give consistent accounts, appear unreliable or “non-compliant”, and miss out on reasonable adjustments, specialist advocacy and trauma-informed responses, leaving them at heightened risk of repeat victimisation and poor justice outcomes.

Workforce and economic participation

The economic cost of FASD to the UK labour market is embedded throughout this report's £9.2 billion annual societal cost estimate, yet it remains the least visible dimension of the policy problem. Undiagnosed FASD and/or un-supported FASD constrains educational attainment, disrupts skills development, increases the likelihood of benefit dependency, and reduces the proportion of affected individuals who can sustain employment — not because of lack of effort or motivation, but because the adjustments and support structures needed to enable participation are never triggered in the absence of diagnosis (Department of Health and Social Care [DHSC], 2021; CanFASD, 2015). Even where there is a diagnosis, too often people with FASD do not receive adequate support to access employment, training or volunteering activities. Across England's *Get Britain Working* agenda, Scotland's Fair Work framework, Wales's Employability Plan, and Northern Ireland's economy and skills strategy, the same structural gap applies: disability employment support, reasonable adjustments, and supported employment programmes are all designed to respond to disclosed or recognised disability. FASD, undiagnosed in over 90% of cases, is invisible to all of them (National FASD, 2026).

Early diagnosis combined with coordinated educational and vocational support is associated with better employment outcomes — including fewer secondary difficulties, lower rates of school disruption, and greater capacity to remain in or enter employment when appropriate adjustments are made (CanFASD, 2015; Centers for Disease Control and Prevention [CDC], 2025). Conversely, where FASD goes unrecognised and un-supported, affected individuals cycle through unemployment, benefits systems, and crisis services in patterns that generate high long-term public cost without addressing the underlying cause. Investment in FASD prevention, diagnosis, and support is therefore not merely a health expenditure; it is a direct contribution to the workforce participation and productivity ambitions that sit at the centre of each nation's economic strategy. Even conservative assumptions about the proportion of currently economically inactive individuals with undiagnosed FASD suggest that improving diagnosis and adjusted employment support would generate meaningful returns to the Exchequer through increased tax receipts, reduced welfare dependency, and lower demand for crisis services (Popova et al., 2018; National FASD, 2026).

The measures proposed in this report address one of the most consistently overlooked drivers of the UK's workforce and productivity crisis: the hidden, systemic impact of undiagnosed and unsupported neurodevelopmental disability — and of FASD in particular. This is not a peripheral concern. It sits at the intersection of four of the government's most pressing economic priorities: reducing economic inactivity, cutting welfare costs, raising productivity, and securing the long-term fiscal position.

> The UK currently pays for FASD through the most expensive possible route — repeated crisis responses, preventable exclusions, benefit dependency, and justice system involvement. Every year that this continues, the bill grows.

In addition, raising a child with FASD imposes substantial productivity losses on parents and caregivers: Popova et al. (2011) identified loss of parental and caregiver productivity as a discrete and significant cost component in the economic burden of FASD, noting that caregiving demands constrain paid employment participation across the life course of the affected individual. More recently, Flannigan et al. (2024) found that caregivers who spend greater time supporting individuals with FASD report measurably low wellbeing and reduced satisfaction with available support, consistent with a pattern of sustained employment disruption driven by unmet care needs that fall to families in the absence of commissioned services.

FASD and the *Get Britain Working* Agenda

The government's *Get Britain Working* White Paper (Department for Work and Pensions, 2024) sets a target of raising the UK employment rate to 80% of working-age adults, with a specific focus on closing health and disability employment gaps and reducing the proportion of young people who are out of work, education or training. Recent analysis for the Milburn *Young People and Work* review underlines the scale of this challenge, identifying nearly one million 16–24-year-olds who are Not in Education, Employment, or Training (NEET) and highlighting health and neurodevelopmental conditions as major drivers of rising youth inactivity (Milburn, 2026). The White Paper identifies ill health as the biggest single driver of economic inactivity and commits to joining up health, skills, and employment support across Integrated Care Boards, local authorities, and the DWP (Department for Work and Pensions, 2024). Despite this, FASD is entirely absent from both the White Paper and the Milburn interim report — a material omission that undermines these programmes' own stated goals.

FASD is a major, under-recognised cause of the health-related inactivity the White Paper and the Milburn review are trying to address. People with undiagnosed FASD are disproportionately represented among those who cycle through jobcentres, benefits assessments, and employment support schemes without sustained improvement, precisely because their neurodevelopmental disability is not identified and their support needs are not accommodated (Department of Health and Social Care [DHSC], 2021; National FASD, 2025). This is mirrored in Milburn's description of a "hidden NEET" population and of young people whose mental health and neurodevelopmental needs leave them stranded between education, welfare and employment systems that are not designed to work together (Milburn, 2026). They are not failing to engage — they are being failed by systems that do not see the condition driving their difficulties.

FASD prevention initiatives — such as consistent advice on the risks posed by alcohol in pregnancy, screening and brief interventions — reduce the number of children exposed to avoidable neurodevelopmental harm, thereby lowering the proportion of future adults whose education, skills development, and employment prospects are constrained by unrecognised impairment (Proof Alliance, 2025; Effective Approaches to Prevention, Diagnosis and Support for FASD, 2021). For those already affected, early diagnosis and coordinated support are associated with fewer secondary difficulties — including school disruption, exclusion, and crisis involvement — and with better chances of remaining in education, obtaining qualifications, and entering or sustaining employment when appropriate adjustments and vocational support are provided (CanFASD, 2015; Centers for Disease Control and Prevention [CDC], 2025; National FASD, 2021; Supporting Employment Success in Adults with FASD, 2018).

> Incorporating FASD into the Get Britain Working and Milburn "Working State" agenda is not an optional add-on but a precondition for meeting their employment and productivity targets.

FASD and the welfare spending trajectory

The Office for Budget Responsibility's (OBR) November 2025 forecast estimated total welfare spending for 2025–26 at £324 billion — approximately 10.8% of GDP — up £44 billion in real terms in recent years (Resolution Foundation, 2025). The OBR's March 2026 *Economic and Fiscal Outlook* identified that the trend labour force participation rate is projected to fall from 63.5% in 2025 to 63.3% by 2030, placing further upward pressure on benefit expenditure (Office for Budget Responsibility, 2026). Analysis from the Disability Policy Centre has warned that inaction on working-age disability will likely see welfare costs breach fiscal rules by 2029–30 (Disability Policy Centre, 2025).

FASD is a material but invisible contributor to these trends. An estimated 2–4% of the UK population — up to 2.8 million people — are affected, with over 90% undiagnosed (McCarthy et al., 2021; National FASD, 2026). Some are drawing Personal Independence Payment, Universal Credit, or other disability-related benefits, not because support is unwarranted, but because without diagnosis, the most cost-effective forms of targeted support and employment adjustment are never put in place (DHSC, 2021).

The estimated lifetime cost difference between a diagnosed and an undiagnosed case is approximately £72,000 per person — with the undiagnosed case costing £431,800 against £359,800 for those who receive a diagnosis. That premium exists precisely because undiagnosed individuals are more likely to reach crisis, more likely to rely on emergency responses, and less likely to access the preventive and supportive interventions that reduce long-run public expenditure (Greenmyer et al., 2018; Popova et al., 2018).

> Diagnosing and supporting this population is not a cost; it is a mechanism for reducing the welfare trajectory that the OBR is forecasting. It shifts people from high-cost, unplanned dependency into planned, lower-cost supported lives — and, for those who are able, into paid work and economic participation (DHSC, 2021; The Burden and Economic Impact of FASD, 2015; Popova et al., 2018).

FASD and the *Get Britain Working* youth guarantee

The *Get Britain Working* White Paper's Youth Guarantee — ensuring every 18-to-21-year-old in England has access to education, training, or help to find a job — is directly undermined by the current absence of FASD identification and support (Department for Work and Pensions, 2024). Young people with undiagnosed FASD are among those most likely to fall through the guarantee's net: they disengage from education, are disproportionately represented in exclusion and alternative provision statistics, and are heavily over-represented in NEET data (DHSC, 2021; National FASD, 2026). They are not young people who lack motivation or capacity; they are young people whose neurodevelopmental disability has never been named, let alone accommodated.

The FASD PRP model described elsewhere in this report — by reaching 3,200 new cases per year by year four, with particular focus on children in care, care-experienced young people, and those in contact with youth justice — directly targets the population that the Youth Guarantee is least likely to reach without this kind of upstream intervention (National FASD, 2026). Eight Youth Guarantee trailblazers funded at £125 million for 2025–26 are attempting to engage precisely this cohort (Department for Work and Pensions, 2024). FASD identification and support should be a core component of those trailblazers — not an afterthought.

Homelessness and NEET

The same neurodevelopmental profile that creates barriers to education and employment also places individuals with FASD at elevated risk of homelessness and of becoming persistently not in education, employment or training (NEET). Difficulties with executive functioning, money management, understanding tenancy obligations, and sustaining the routines that stable housing and employment require are not volitional — they are organic features of prenatal alcohol-related brain injury (FASD Network of Southern California, n.d.; Streissguth et al., 2004). Yet homelessness strategy across all four nations, and the frameworks designed to reduce NEET rates, are built without any reference to FASD as either a driver of risk or a reason why standard interventions fail. In January to March 2026, 13.5% of all 16 to 24-year-olds in the UK — approximately 900,000 young people — were NEET, with mental health conditions and neurodevelopmental diagnoses accounting for more than two-thirds of those reporting health as a barrier to work (Office for National Statistics [ONS], 2026; Health Foundation, 2026). FASD, unrecognised in the overwhelming majority of cases, is embedded within that figure; its contribution is invisible only because identification systems have never been designed to find it.

The consequences of this invisibility are not abstract. Nearly 80% of adults with FASD do not live independently (FASD Network of Southern California, n.d.), and the cognitive and adaptive profile of the condition — impulsivity, suggestibility, difficulty with cause and effect, and vulnerability to exploitation — creates compounding risks at each transition point from education into the adult world (Streissguth et al., 2004; Flannigan et al., 2022). Where homelessness services, NEET reduction programmes, and employability support do not recognise FASD, they will offer interventions calibrated to the wrong model: short-term, verbally complex, reliant on self-advocacy, and assuming a capacity for independent decision-making that the condition specifically impairs (Homeless Hub, 2021). The result is repeated re-presentation, programme dropout, and long-term welfare dependency — all of which represent avoidable public expenditure. In Scotland, this failure has particular resonance: the *No One Left Behind* employability framework and the National Improvement Framework 2026 both identify disability and health as central barriers to participation (Scottish Government, 2025; Employability in Scotland, n.d.), yet neither names FASD as a condition requiring specific identification and adjusted support within those frameworks (GIRFEC Ayrshire, 2020). Scotland's GIRFEC *Getting it Right for Every Child* principles, SIGN 156, and the National Neurodevelopmental Specification for Children and Young People collectively provide a statutory foundation for FASD-informed practice — but that foundation is inert without explicit inclusion of FASD in the training, assessment, and commissioning guidance that NEET and homelessness services actually use (Scottish Intercollegiate Guidelines Network [SIGN], 2019; Scottish Government, 2021).

The government has committed £240 million to the *Get Britain Working* programme for 2025–26 and £5 million across ten ICSs to support economically inactive people into employment through the 10

> Embedding FASD identification, support, and prevention into the Get Britain Working trailblazers, the Youth Guarantee, and the 10 Year Health Plan is not an additional ask. It is a prerequisite for those programmes to deliver.

Year Health Plan (Department for Work and Pensions, 2024; NHS England, 2025). These are not large sums against the scale of the problem — and they will underperform if FASD continues to be the invisible driver of the inactivity they are trying to address.

Maternity services policies and goals

The need to think differently about ethnicity, deprivation and alcohol-exposed pregnancies

Alcohol use in pregnancy is socially patterned, with peer-reviewed evidence showing that white/Caucasian, older and more socioeconomically advantaged women are often more likely to drink in pregnancy than women from minority ethnic groups, which challenges stereotypes about who is "at risk" of alcohol-exposed pregnancy. (This can vary by country.) A large pooled cohort analysis found that, compared with Caucasian women, non-Caucasian women were significantly less likely to report alcohol use during pregnancy (McAndrew et al., 2015), while broader review evidence similarly indicates that alcohol use later in pregnancy is more common among women who are white, older and more socioeconomically advantaged (Stanesby et al., 2018). UK survey data remain consistent with the broader point that alcohol use in pregnancy varies by age, ethnicity and deprivation: the Infant Feeding Survey 2024 for England reported that around 15% of mothers drank alcohol after becoming pregnant but before they knew they were pregnant, and 5% drank alcohol after they knew they were pregnant, with statistically significant variation by age, ethnicity and deprivation (Office for Health Improvement and Disparities, 2026).

This evidence is particularly important in the context of current maternity policy, which rightly focuses on ethnic and socio-economic inequalities because women from Black and Asian ethnic groups and women living in the most deprived areas face higher risks of adverse outcomes, including stillbirth, preterm birth, neonatal admission, maternal mortality and severe morbidity (NMPA Project Team, 2024; Jardine et al., 2024; Care Quality Commission, 2024). However, alcohol-exposed pregnancy does not map neatly onto the same demographic risk profile as wider maternity inequalities. If clinicians rely on assumptions based on ethnicity, deprivation, age, class or perceived religiosity when deciding whom to ask about alcohol use, they risk both missing exposure among women who may not be perceived as "at risk" and compounding inequities through inconsistent practice. Taken together, the evidence supports routine, universal alcohol enquiry for all pregnant women rather than selective questioning based on stereotypes (McAndrew et al., 2015; Mamluk et al., 2017).

Alongside this published evidence, National FASD has received anecdotal reports from midwives that some Muslim women were distressed at not being given advice about the risks of alcohol and pregnancy because staff assumed they would not be drinking. Although anecdotal, this illustrates how cultural assumptions can create blind spots in practice and reinforces the case for asking all women the same evidence-based questions in a respectful and non-stigmatising way.

Alcohol-exposed pregnancies are a potential contributor to intrapartum risk

Current maternity policy and operational pressure in the UK are heavily focused on the intrapartum period, particularly recognising fetal compromise, escalating care in labour, managing induction pathways, and ensuring timely operative intervention where risk is identified. National maternity safety work has therefore concentrated strongly on labour and birth, especially intrapartum monitoring, escalation and the prevention of avoidable stillbirth, neonatal death and brain injury (Health Services Safety Investigations Body, 2021; NICE, 2023; NHS England, 2021).

However, an intrapartum-centred response can obscure the fact that many poor outcomes have roots earlier in the pathway. Miscarriage, stillbirth, preterm birth and low birth weight are all adverse outcomes that may be associated with prenatal alcohol exposure, in addition to the lifelong neurodevelopmental harms captured within FASD (Mamluk et al., 2017; Every Moment Matters, 2022). This means alcohol-exposed pregnancy should not be understood only as a paediatric or postnatal issue, but also as a maternity prevention, safety and quality issue.

A stronger FASD response should therefore be positioned as part of improving maternity outcomes overall. If maternity strategy remains primarily focused on managing complexity at the point of labour, without equivalent attention to preconception counselling, antenatal identification of alcohol use, brief intervention and early support, an important upstream driver of poor outcomes will remain insufficiently addressed (Health Services Safety Investigations Body, 2021; Mamluk et al., 2017; NHS England, 2021). Prioritising prevention of alcohol-exposed pregnancy would align with current ambitions to reduce stillbirth, prematurity and poor neonatal outcomes, while also reducing the longer-term burden of neurodevelopmental disability associated with FASD.

Missed opportunity for maternity policies across all four nations

Failing to identify alcohol-exposed pregnancies represents a missed opportunity across the maternity and wider health policies of all four UK nations because each nation already has policy levers that depend on routine enquiry, clear advice, and recording of prenatal alcohol exposure.

- In England, this is a missed opportunity because NICE Quality Standard 204 expects maternity services to advise all pregnant women that the safest approach is not to drink alcohol and to discuss and record alcohol consumption during antenatal care, yet inconsistent implementation means opportunities for prevention, brief intervention, and later FASD-informed assessment are lost (NICE, 2022; NHS, 2020).
- In Scotland, the gap is especially striking because the policy architecture is stronger: SIGN guidance recommends enquiry about prenatal alcohol exposure, Scotland has a national Alcohol Brief Interventions programme, and maternity staff can access ABI training and pregnancy-specific guidance, but where alcohol use is not consistently identified or documented, women may still miss timely ABI delivery, referral, and follow-up support (Scottish Intercollegiate Guidelines Network [SIGN], 2019; Scottish Government, 2018; Public Health Scotland, 2024).
- In Wales, where NICE QS204 also applies, failure to capture alcohol exposure in routine maternity records weakens the ability of services to translate national advice on alcohol avoidance into prevention, early support, and future diagnostic pathways for children affected by prenatal alcohol exposure (NICE, 2022a, 2022b; National FASD, 2024).
- In Northern Ireland, where national advice also reflects the UK Chief Medical Officers' position that avoiding alcohol in pregnancy is the safest option, inconsistent identification of alcohol-exposed pregnancies limits opportunities for targeted maternal support and contributes to the continuing invisibility of FASD in child health planning and neurodevelopmental care (IAS, 2019; NHS, 2017).

The need for better training and resources for maternity teams

Alcohol exposure is being routinely missed in maternity services because FASD and prenatal alcohol exposure are still largely absent from pre-registration training and are not a mandatory part of ongoing CPD, so many midwives are not confident to give clear, up-to-date advice about the risks. As a result, NICE QS204's expectation that all pregnant women are advised throughout pregnancy to avoid alcohol and are repeatedly asked about, and have recorded, any prenatal alcohol exposure is not being embedded in practice, and alcohol questions are often optional fields in digital records rather than mandatory prompts. National FASD's *Not Commissioned* report shows that most Integrated Care Boards and Trusts are not taking systematic action on NICE QS204, are not using its indicators to track improvements and have not reviewed training or pathways, leading to wide variation in what is asked, recorded and communicated between services. This means alcohol histories are frequently not documented in a consistent, detailed way or transferred into the child's notes, so crucial information about prenatal alcohol exposure is lost, closing off opportunities both to prevent harm during pregnancy and to support timely FASD assessment and diagnosis later in childhood.

Legislative and scrutiny bodies

Select committees and parliamentary bodies dealing with mental health, SEND, children's social care, justice, welfare, and alcohol harm should take specific evidence on FASD. National FASD's Hansard analysis (see next section) suggests that one reason policy remains weak is that FASD is rarely brought into formal scrutiny despite being directly relevant to multiple reform areas.

Ministers should be asked to explain how reforms align with NICE QS204, SIGN 156, and the DHSC FASD health needs assessment. This is especially important where reforms affect care-experienced children, disabled young adults, and people moving between children's and adult services

Parliament should also close the visibility gap through routine written and oral questions, cross-party engagement, and lived-experience evidence. National FASD's materials emphasise that people with FASD and their families want not special treatment but equal respect, visibility, and appropriately designed support.

Central policy conclusion

The combined evidence leads to a consistent policy conclusion. FASD is a common, lifelong, high-need neurodevelopmental disability that is deeply entangled with many of the UK's most urgent reform agendas. It is more common than autism, heavily overrepresented among care-experienced and justice-involved populations, and frequently hidden inside ADHD, autism, trauma, behavioural, and mental health caseloads.

The policy choice is clear

The UK can continue with FASD-blind reform and accept ongoing exclusion, crisis, criminalisation, family breakdown, and escalating public cost. Or it can mainstream FASD across health, education, social care, justice, welfare, and parliamentary scrutiny, creating a fairer and more evidence-based system for a population that has remained too long invisible. This report shows how this can be accomplished.

Reforms across Government services in all four nations which do not explicitly incorporate FASD will not simply be incomplete in an abstract sense. They will misread the causes of rising demand, underestimate the needs of the most impaired subgroups, fail to reduce inequity, and waste public money by funding repeated misdiagnosis and poor intervention fit. The likely economic burden of inaction is already measured in billions of pounds annually, and the human cost is borne by some of the most vulnerable children, young people, adults, and families in the country.

SECTION 4

Invest to Save: The Economic Case for Funding

Just 0.25% of UK alcohol duty could fund a four-nation programme — every £1 invested returns £4–£5.

AT A GLANCE · SECTION 4

Invest to save: the economic case for funding FASD

FASD is the UK's most common preventable neurodevelopmental condition — yet there is no dedicated national budget for it. A modest share of alcohol duty could fund a comprehensive four-nation programme that pays for itself many times over.

0.25%
of UK alcohol duty — **~£31m a year** — could fund the programme

£4–£5
returned for **every £1** spent on alcohol screening & brief intervention

3.56 : 1
lifetime **benefit–cost ratio** of the proposed programme

£0
current England DHSC **FASD prevention** messaging budget per year

The cost of action — a fully costed five-year model

A 0.25% share of alcohol duty creates an envelope that comfortably funds the whole programme.

£157.5m	Five-year funding **envelope** from 0.25% of alcohol duty	**£106m**	Five-year **programme cost** — well within the envelope
£170.2m	Net public-sector **benefit** over the cohort's lifetime (PV)	**10,400**	People **supported** across the UK over the first five years

What 0.25% buys: a four-nation programme

Four national FASD centres of excellence and twenty regional centres, plus five evidence-led system-change components.

Prevention & awareness

The UK's first national alcohol-in-pregnancy campaign and systematic prevention of alcohol-exposed pregnancies across all four nations.

Lived-experience support

Peer and family support and lived-experience leadership embedded in every centre, not bolted on afterwards.

Workforce & training

Multidisciplinary FASD diagnosis and post-diagnostic support, with training to build capacity across health, education and care.

Data & surveillance

A national FASD registry, a UK-wide prevalence study and data linkage to finally make FASD visible in routine data.

Innovation & equity fund

A ring-fenced, NIHR-aligned fund so the programme can adapt — the difference between funding a service and funding system change.

Feasible, not aspirational

At a rounding error on alcohol duty, an £106m programme sits inside a £157.5m envelope — with headroom to spare.

Investment in FASD is not a cost — it is a saving

The Soft Drinks Industry Levy is the precedent: a fraction of one revenue stream funds a coherent public-health response. A 0.25% share of alcohol duty would fund the UK's first four-nation FASD Prevention and Response Programme — returning £3.56 for every £1 spent. All that is missing is political will.

Sources: Greenmyer et al. (2018, 2020) FASD lifetime & prevention costs; Purshouse et al. (2013) alcohol SBI cost-effectiveness; Thanh et al. (2015) & Schwartz et al. (2024) PCAP/Native CHOICES; FASD United (2025); NICE (2010); HM Treasury alcohol duty receipts; National FASD programme model (Appendix E).
From: The Cost of Inaction on FASD (June 2026), Section 4. The programme model is an illustrative proof of concept — details to be agreed via four-nation consultation.

Section 4: Invest to save: the economic case for funding an FASD Prevention and Response Programme

This section shows how a 0.25% allocation of UK alcohol duty could fund a four-nation FASD Prevention and Response Programme clinical network alongside prevention, lived-experience support, workforce, data and innovation. This is a model for discussion to prove the concept – the exact details of how an FASD Prevention and Response Programme plan would be structured would be thoroughly debated as part of a UK-wide dialogue via synchronous national consultations and involving people with FASD and their families.

The UK is not funding FASD

Fetal Alcohol Spectrum Disorder (FASD) is the most common preventable neurodevelopmental condition in the UK and one of the most under-resourced. National FASD estimates, anchored in the Salford prevalence study (McCarthy et al., 2021) and the Greenmyer et al. (2018) US lifetime cost estimate adjusted for the UK using purchasing power parity (Shemilt et al., 2010), places the recurring societal cost at approximately £9.2 billion per year and £160 billion in 30-year present value. Peer-reviewed evidence is unambiguous: every £1 invested in alcohol screening and brief intervention returns £4 to £5 in averted health and social costs (Purshouse et al., 2013); every FASD case prevented saves between £360,000 and £432,000 in lifetime societal cost (Greenmyer et al., 2018); and prevention can cost as little as £13,900 per case averted in the highest-risk groups (Greenmyer et al., 2018; Thanh et al., 2015).

The UK currently has no dedicated national budget line for FASD prevention and response. Comparable countries do – see for example Appendix C which shows the US NIH database shows 2,449 FASD-funded research projects totally of $729,637,722 between 1999 – 2026. The UK funded a one-off DHSC £473,000 grant fund in 2020–21 (DHSC, 2019). It has not funded a national campaign about alcohol on pregnancy, though it has funding a smoking in pregnancy campaign (see box below). Last year alone the NIH database shows 110 active research projects totaling nearly $50,000,000. Here in the UK, the country's leading researchers instead have been unable to fund potentially transformative projects on prevalence, tracking and post-diagnostic support – to name a few. One of the longest funded UK research projects at Oxford University is getting funding from the USA.

Initial comparison with other countries' spending

The following comparative table of FASD-specific spending is illustrative rather than exhaustive and should be interpreted with caution. It is difficult to find budgets to compare. To our knowledge, there are currently no peer-reviewed studies that systematically compare government FASD budgets across countries, so this analysis necessarily draws on official budget documents, government evaluations and credible grey literature rather than a single harmonised academic source. It doesn't include, for example, US state-level funding.

While more needs to be done to understand what different countries are investing in FASD, the figures presented are sufficient to demonstrate that dedicated UK funding for FASD is far below the scale of clearly identified programmes in countries such as Canada, the United States, Australia and New Zealand. Our wider report shows that it is also far out of line with the level of need in the UK itself.

An incomplete list of funding for FASD in selected countries

This chart is not definitive. It is provided to show how the UK funding for FASD significantly lags behind other countries. See Appendix C for a case study of US research funding on FASD.

Country / region	Level	Programme / mechanism	FASD / AEP-specific allocation (order of magnitude)	Notes on source / completeness
Canada	Federal (Canada-wide)	Direct research support to CanFASD	811,909 CAD reported federal funding to the Canada Fetal Alcohol Spectrum Disorder Research Network.	Government research-funding disclosure; only captures funding to one national research network.
Canada	Federal + Manitoba	PHAC FASD National Strategic Projects Fund	CAD $1.5m per year, plus Manitoba's renewed FASD Strategy with CAD $15.5m annual provincial spending on FASD-related programmes. (Public Health Agency Canada 2017-18, 2021-22.)	
Canada – New Brunswick	Provincial	FASD Centre of Excellence support	800,000 CAD provincial allocation to increase FASD support.cbc	Provincial announcement; does not capture other provincial FASD lines.
United States – NIAAA summary	Federal – research	NIAAA-reported FASD research portfolio	NIAAA states that about 7% of its extramural budget – roughly 30 million USD in FY2023 – was allocated to FASD-related grants. (See Appendix C for more details)	Official NIAAA statement; this aligns with the scale seen in the Reporter scrape.
United States - CDC	CDC line	CDC NCBDDD Fetal Alcohol Syndrome budget line	USD $11.5m in FY2024, funding surveillance, research and prevention activities within CDC.	
United States programmes (authorised)	Federal – services and prevention	FASD Respect Act (new)	Authorises 50 million USD per year for FASD prevention, screening/identification and FASD-informed services, to support federal, state, tribal and local programmes.	Authorisation figure; actual appropriations may vary by year but set the intended federal FASD programme scale.
Australia	Federal (Australia-wide)	Every moment matters national FASD awareness campaign	AUD $5 million in the 2024–25 Federal Budget to continue the campaign, on top of previous multi year funding for the National FASD Program.	
Australia	Federal with state targeting	National diagnostic and awareness package	"More than" 37 million AUD for FASD diagnostic services and a national awareness campaign, bringing total Commonwealth FASD investment since 2014 to >78 million AUD.	Federal health minister announcement; clearly labelled as FASD funding.
Australia – selected states	State-linked via federal grants	Named grants to NSW, Queensland, Victoria services	Approx. 4.85m AUD (University of Sydney), 2.15m AUD (Patches, NSW youth justice), 1.57m AUD (University of Queensland), 1.25m AUD (Victorian Fetal Alcohol Service).	Part of the 37m AUD federal package; these are explicit state-level allocations.

New Zealand	National	FASD Action Plan and associated initiatives	Around 7.25m NZD for FASD prevention, diagnosis and support under the national action plan, plus an additional 4.85m NZD FASD prevention/support package and 600k NZD per year for FASD-CAN navigators and Tītoki.	Based on government-linked announcements summarised by FASD-CAN and the Children's Commissioner.
France	National	Multi-year SAF France (Syndrome d'alcoolisation fœtale) prevention partnership	No single consolidated FASD budget line published; prevention is delivered through national alcohol-policy and maternity-health channels and the mandatory labelling regime	
Ireland	National	No dedicated national FASD strategy or ring-fenced funding stream; FASD-related activity sits within broader alcohol-harm and disability services	No dedicated HSE budget line identified for FASD diagnosis, prevention or support. FASD Ireland received some €200,000 per year in 2024/2025 but this dropped to €27,500 for 2026.	FASD Hub Ireland (2025); HSE — no dedicated FASD funding line published
United Kingdom – England	National (England)	DHSC 2019 FASD grant round (Section 64)	In England, the only national FASD-specific grant round was a one-off DHSC Section 64 scheme for 2020–21, with a total FASD grant pot of £473,000 for voluntary-sector FASD interventions. No further England-wide FASD grant rounds or standing programme budgets have been announced since. No standing UK-wide, multi-year, FASD-specific allocation comparable to the dedicated national budgets in Canada, the US, Australia or New Zealand.	Non- recurrent; there is no continuing England-wide FASD programme budget after this 2019 cycle.
Scotland	National within UK	FASD Hub Scotland (Adoption UK Scotland)	2,087,887 GBP in Scottish Government funding to Adoption UK Scotland/FASD Hub Scotland between 2018 and 2024, ≈350k GBP per year on average. 140k GBP in 2019/20 for FASD Hub Scotland plus 17k GBP to extend to birth families, and 110k GBP to six health boards under FASD Programme for Government third-sector	Scottish Government FOI; clearly identified as FASD support funding.
Scotland	National within UK	FAAST (training and support)	Scottish Government-funded national advisory/training service on FASD; FOI examples show six-figure annual grants.	Adds to Scotland's dedicated FASD infrastructure.
Greater Manchester (England)	Regional (GMHSCP / GM ICB)	Alcohol Exposed Pregnancies (AEP) programme and #DRYMESTER	1.6m GBP non-recurrent transformation funding committed in 2018 by Greater Manchester Health and Social Care Partnership for AEP prevention and related work; often described in summaries as	Evaluation report; prevention-focused and closely tied to FASD but coded as AEP.

			"around £1.8m" over the programme period.	
Greater Manchester (England)	Regional (ICB / VCSE)	Greater Manchester FASD Network	Dedicated contracts from NHS Greater Manchester ICB to National FASD to develop the GM FASD Network (£89,897 - 2024-2025, £40,000 - 2025-2026)	Explicitly FASD specific
Greater Manchester (England)	Regional (VCSE small grants)	FASD peer-support small grants (10GM)	Small grants scheme for local groups to run FASD peer-support activities; individual grant amounts small and time-limited.	VCSE funding notice; illustrates scale (hundreds rather than millions of pounds).

Comparison with UK funding for smoking in pregnancy prevention programmes

The contrast between the UK's response to smoking in pregnancy and its response to alcohol in pregnancy is one of the starkest examples of unequal public health investment in the maternity system across all four nations. All four UK nations are funding tobacco-in-pregnancy prevention in some form.

Smoking in pregnancy is the subject of a comprehensive, funded infrastructure in each country, with England's National Smoke-Free Pregnancy Incentives Scheme (NSPIS) providing the clearest example of a centrally driven, long-term programme. NSPIS, launched by NHS England in September 2024 and expanded in January 2026, now operates across more than 80% of maternity trusts and offers up to £400 in financial incentives to pregnant women who quit, backed by national funding committed to March 2029. The government has ringfenced £152.8 million in 2026–27 specifically for smoking cessation through the public health grant, with dedicated tobacco dependency treatment services embedded in maternity settings nationally following a £42 million NHS Long Term Plan investment (HM Government, 2026; HFMA, 2022). The result has been a measurable public health success: the proportion of women smoking at time of delivery in England fell from 11.7% in 2014–15 to 6.1% by 2024–25 — meeting the national target set by the Tobacco Control Plan (ASH, 2025; NHS England, 2025).

Alcohol in pregnancy receives no equivalent UK-wide campaign. There is no four-nation campaign, no national incentive scheme, no dedicated maternity-embedded advisory service, no routinely commissioned maternity-embedded advisory service for alcohol comparable to tobacco, and no national prevalence target in any UK country. While some local and national initiatives exist — for example, midwife-delivered alcohol brief interventions in Scotland and pockets of local practice and pilots elsewhere, such as the Greater Manchester Alcohol-Exposed Pregnancies/ Drymester programme (which has been significantly cut back) — these are fragmented, time-limited, and not underpinned by a coherent, funded UK or nation-level programme. In England, the DHSC's specific public health messaging investment in FASD prevention stands at £0 per year.

Yet by every measure, alcohol in pregnancy represents a larger preventable harm: 15-41% of UK women drink alcohol during pregnancy compared with 11.5% who smoke, and approximately 45% of UK pregnancies are unplanned — meaning many women are exposed before they know they are pregnant. The neurodevelopmental consequences of prenatal alcohol exposure are more extensive than those of nicotine: alcohol has a strong, evidenced effect across growth, behaviour, cognition, language, and academic achievement, and FASD is associated with up to 428 co-occurring conditions, affecting an estimated 2–4% of the population — double the prevalence of autism.

The #DRYMESTER campaign in Greater Manchester — developed with midwives and families with lived experience — demonstrates that a well-designed alcohol-in-pregnancy campaign can achieve national reach: Phase 1 alone generated 4.5 million views with strong engagement among women of childbearing age (Greater Manchester Integrated Care, 2025; ASH, 2025). This was locally funded, locally delivered, and structurally isolated. There is no national equivalent.

The asymmetry is not justified by the evidence. Both behaviours are harmful and both are modifiable. A UK-wide alcohol-in-pregnancy campaign — resourced and sustained at a level proportionate to the scale of the harm — is not a supplementary ask. It is a correction of a long-standing and indefensible imbalance in how the UK responds to preventable harm in pregnancy.

	Smoking in pregnancy	**Alcohol in pregnancy**
Prevalence in UK pregnancies	11.5%	41%
National awareness campaign	✓ Funded, sustained	✗ None
National incentive scheme	✓ NSPIS — up to £400 per woman (2024–2029)	✗ None
Dedicated maternity support	✓ Tobacco dependency advisers in 80%+ of trusts	✗ Not mandated
Ring-fenced public health budget	✓ £152.8 million/year (smoking cessation, England, 2026–27)	✗ £0 dedicated FASD prevention budget
National prevalence target	✓ 6% at time of delivery — met (2024–25)	✗ No target set
Neurodevelopmental impact	Growth, stillbirth risk	FASD: behaviour, cognition, language, achievement — up to 428 co-occurring conditions
Estimated population prevalence of associated condition	~1% (smoking-related growth restriction)	2–4% FASD — more common than autism (1%)
Proportion of unplanned pregnancies at risk before awareness	Lower — nicotine effects later in pregnancy	Higher — alcohol affects fetal brain from early in pregnancy

An equivalent of 0.25% of the alcohol duty can change the national picture

As discussed below, benchmarking a stable, recurring funding stream set at around 0.25% of UK alcohol duty receipts — approximately £31 million per year, rising to £32 million by year five — could fund a coherent five-year UK-wide FASD Prevention and Response Programme costing £106 million against a £157.5 million envelope.

How the actual FASD Prevention and Response Programme would roll out is subject to national consultation engaging a wide range of stakeholders, including people with FASD and their families.

Not only is it desirable to fund an FASD Prevention and Response Programme – it is feasible.

The programme model delivers a UK-wide FASD Prevention and Response Programme (PRP) including five evidence-led components (prevention, lived-experience support, workforce, data and innovation). It reaches 10,400 supported individuals over five years, and generates a 3.56 to 1 lifetime benefit-cost ratio.

This is a model to start discussion – not a definitive roadmap

The FASD Prevention and Response programme suggested below (and further outlined in Appendix E) is put forward as a proof of concept. It is not meant to be definitive. It is meant to show that with a rounding error on the alcohol duty, a funded, comprehensive four-nation FASD Prevention and Response Programme is feasible. The details can and should be worked out, possibly through synchronous national consultations which should engage a wide range of people with FASD and their families and other stakeholders. There are differences in how this would roll out in each of the four nations and differences in how the Programme should like. Our purpose is to show it is possible to fund a truly comprehensive national response at the scale needed across the four-nations. We reemphasise, if we can produce a vision like this as a small charity, imagine what could be done with the four national Governments putting their considerable expertise and resources to the task. All that is missing is political will.

The soft drinks industry levy is a precedent

The Soft Drinks Industry Levy provides the most direct precedent: receipts fund school sport, breakfast clubs and the Healthy Pupils Capital Fund. (See Appendix D for more information.)

FASD prevention is a direct logical extension of the same principle — using a fraction of alcohol revenue to address the most serious preventable consequence of alcohol consumption.

The 0.25% rate is deliberately modest — a fraction of one percent of annual alcohol duty receipts. It is below the year-on-year variation in receipts themselves, and well within the range of similar arrangements (the Soft Drinks Industry Levy redirects approximately 100% of its receipts; the proposed FASD share is 0.25% of one alcohol-related revenue stream).

The financial savings of funding prevention

While this model includes but goes beyond just prevention, it is important to note up front the economic case for FASD prevention has been established by a coherent body of peer-reviewed research over the last two decades. Greenmyer, Popova, Klug, and Burd (2020) conducted the most comprehensive systematic review of FASD prevention costs in the United States and Canada, concluding that one case of FASD can be prevented for as little as USD $20,200–$47,615 — a fraction of the lifetime cost of care, which Popova, Lange, Burd, and Rehm (2016) estimated at USD $1.8 billion annually in Canada alone. Adjusting Greenmyer et al.'s prevention cost using the OECD GDP purchasing power parity factor of 0.69 GBP per international dollar (World Bank, 2024) yields a UK-equivalent prevention cost of approximately £13,900–£32,900 per case averted. Set against a UK lifetime societal cost of £359,835 per diagnosed case, the implied prevention return is between 11:1 and 26:1.

At the population level, Purshouse, Brennan, Latimer, and Meier (2013) modelled universal alcohol screening and brief intervention (SBI) in English primary care and found a programme delivered by practice nurses to be cost-effective at £6,900 per quality-adjusted life year (QALY) gained, generating modest direct savings of £120 million over 30 years and 32,000 QALYs in net health gain. The US group, FASD United (FASD United, 2025) confirms a £4–£5 return on every £1 of alcohol SBI spend across the lifetime, a ratio replicated in NICE's own cost-effectiveness review of brief interventions (NICE, 2010).

Specific to FASD, the Parent–Child Assistance Program (PCAP) provides the strongest single piece of intervention-level evidence. Thanh, Jonsson, Moffatt, Dennett, and Chuck (2015), using Albertan PCAP data, estimated an incremental cost of CAD $97,000 per FASD case prevented and a net monetary benefit of CAD $22 million across 366 high-risk women over three years. Schwartz et al. (2024) replicated this finding in the Native CHOICES randomised controlled trial, with a cost-efficiency ratio of USD $84,887–$93,709 per FASD averted and USD $2,330–$2,572 per QALY gained — well below the WHO's cost-effectiveness threshold of one to three times GDP per capita.

The cost of action: funding a UK-wide FASD Prevention and Response Programme with the equivalent of 0.25% of alcohol duty

Earlier sections quantified the cost of inaction. This section quantifies the cost of action. It sets out a single coherent ask: benchmarking an ongoing share of alcohol duty revenues (around 0.25% each year) for an FASD Prevention and Response Fund — approximately £31 million in Year 1, rising to £32 million by Year 5 — generating a five-year envelope of £157.5 million (£147.1m PV). Against this envelope, the proposed programme costs £106 million over five years (£97.5m PV), leaving £49.6

million PV in headroom and peaking at 88% of envelope utilisation in Year 4. The lifetime benefit-cost ratio is 3.56 to 1, drawing on £236.7m PV in avoided lifetime costs.

> The case rests on a single shape, drawn from an AI generated national programme. The model is based on illustrative ideas that have been discussed among the FASD community and researchers over recent years. It is summarised below and further detailed in Appendix E. We lay out the case for a five-year ramp of programme cost against a five-year curve of avoided cost.
>
> By Year 5, the network is supporting a cumulative cohort of 10,400 children, young people and adults; annual avoided costs reach £11.9 million; and the cumulative net-benefit position turns positive in Year 9 of the lifetime horizon. Across the lifetime of the cohort, £236.7 million in present-value avoided costs are generated against £66.4 million in present-value programme spend — a net public-sector benefit of £170.2 million on the central scenario.

What 0.25% buys

An illustrative model UK-wide FASD Prevention and Response Programme (FASD-PRP)

As a thought exercise, our model is based on the idea that over 5 years, each nation would have a national FASD centre of excellence, supported by additional regional centres. These would support ongoing more diffuse FASD prevention, diagnosis, research and support at local levels and would be embedded in existing services. (See Appendix E for more details of the model used and what the FASD PRP might look like.)

The proposed FASD Prevention and Response Programme would create, for the first time, a four-nation clinical and support infrastructure, not just a handful of diagnostic clinics. It is built around four national FASD centres of excellence and twenty regional centres. In England, Wales and Northern Ireland, this could be best described as a ‘hub and spoke’ model as referenced in the DHSC FASD Health Needs Assessment. In Scotland this could be a national specialist function supported by other FASD centres. How it is set up in each nation will be determined via national consultations. This is just one example of how it might roll out.

Each national centre is costed as a multidisciplinary FASD service with a common core offer that includes diagnosis, systematic prevention of alcohol-exposed pregnancies, post-diagnostic support for children, young people and adults, workforce training, applied research, and grants to voluntary and community partners, scaled differently at national and regional levels. Together, these centres anchor a UK-wide system that can reach around 10,400 people over five years, and then continue to support new cohorts each year as the network matures.

Crucially, this is a programme model, not just a clinical service roll-out. The FASD PRP network is backed by five evidence-led components that turn FASD work into a genuine system-change agenda:

a national FASD linked database and registry to make the condition visible in routine data; a UK-wide prevalence study to close the evidence gap; a standing, NIHR-aligned research fund to translate innovation into practice; sentinel surveillance and data linkage to track outcomes; and a ring-fenced innovation and equity fund to support prevention, lived-experience leadership, and workforce development at local level. Within a five-year envelope benchmarked at just 0.25% of UK alcohol duty, this model funds national and regional centres plus these enabling functions, delivering a lifetime benefit–cost ratio of 3.56:1 and demonstrating that a comprehensive, four-nation response to FASD is both structurally and fiscally achievable.

Without innovation funding, the programme cannot adapt

The 0.25% envelope addresses this. It includes an additional £33.5 million nominal over five years funds five evidence-led components that turn a clinical service into a national programme: prevention and public awareness, lived-experience and peer support, workforce training and research, data and outcomes infrastructure, and a ring-fenced innovation and equity fund.

This is the difference between funding a service and funding a system change.

FASD Prevention and Response Programme (PRP): what each level does

Source: National FASD (2026). The Cost of Inaction on FASD.

NATIONAL CENTRES

(one per nation)

Cost: £1.75m / year

Complex Diagnostics

Full MDT: paediatrician, psychologist, SLT, OT · neuropsychology

Post-Diagnostic Support

Me & My FASD · SPECIFiC parenting

Family coordination & workshops

Workforce Training

National CPD for GPs, midwives, schools, social workers, CAMHS

VCSE Grants

Lived-experience networks

Adoption, fostering & peer support

Prevention Campaigns

Alcohol-in-pregnancy messaging

revised AUDIT-C antenatal screening

Clinical Leadership

National standards & quality assurance

Devolved nation coordination

Data & Research

National FASD Linked Database / Registry · Sentinel surveillance · NIHR fund

feeds into ▾ ⇣ *▴ escalates to*

REGIONAL CENTRES

(up to 20 across UK)

Cost: £635k / year

Local Multi-Disciplinary Assessments

Less complex cases assessed locally; complex cases escalated to national centre

Local Training & Prevention

CPD: GPs, midwives, schools, social workers · outreach

Family-Facing Support

Workshops · community groups

SEND toolkit · SPECIFiC groups

VCSE Grants

Small local grants for peer support, mentoring, targeted prevention

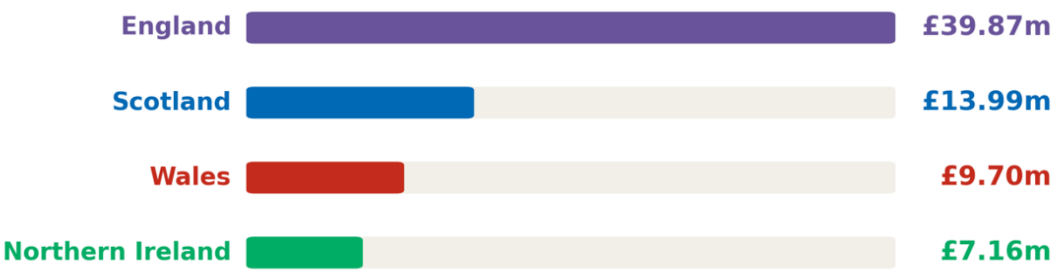
Data Contribution

Registry entries · service audits

Contributes to national studies

Each regional centre works to the same national specifications, tailored to local ICS/health board, LA SEND teams and schools and other services. Regional centres are the main interface for families and professionals and are embedded in existing services. | National FASD (2026).

Line	Five-year present-value cost
FASD Prevention and Response Programme (PRP) network (4 national centres, 20 regional centres (spokes)	£66.4m (PV) — £72.5m undiscounted
1. National FASD Linked Database/Registry	£9.2m
2. UK FASD prevalence study	£7.2m
3. NIHR-aligned research fund	£12.0m
4. Sentinel surveillance and data linkage	£2.9m
5. Implementation science and evaluation	£2.2m
Total programme cost	£100.0m (PV) / £106.0m undiscounted
0.25% envelope, five-year total	£157.5m
Headroom	£49.6m (PV)



5-year funding by nation

Per-nation allocation across Years 1–5 of the FASD-PRP network (£70.7m total).

Source: The Cost of Inaction on FASD (June 2026). Hub £1.75m/yr; spoke £635k/yr; PV at 3.5% Green Book STPR.

The invest-to-save J-curve

The above figure plots three series across the five funding years of the programme.

- **Programme cost (£m).** The annual cost of the four-nation FASD Prevention and Response Programme, built bottom-up from nine service lines — clinical staffing, multidisciplinary diagnostics, training, prevention, research, estates, post-diagnostic support drawing on the Me and My FASD resources, the University of Salford SPECIFiC parenting programme, and grants to the voluntary sector. Costs rise from £4.3 million in Year 1 to £20.5 million at steady state in Year 5, reflecting the planned ramp from one lead national hub and four regional centres (spokes) to four national hubs and twenty regional centres (spokes) UK-wide.

- **Avoided costs (£m).** The cohort-attributable public-sector savings released by the network in each funding year. These build slowly — £0.1 million in Year 1, £11.9 million in Year 5 — because the cohort accumulates over time and because secondary-disability reduction is, by nature, a lagged outcome. The full benefit stream is realised over the lifetime of the cohort, not within the five-year funding window.

- **Net benefit (£m).** The annual difference between avoided costs and programme cost. Negative in the funding years (the investment phase) and strongly positive thereafter — by the end of the lifetime horizon, the cohort generates £236.7 million in present-value avoided costs against £66.4 million in programme spend.

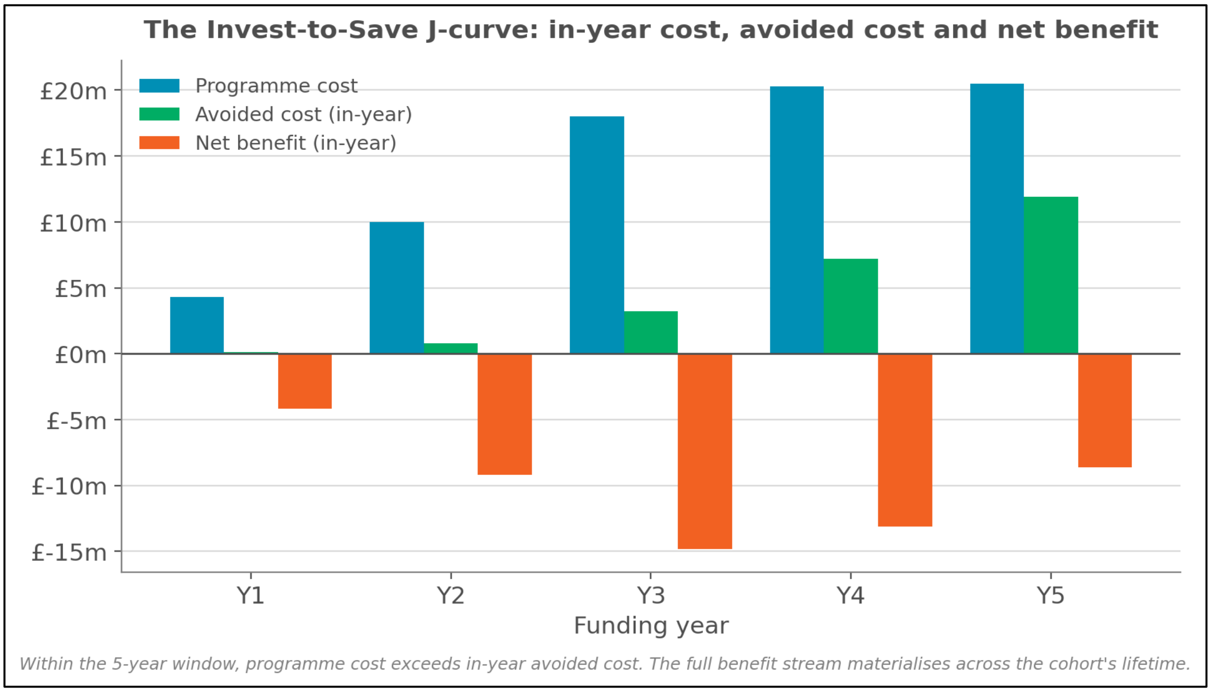


Figure: Invest-to-Save J-curve for the FASD PRP network. Annual network cost rises from £4.3m in Year 1 to £20.5m at steady state in Year 5; in-year avoided cost rises from £0.1m to £11.9m. The full programme adds the five evidence-led components on top of this (see Figure 3), and the total sits inside the 0.25% envelope at 88% peak utilisation.

The chart is, deliberately, an honest one. It does not flatter the five-year window. It shows what every Invest-to-Save case eventually shows: that public-health prevention is a J-curve, with the costs front-loaded and the savings back-loaded. The point of the chart is not to claim within-period payback. It is to show that, even on a conservative within-cohort attribution and a Green Book 3.5% discount rate, the lifetime benefit-cost ratio is 3.56 to 1, and the breakeven point is reached well within the working lifetime of the children diagnosed in Year 1.

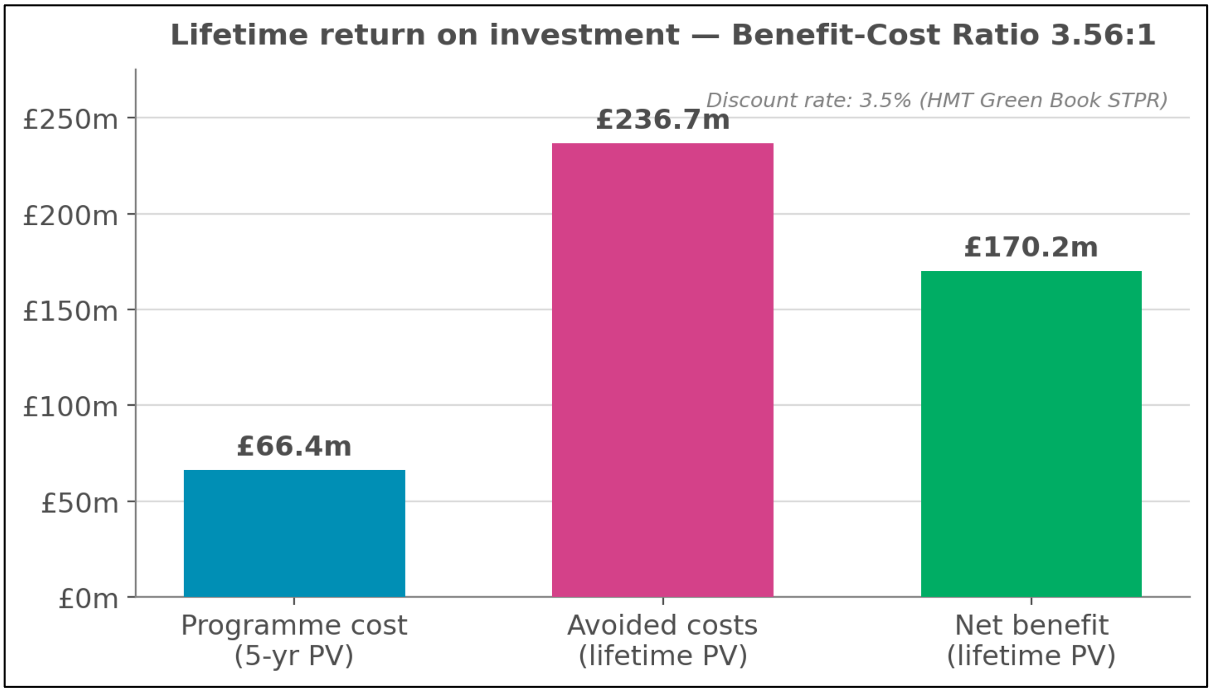


Figure: Lifetime present-value summary. Programme spend of £66.4m delivers £236.7m in avoided cost — a net public-sector benefit of £170.2m and a benefit-cost ratio of 3.56 to 1.

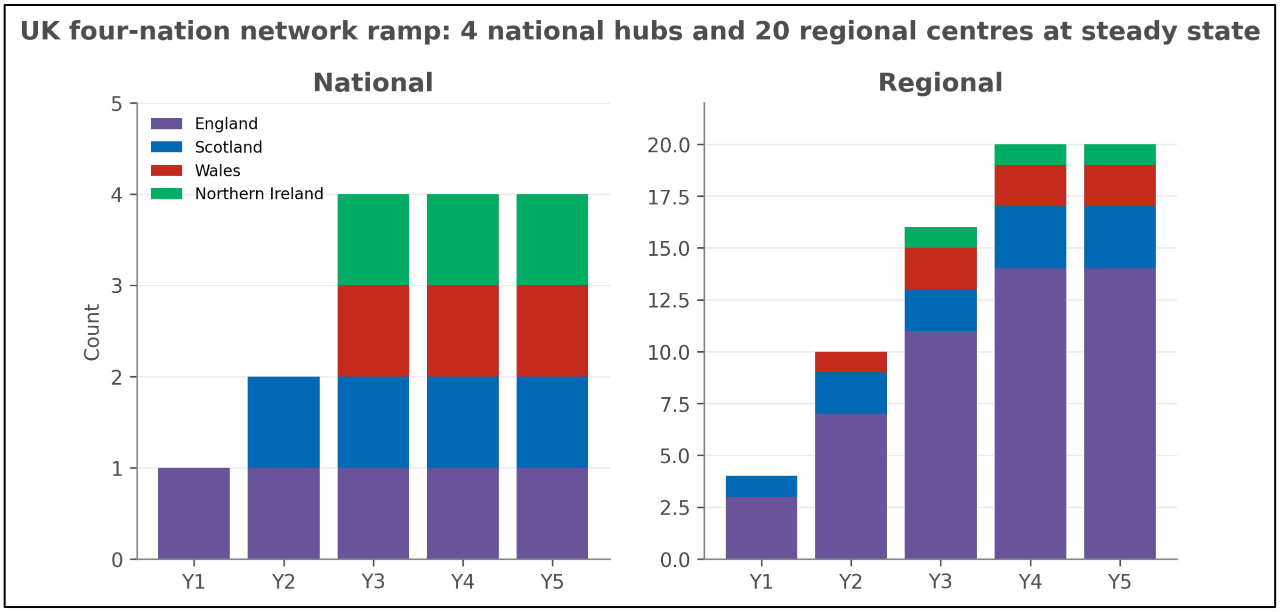


Figure: FASD PRP build profile by nation: from one national centre and four regional centres in Year 1 to four national centres and twenty regional centres by Year 5.

The five evidence-led components that are part of the FASD PRP centres

The centres alone costs £72.5 million nominal (£66.4m PV) over five years — a fully-costed business case for a national FASD clinical service. But a clinical network in isolation will not deliver the lifetime returns that the wider literature documents. Without prevention, the inflow of new cases continues. Without lived-experience and peer support, families fall out of the system between appointments. Without workforce training, the network has no clinicians to staff it. Without data, commissioners cannot demonstrate value. Without innovation funding, the programme cannot adapt.

The 0.25% envelope addresses this. The additional £33.5 million nominal over five years funds five evidence-led components that turn a clinical service into a national programme: prevention and public awareness, lived-experience and peer support, workforce training and research, data and outcomes infrastructure, and a ring-fenced innovation and equity fund. This is the difference between funding a service and funding a system change.

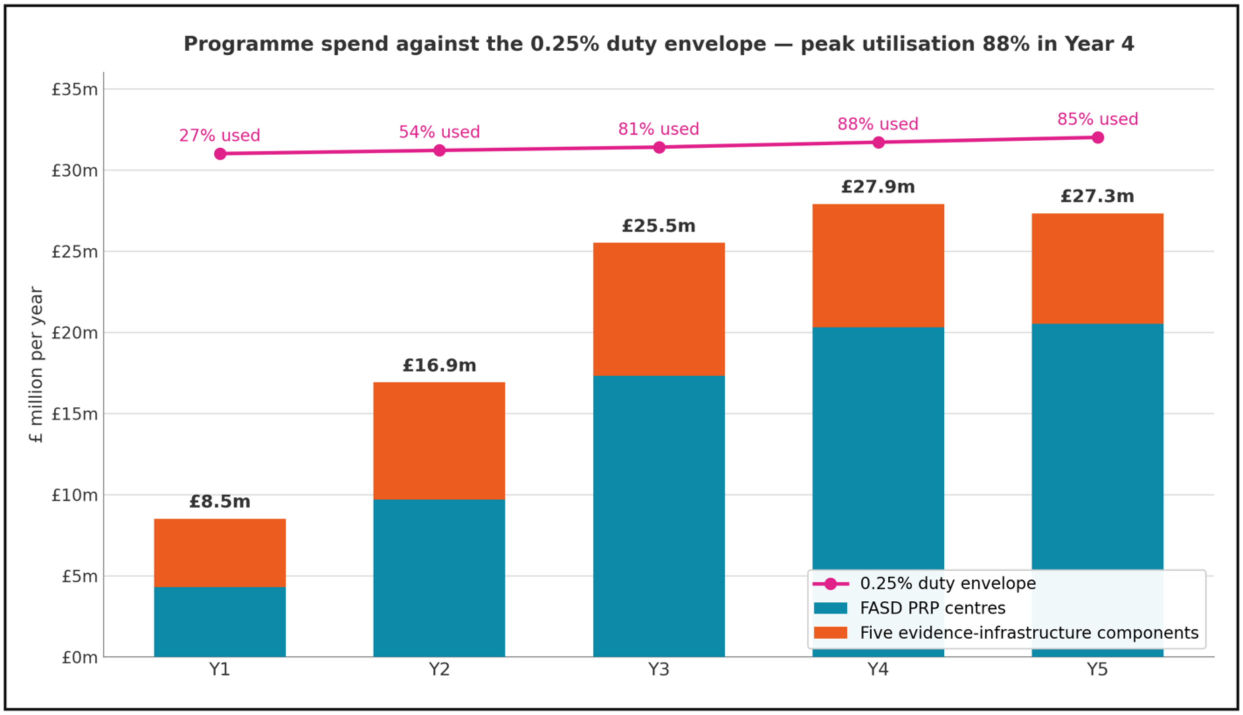


Figure:. Combined programme spend (network plus five evidence-infrastructure components) against the 0.25% envelope. Peak annual utilisation is 88% in Year 4; cumulative headroom across the five years is £49.6m.

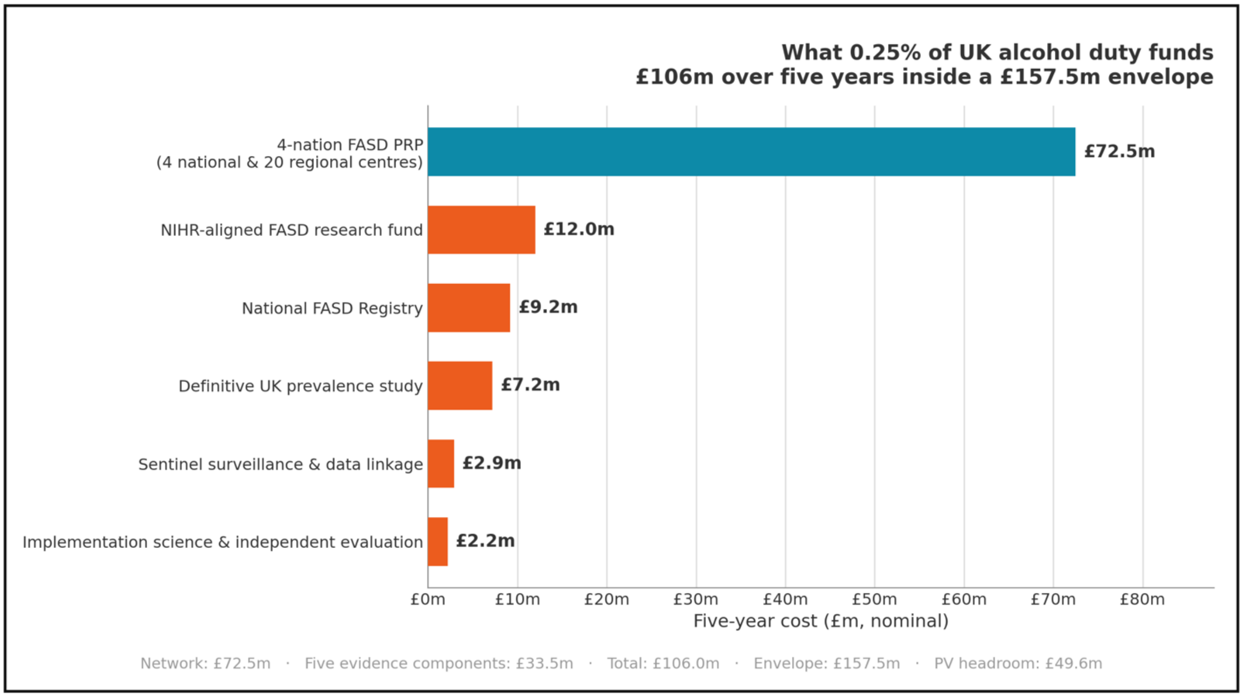


Figure: What the 0.25% envelope delivers over five years: a £72.5m totalling £106m against a £157.5m envelope.

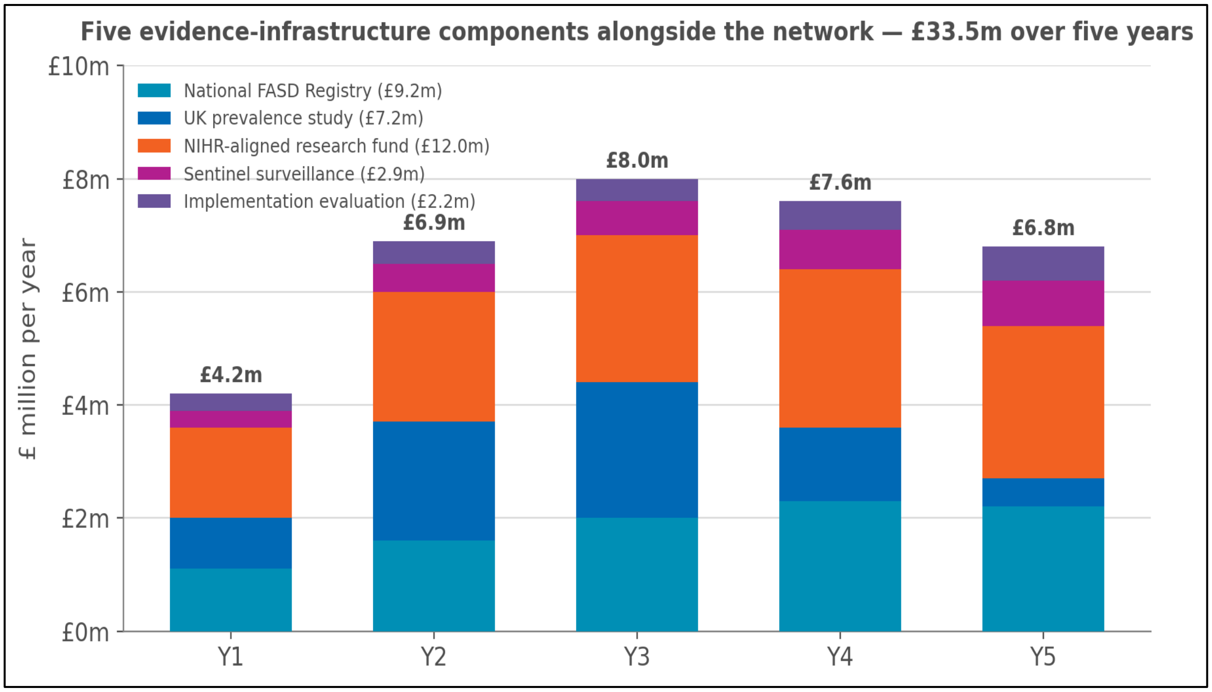


Figure: The five evidence-led components funded alongside the FASD PRP clinical network — total £33.5m nominal over five years.

Relationship to funding and avoided costs

Programme network spend rises from £4.3m in Y1 to around £20.5m per year in Y5 as new centres are added, with total 5-year PV network cost of £66.4m. The full programme adds the five evidence-led components on top of this, taking total 5-year cost to £97.5m PV. Avoided costs grow more slowly but reach £11.9m per year by Y5 and £236.7m in lifetime PV for the Y1–Y5 cohorts, with a lifetime benefit–cost ratio of about 3.56. The whole five-year programme is sized so that, at steady state, it sits comfortably within a 0.25% benchmark of UK alcohol duty receipts (approximately £31m per year, rising to £32m by Year 5), giving a clear “duty-funded FASD programme” narrative.

The model is not designed to show “full” savings within five years because most of the benefits of better FASD diagnosis, support and prevention emerge over decades, while the FASD PRP network has to be fully built and paid for upfront in those first years.

Why savings look modest in 5 years

In the AI generated spreadsheet, network costs ramp quickly from £4.3m in year 1 to about £20.5m a year by year 5 as you add centres. Over the same period, in-year avoided costs grow from only about £0.1m to £11.9m, so the first five years show a negative net benefit in-year of around £8.6m in year 5 and about £49m cumulatively. That pattern is typical for neurodevelopmental conditions: you are investing in earlier diagnosis, support and prevention now, but major savings in adult services, criminal justice and productivity only start to materialise much later in the life course. The model therefore uses five years as a build-out window for the network, not as the full horizon for cost savings, which is why it also reports lifetime avoided costs and lifetime benefit-cost ratios for the cohorts supported in years 1–5.

How the FASD PRP network creates long-term savings

The design means that, once the four national centres of excellence (hubs) and 20 regional centres (spokes) are in place, a steady stream of new cohorts benefit each year from:

- Earlier and more accurate diagnosis (fewer “missed” children and adults).
- Better targeted SEND and social care support.
- Stronger family support and parenting interventions.
- Systematic prevention of alcohol-exposed pregnancies.

In the model, for every cohort reached (3,200 new cases per year from year 4), a percentage of the lifetime cost in each component (healthcare, SEND, social care, criminal justice, productivity, housing/benefits) is gradually averted: for example, healthcare costs averted per case rise from 10% of the component in year 1 to 25% by year 5, SEND from 5% to 20%, and social services from 8% to 22%. These percentages reflect how early support reduces crisis mental-health use, high-tariff SEND placements, out-of-home care, and later criminal justice involvement. Because those “big ticket” costs are heavily concentrated in adolescence and adulthood, the model projects lifetime avoided costs for each supported cohort and discounts them over a 75-year horizon.

What the lifetime numbers show

When looking at the lifetime impact of the cohorts supported in the first five years, the picture flips: the 5-year programme has a present-value cost of about £66.4m but generates lifetime avoided costs of about £236.7m, giving a lifetime benefit–cost ratio of about 3.56. In other words, even though the first five years look like an investment period with limited short-term savings, over the lifespan of the children and young people helped, every £1 invested now avoids roughly £3.50 in later costs to health, education, social care, criminal justice and the wider economy. This is exactly what you would expect for an early-intervention, prevention-focused programme: you build the capacity and systems in the first phase, and the fiscal and social returns accumulate gradually as those cohorts move through school, adolescence and into adulthood.

Sensitivity: why 0.25% is the right rate

The choice of 0.25% is not arbitrary. Sensitivity testing across the 0.20%–0.30% range, holding the programme cost ramp constant, shows three regimes. At 0.20%, the envelope cannot absorb the full programme: peak Year 4 utilisation reaches 110% and Years 3–5 turn negative (a cumulative £4.5m shortfall), so the programme would have to be cut or supplemented from general taxation. At 0.22%, the envelope is at the absolute feasibility floor: peak utilisation hits 100% in Year 4 with no margin for error. From 0.23% upwards, the envelope absorbs the programme with progressively more headroom: 0.25% delivers £49.6m PV headroom at 88% peak utilisation, and 0.30% delivers £79m PV headroom at 73% peak. The 0.25% rate is therefore the lowest estimate that funds the full programme with realistic sensitivity headroom — sufficient to absorb a 10–15% cost over-run or receipts softening without breaching the cap. It is also a fraction of one percent of UK alcohol duty receipts, and well within the year-on-year variation in receipts themselves.

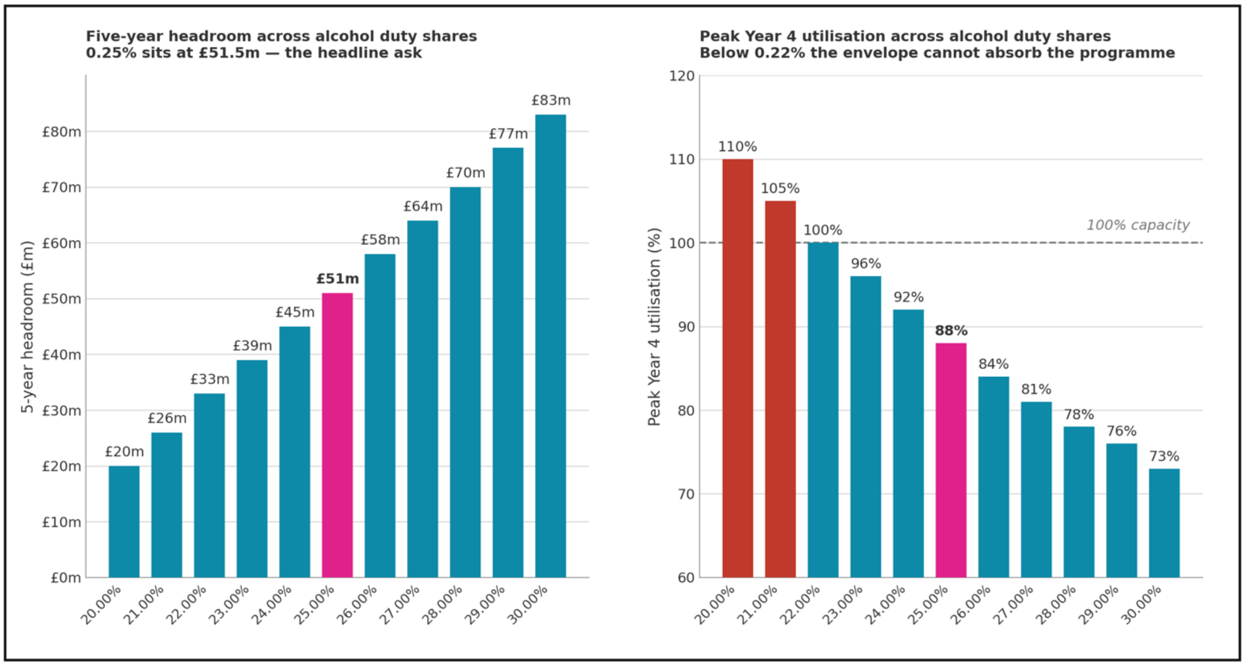


Figure: Sensitivity. Peak Year 4 utilisation and 5-year PV headroom across rates from 0.20% to 0.30%. The 0.25% rate is the lowest that funds the full programme with sensitivity headroom; 0.22% is the absolute feasibility floor.

The funding case for the four-nation FASD Prevention and Response Fund

A 0.25% benchmarking of UK alcohol duty funds the FASD Prevention and Response Programme across the 4 nations, includes five evidence-led components, and leaves headroom for sensitivity, and delivers a 3.56 to1 lifetime return.

Programme cost (5-year PV): £66.4m for the clinical network; £106.0m including the five additional evidence-infrastructure components.

Funding envelope at 0.25% of UK alcohol duty: £157.5m over five years — peak annual utilisation 88% in Year 4, headroom £49.6m.

Lifetime present-value avoided cost (central scenario): £236.7m.

Lifetime net public-sector benefit: £170.2m. Lifetime benefit-cost ratio: 3.56 to 1.

Cohort supported within the five-year funding window: 10,400 children, young people and adults across the four nations.

This model was created with AI. It is a model for discussion to prove the concept that it is possible to fund a comprehensive response across the four nations to FASD prevention, diagnosis and support with a very small percentage of the alcohol duty receipts. National consultations should engage people with FASD and their families before the FASD PRP is decided.

England: How the FASD PRP fits into the new NHS

The case for a stable, recurring FASD Prevention and Response Fund, benchmarked to 0.25% is not only an economic case. It is a policy-fit case. The *10 Year Health Plan for England*, published in July 2025, set out three radical shifts that now govern NHS commissioning: from hospital to community, from analogue to digital, and from sickness to prevention (DHSC, 2025). The FASD PRP delivers against all three.

Shift 1: From hospital to community

In England, the hub-and-spoke architecture endemic to the FASD PRP is, by design, a community-first model. Four national hubs provide the specialist diagnostic and clinical leadership that no neighbourhood can stand up alone; twenty regional spokes deliver assessment, family support, and workforce development close to home. The model maps cleanly onto the new neighbourhood health service described in the 10 Year Plan and the neighbourhood health guidelines for 2025/26, which ask Integrated Care Boards (ICBs) to deliver "more care at home or closer to home" through multidisciplinary teams working at place and neighbourhood level (NHS England, 2025a). Spoke services are precisely the kind of community-based specialist support — paediatric, psychological, educational, family-facing — that the neighbourhood model is designed to scale. The NHS Grampian FASD Hub has already demonstrated, at £113,982 in Year 1 and £131,136 in Year 2, that a peer-led, professionally backed regional service can be stood up at modest cost and run within a community setting (NHS Grampian, 2022).

The model is also explicitly designed to complement, not duplicate, the new neighbourhood health centres that will become the front door of the reformed NHS in England (DHSC, 2025). Spokes will sit alongside neighbourhood health centres as the specialist neurodevelopmental tier that GPs, health visitors and school nurses refer into — closing the referral gap identified in the recent British Journal of General Practice review of FASD in primary care, which found that referrals to FASD assessment are routinely denied where no FASD pathway exists, but proceed where the pathway is in place (Mukherjee et al., 2025).

Shift 2: From analogue to digital

The investment in a national FASD National Linked Database/Registry, in sentinel surveillance, and in routine use of the new FASD SNOMED CT codes is the digital infrastructure shift, applied to a previously invisible population. The 2024 introduction of the three FASD SNOMED codes — sentinel facial features, without sentinel facial features, and at increased risk — means that, for the first time, primary care can record FASD in EMIS and SystmOne and that the condition becomes visible in routine NHS data (Mukherjee et al., 2025, Harding et al., 2024). The registry and surveillance functions turn that coding capacity into a working evidence system: a Single Patient Record contribution for FASD, linked across maternity, paediatric, primary care, and educational and justice data, that supports both clinical decision-making and ICB-level population health management. This is the FASD field’s analogue-to-digital shift.

Shift 3: From sickness to prevention

This is where the model is at its strongest. FASD is, by definition, preventable: every case is the result of prenatal alcohol exposure. The hub-and-spoke network funds primary prevention through the public-awareness, training, and antenatal advice work delivered by hubs; secondary prevention through earlier identification and reduced secondary disability among children already affected; and tertiary prevention through reducing the risk of future alcohol-exposed pregnancies among women already known to have an affected child (DHSC, 2021). The DHSC Health Needs Assessment is explicit that early diagnosis and FASD-informed support are the single most powerful levers for reducing the lifetime cost of the condition — and that both depend on the kind of specialist infrastructure the network delivers (DHSC, 2021).

The prevention case is also a maternity case. Universal antenatal alcohol-history taking, implemented consistently across all four UK nations, is the keystone preventive intervention the network is designed to support. The Scottish Intercollegiate Guidelines Network (2019) has already mandated it; NICE has reinforced it in QS204 (NICE, 2022); the network's hubs would provide the training, the supervision, and the data feedback loop that turn the guidance into routine practice.

How the model fits the ICB restructuring in England

The case for 0.25% is also a case for funding the ICB reform agenda, not adding to its costs. In March 2025, the government announced the abolition of NHS England, the reduction in the number of ICBs in England from 42 to approximately 26, and a 50% cut to ICB running costs by October 2025, on top of an earlier 30% reduction (BMA, 2025; The King's Fund, 2025). The remaining ICBs are being repositioned as strategic commissioners — leaner organisations responsible for population health, pathway commissioning, and inequalities, with operational delivery devolved to providers and integrated health organisations (NHS England, 2025b). The reformed ICBs have neither the capacity nor the remit to design and stand up specialist neurodevelopmental pathways from scratch in 26 separate footprints.

A nationally funded hub-and-spoke FASD model solves precisely this problem. By providing a single, four-nation specialist tier that ICBs can commission against rather than build from scratch, the network gives the reformed ICBs a ready-made strategic commissioning offer for one of the most under-served neurodevelopmental populations in the country. The four hubs become the natural counterpart to a smaller number of larger ICBs; the twenty spokes give every regional ICB footprint a local specialist resource it can refer into. The network also gives ICBs the evidence base — through the registry and the surveillance function — that the new strategic-commissioner role requires them to act on (NHS England, 2025b).

This matters for the financial logic too. The Strategic Commissioning Framework published by NHS England in 2025 makes clear that ICBs are now expected to focus on commissioning value rather than service delivery, and to demonstrate population-health return on investment for the populations they serve (NHS England, 2025b). A network with a documented 3.56-to-1 lifetime BCR, four-nation coverage, and a built-in evaluation function is exactly the kind of investment the reformed commissioning system is being designed to identify, fund, and scale.

How the model fits Core20PLUS5 and the inequalities agenda

FASD sits squarely within the Core20PLUS5 framework for children and young people, which identifies PLUS population groups including ethnic minority communities, inclusion health groups, people with a learning disability and autistic people, and protected characteristic groups as priorities for healthcare-inequalities improvement (NHS England, n.d.). FASD is over-represented in three of these PLUS groups in particular: in looked-after and adopted children, where prevalence estimates run an order of magnitude above the general population (DHSC, 2021); in inclusion health groups, particularly those experiencing the consequences of intergenerational alcohol harm; and in the learning-disability and neurodevelopmental population, which Core20PLUS5 names explicitly.

A recent BMJ Open content analysis of ICB joint forward plans found that, while alignment with Core20PLUS5 was generally evident, there was significant variation in how plans addressed inclusion health groups, particularly people with learning disabilities and autism (Stewart et al., 2025). FASD has, to date, been largely absent from those plans — not because the population is small, but because the data, the workforce, and the specialist pathway have all been missing. The hub-and-spoke network, combined with the registry and surveillance function the 0.25% ask would fund, would for the first time make FASD a population that ICBs can see, commission for, and report against under the Core20PLUS5 framework.

What “invest to save” means at three levels of the system in England

National (Department of Health and Social Care, NHS England)

At the national level, FASD prevention is structurally aligned with the three radical shifts in the 10 Year Health Plan for England — hospital to community, analogue to digital, and sickness to prevention (NHS England, 2025; Department of Health and Social Care, 2025). The FASD PRP’s framing of prevention as the system’s organising principle is the single most consequential opportunity to embed FASD into mainstream NHS commissioning since the publication of the DHSC Health Needs Assessment for FASD (Department of Health and Social Care, 2021). National investment of £10–15 million per year in FASD prevention would, on the modelling above, avert between 300 and 700 cases per annual birth cohort, generating lifetime savings of £110–£250 million in present value — a return that exceeds the threshold for any NICE-appraised intervention.

Regional (Integrated Care Systems and NHS regions)

Regionally, the 26 Integrated Care Systems (ICSs) in England are the natural commissioning unit for FASD diagnostic pathways and Alcohol Care Teams. The NHS Long Term Plan committed to rolling out Alcohol Care Teams to the 25% worst-affected hospital trusts by 2024 (NHS England, 2019), preventing an estimated 50,000 admissions and 250,000 bed days. While this would only reach a small subset of families impacted by FASD, embedding FASD diagnostic capability within these teams — at marginal cost — would deliver the early-diagnosis dividend identified by the Royal College of General Practitioners (Mukherjee, 2025) and the SIGN 156 guideline (Scottish Intercollegiate Guidelines Network, 2019).

> Each ICS that doubles its FASD diagnosis rate from 10% toward 20% would reduce its undiagnosed-case premium by approximately £5–10 million in lifetime cost per annual cohort — a result that more than pays for the diagnostic pathway it requires. However, most children with FASD are not born to alcohol-dependent mothers, so commissioning must extend beyond Alcohol Care Teams.

Local (Local Authorities and Local Maternity & Neonatal Systems)

Locally, the OHID Maternity High Impact Area on reducing the incidence of harms caused by alcohol in pregnancy (Public Health England, 2020; reissued by OHID, 2023) provides the operational specification: routine alcohol identification and brief advice in mandatory midwifery training, AUDIT C (which National FASD believes should be adapted in line with CMOs’ guidance) screening at every antenatal appointment, FASD awareness in the Healthy Child Programme, and community-based programmes such as those in Better Start sites. NICE Quality Standard QS204 (NICE, 2022) reinforces this with two specific quality statements requiring discussion of alcohol consumption at every antenatal appointment and provision of advice (including written materials) consistent with the UK Chief Medical Officers' low-risk drinking guidelines (Department of Health, 2016). Local authority public health teams operate on the tightest budgets in the system; an evidence-based local FASD prevention programme using an adapted AUDIT-C plus brief intervention costs approximately £150,000–£250,000 per year for a 50,000-population area, against which preventing a single case returns the entire investment.

Health and innovation and improvement networks (England)

Health innovation and improvement networks across the four nations (including the 15 Health Innovation Networks in England)" rather than implying one identical network exists everywhere can act as the delivery engine for a national FASD Prevention and Response model, using existing structures rather than creating new bureaucracy. They are well placed to spread consistent, evidence-based practice across maternity, primary care and neurodevelopmental pathways, supporting universal, routine alcohol enquiry in pregnancy and wider prevention activity. By providing shared training, implementation support and real-world evaluation, these networks can help local systems embed FASD into neurodevelopmental and maternity pathways, link health with education and social care, and demonstrate "invest-to-save" benefits over time. This means that a small, stable stream of funding linked to alcohol duty can be translated into practical change on the ground, with health improvement networks coordinating regional roll-out, supporting workforce development, and feeding learning back into the national FASD hub so that the model remains genuinely holistic rather than focused only on diagnosis.

Ties to the I-Thrive model (England)

I-Thrive is an England-wide mental health system-change framework and programme**.** FASD could be embedded within local i-THRIVE implementation as a cross-cutting neurodevelopmental need, with prevention and early advice reflected in the *Thriving* and *Getting Advice and Signposting* groupings, tailored interventions and specialist input available through *Getting Help* and *Getting More Help*, and coordinated multi-agency planning for those with complex vulnerability under *Getting Risk Support*. Within an i-THRIVE model, FASD could be embedded across the whole pathway rather than located only in specialist assessment services. In the Thriving and Getting Advice and Signposting groupings, this would include alcohol-in-pregnancy prevention, accessible information for families, and FASD-informed support in universal services such as maternity care, health visiting, schools and primary care (Wolpert et al., 2019; National i-THRIVE Programme, n.d.). In Getting Help and Getting More Help, FASD could sit within local neurodevelopmental and mental health pathways through adapted parenting support, formulation-led interventions, consultation to schools and carers, and access to specialist assessment or diagnostic hubs where needed (Wolpert et al., 2019; National FASD, 2022). In Getting Risk Support, children and young people with FASD who are at risk of exclusion, placement breakdown, exploitation, offending or crisis presentation could receive coordinated, multi-agency planning that recognises the interaction between neurodevelopmental vulnerability, trauma and environmental adversity (National i-THRIVE Programme, n.d.) While this would support FASD integration into broader neurodevelopmental pathways, provided there must be clear guidance, workforce capability and explicit recognition of the additional adjustments and supports that children, young people and families may require (National FASD, 2022; NICE, 2022).

Scotland – how the FASD PRP fits with existing services

Unlike other parts of the UK, Scotland embeds FASD within a broader neurodevelopmental (ND) approach rather than treating it as a stand-alone condition. National guidance and training emphasise that FASD should be recognised within multidisciplinary ND pathways, and Scottish Government funding has supported both specialist training and family support through resources such as FAAST(Fetal Alcohol Advisory Support Team) and FASD Hub Scotland (FAAST, 2025; Scottish Government, 2020; Scottish Government, 2026). This gets two things right: it frames FASD as a core neurodevelopmental issue rather than a niche diagnosis, and it recognises that diagnosis alone is not enough without practical support for families and the wider workforce.

However neurodevelopmental pathways vary across areas, FASD can be diluted within broader ND systems, and specialist expertise remains unevenly distributed despite the national policy steer (Children's Neurodevelopmental Pathway, 2021; Scottish Parliament Information Centre, 2025; Plant, 2025).

The FASD Prevention and Response Programme — better described in Scottish system terms as a national specialist function with linked local ND pathways and outreach as opposed to a "hub and spoke model" — could add value by supplementing the existing approach with a more explicit, whole-system model that connects specialist expertise to local delivery.

In Scotland, the national specialist function would strengthen the neurodevelopmental pathway by providing national leadership on prevention, diagnostic quality, workforce development, consultation for complex cases, family advice and support, data improvement, and research and evaluation. (This could be through expanding the current FAAST team, for example.) Additional FASD expertise could be made available in other areas by establishing FASD centres where the local ND service engages explicitly with maternity pathways, community paediatrics, CAMHS, education, social work and third sector supports, to work on research, surveillance, the database/registry, supportive VSCEs, etc. (FAAST, 2025; FASD Hub Scotland, n.d.; NHS Lanarkshire, 2024).

This aligns with the direction of wider Scottish reform. Recent Scottish Government investment in neurodevelopmental support has explicitly backed holistic models, family support, digital tools, and hub-based approaches that bring together health, education and third sector input, while stressing that diagnosis is only one part of the support families need (Scottish Government, 2026). A dedicated share of funding equivalent to around 0.25% of alcohol duty revenues could therefore be used not to replace Scotland's current ND model, but to deepen and extend it: expanding specialist FASD consultation into ND pathways, supporting local outreach and family navigation, improving workforce capability, strengthening prevention in maternity and public health, and ensuring more consistent access to high-quality support across all areas. The proposed model is not simply about diagnosis; it is about creating a rounded national FASD prevention and response system that fits Scotland's existing structures while making them work better for children, families and services.

How the model might look in Wales and Northern Ireland

These two nations would choose one of the models – hub and spoke or national/ regional centres, and the model would be adapted for each nation. We did not develop this further for this report as that would come out in further discussions and national consultations and the model has been described in prior sections.

How the FASD PRP model fits wider policy goals

The case extends beyond NHS reforms.

In special educational needs, the Institute for Fiscal Studies has documented that the high-needs block in England now exceeds £11 billion, with cumulative local authority deficits projected to reach over £8 billion by 2027 (Sibieta and Snape, 2024). Independent special school placements — disproportionately used by young people with complex, undiagnosed neurodevelopmental presentations, of which FASD is a leading example — cost £61,500 per pupil per year against £23,900 in state-funded special provision (Sibieta and Snape, 2024). A small reduction in placement intensity for the FASD cohort alone would justify the entire network cost several times over.

In maternity safety, the network's prevention work supports wider commitment to reducing avoidable maternal and infant harm. The Chief Medical Officers' guidance on alcohol in pregnancy is unambiguous — no alcohol is the safest option — but implementation has been variable (Mukherjee et al., 2025). The training function gives every maternity service in the UK access to consistent, evidence-based antenatal advice and consistent recording of prenatal alcohol exposure.

In justice, the over-representation of people with FASD in the youth justice and adult prison populations is one of the most striking and least addressed findings in the UK criminal justice evidence base (DHSC, 2021). The network's diagnostic and post-diagnostic support reduces secondary disability — the cluster of school exclusion, mental ill-health, substance misuse, and contact with the justice system that follows undiagnosed FASD into adolescence and adulthood. The Ministry of Justice has no specific FASD pathway; the network would give it one to refer into.

In devolved policy, the four-nation design of the network — with dedicated hubs in Scotland, Wales, and Northern Ireland alongside England — respects the constitutional reality that health is a devolved competence. The Scottish Government has already invested in FASD prevention and clinical infrastructure (Scottish Government, 2020); the network builds on that work and gives Wales and Northern Ireland equivalent capacity for the first time.

Implementation route

The proposed allocation can be implemented without primary legislation. Two routes are available. First, the Chancellor can include a 0.25% Alcohol Duty Health Allocation as a Budget measure, with proceeds transferred to a ringfenced DHSC FASD Programme Budget administered jointly with NHS England, the Office for Health Improvement and Disparities, and equivalent bodies in the devolved nations. Second, the same outcome can be achieved through the existing Alcohol Duty Reform machinery (HM Treasury, 2024), under which a small share of duty is already directed to public health initiatives. Either route is administratively light and politically uncontroversial: it does not raise duty rates, it does not create a new tax, and it does not require renegotiation of the alcohol industry's fiscal relationship with the Treasury.

In both cases, this creates a UK-level spending decision on health/public health, which then triggers devolved funding changes.

How the devolved nations get their share

For Scotland, Wales and Northern Ireland, additional money would flow via the block grants using the Barnett formula, not by earmarking duty directly:

- The UK government increases DHSC’s DEL (or creates a specific UK-level FASD/public health line) for England.
- Because health and public health are devolved, this counts as an increase in “comparable spending” in England, which generates Barnett consequentials for the three devolved governments.
- The Barnett formula takes the change in the relevant English programme, multiplies it by a comparability factor and the devolved country’s share of the English population, and adds that to each nation’s block grant.

Integrating lived experience & co-production

The proposed FASD Prevention and Response Programme are built on evidence — but the evidence that matters most, and that is most routinely absent from health and care commissioning decisions, is the evidence held by people with FASD themselves, and by the parents and carers who have navigated failing systems on their behalf. The UK FASD Manifesto could not be plainer: *"We are sick of people saying they understand, or that they are trying to help, but they do nothing"* (National FASD, 2023). If this programme is to fulfil its stated aims, it must be designed, governed, and continuously improved with people with FASD and their families as genuine co-production partners — not consulted after key decisions have been made, but involved from the outset in shaping what is built, how it works, and whether it is working.

This is not simply an ethical commitment. The National Institute for Health and Care Research (NIHR) distinguishes involvement — research and programme design done *with or by* patients and the public, not *to, about, or for* them — from engagement and participation, and requires meaningful involvement as a condition of funding (NIHR, 2024). The ERA-NET NEURON framework for neurodevelopmental research similarly specifies that applicants must engage patients, their parents, or carers in the research process at the levels of planning, conduct, and dissemination (ERA-NET NEURON, 2023). For FASD, this standard is especially important because the condition's cognitive profile — including difficulties with executive functioning, memory, processing speed, and self-advocacy — means that conventional PPI approaches, designed for neurotypical participants, will systematically exclude the very people they are intended to include unless deliberate adaptations are made (Flannigan et al., 2024; Wrap2FASD Research Group, 2024).

Lived Experience and co-production in the FASD PRP

Each national centre should have a formal Lived Experience Advisory Panel (LEAP) comprising people with FASD, birth, adoptive, kinship and foster families, with proportionate paid representation. The LEAP should hold a standing role in reviewing the centre's diagnostic protocols, evaluating the post-diagnostic support offer, co-producing accessible information resources, and contributing to annual quality reporting. It should not be constituted as a token consultation group: members should have defined terms of reference, receive appropriate remuneration at NIHR recommended rates, and be supported to participate through accessible meeting formats, plain-language materials, advance preparation time, and a named support worker where required (NIHR Oxford BRC, 2019; West Yorkshire Partnership, 2022). The practical reality is that attending a clinical governance meeting is not accessible to many people with FASD without active facilitation — and failing to provide it is not inclusion, it is the appearance of inclusion.

At regional (spoke) level, lived experience integration should be structural rather than advisory: each centre should employ or commission at least one FASD peer support worker — an individual with lived experience of FASD, either personally or as a close family member — whose role is to support newly diagnosed adults and children's families through the post-diagnostic period, and to feedback service-user experience to the centre's clinical team and the regional hub on a regular basis. Peer support of this kind is not a soft add-on: evidence from neurodevelopmental and mental health services consistently shows that peer workers improve engagement, reduce dropout, and increase the likelihood that individuals act on clinical advice, precisely because they provide the relational trust that formal clinical relationships cannot always replicate (MQ Mental Health Research, 2026; West Yorkshire Partnership, 2022).

PPI as a condition of funded projects

All research, service development, and innovation projects funded through the FASD Prevention and Response Fund should be required to demonstrate meaningful Patient and Public Involvement and Engagement (PPIE) as a condition of award — not as a box-tick statement in a grant application, but as a funded, costed, and evaluated component of the project itself (NIHR Oxford BRC, 2019; British Heart Foundation, n.d.). This means:

Budgeting explicitly for PPIE at the application stage, including payment of lived-experience contributors at NIHR recommended rates, travel and access costs, support worker time where needed, and accessible materials preparation (NIHR Oxford BRC, 2019).

Involving people with FASD and families at the earliest stage — in defining research questions, selecting outcome measures, and reviewing protocols — not only in dissemination (ERA-NET NEURON, 2023).

Adapting involvement methods to the specific cognitive profile of FASD: shorter meetings, written agendas in advance, visual summaries, the option of asynchronous contribution (written or video responses in participants' own time), and plain-language versions of all materials. Where participants have significant executive functioning difficulties, one-to-one pre-meeting preparation with a trusted facilitator should be offered as standard (Wrap2FASD Research Group, 2024; Bryant et al., 2024).

Closing the feedback loop: contributors should always be told how their input shaped decisions. The failure to close this loop is one of the most commonly cited reasons that people with lived experience disengage from research and advisory processes (BHF, n.d.; MQ Mental Health Research, 2026).

Enabling co-applicant status for lived-experience contributors on research grants, where appropriate, ensuring they share decision-making authority rather than serving only in an advisory capacity (NIHR Oxford BRC, 2019).

Supporting people with FASD to participate

The single most important practical point is this: lived experience involvement that does not provide adequate support is not true, accessible co-production — it is exclusion by design. People with FASD vary enormously in their capacity and confidence for formal advisory roles; some are highly capable self-advocates, others will need significant facilitation. Neither group should be left out. The national programme should fund a dedicated FASD Lived Experience Participation Coordinator within the central data and governance infrastructure — a role responsible for recruiting, training, supporting, and connecting lived-experience contributors across the PRP, and funded research projects, and for producing annual reporting on how lived-experience input has shaped the programme (National FASD, 2026; ERA-NET NEURON, 2023). This role is not a luxury; it is the mechanism by which the commitment to lived-experience partnership is operationalised rather than aspirational.

Parents and carers — the majority of whom are raising children with FASD without diagnosis, without understanding, and without meaningful support (National FASD, 2025) — must be included as a distinct constituency in their own right. Their experience of navigating health, education, social care, and justice systems is irreplaceable intelligence for service design. Carer-specific PPI streams, parent forums linked to services, and online participation options that accommodate the time constraints of full-time caring should all be built into the programme from Year 1 (Flannigan et al., 2024; National FASD, 2025). The evidence is consistent: when families are heard and their expertise is acted on, the interventions that follow are more relevant, more trusted, and more effective (West Yorkshire Partnership, 2022; NCBI, 2012).

What the proposed changes will mean for adults with FASD

The next five years: reaching those the system has already failed

The honest starting point is that the five-year programme will not transform the lives of adults with FASD immediately — and any account that suggests otherwise would be misleading. The FASD PRP network reaches a cumulative cohort of 10,400 children, young people, and adults in its first five years, ramping from 400 new cases per year in Year 1 to 3,200 per year from Year 4 onward. Within that cohort, adults — including those in contact with mental health services, the justice system, supported housing, or employment support programmes — are an explicit priority group, precisely because they represent the population for whom the cost of inaction is already fully realised. For these individuals, the near-term benefits of the programme are concrete and reachable. Access to a funded multidisciplinary diagnostic pathway — rather than a postcode lottery in which most adults are currently turned away — provides an explanatory framework that reduces self-blame, triggers entitlement to reasonable adjustments under the Equality Act 2010, supports benefits claims and advocacy, and opens access to post-diagnostic support including FASD-informed mentoring, structured vocational guidance, and family coordination (Department of Health and Social Care [DHSC], 2021; Kapasi et al., 2019; National FASD, 2021). The lived-experience testimony gathered by National FASD is unambiguous on what adults are asking for: not more leaflets, but practical, ongoing, coordinated support — and the recognition that their difficulties are real, lifelong, and organic rather than volitional. The five-year programme creates, for the first time, a funded infrastructure to deliver precisely that — through 20 regional centres (spoke) services embedded in adult mental health, neurodevelopmental, and community pathways, each carrying grants to voluntary sector organisations that provide the day-to-day peer support and lived-experience advocacy that clinical services alone cannot replicate).

The long term: a generation entering adulthood differently

It is important to note this period as someone enters adulthood could be particularly overwhelming and confusing for those who have not been diagnosed; who are unaware that they have the condition and so cannot themselves seek the support they need. This is exacerbated by the fact that the condition can be truly invisible for those not aware of the condition. If a National FASD

Prevention and Response programme was in place, this should be flagged well before they reach this critical stage and support put in place.

The transformative case for investment compounds over decades. The report's financial model is deliberately honest: in-year avoided costs are modest in the early years precisely because the greatest benefits of early diagnosis and prevention accrue not in childhood but across the working life of those supported. Children diagnosed through the network in Years 1 to 5 — identified in mainstream schools, LAC health reviews, or antenatal pathways rather than at crisis point in adolescence — will enter adulthood with something their predecessors did not have: a named, understood disability; an EHCP or equivalent that reflects their actual neurodevelopmental profile; a family and professional network that knows how to support them; and, where appropriate, an employment or further education pathway with adjustments in place (DHSC, 2021; Flannigan et al., 2022; National FASD, 2022). The evidence from comparable neurodevelopmental conditions is clear that earlier identification, combined with FASD-informed educational support and transition planning, is associated with better post-school outcomes — fewer secondary disabilities, lower rates of mental health crisis, and greater likelihood of sustained employment or supported living (Kapasi et al., 2019). As prevention also takes effect — through universal antenatal alcohol screening and brief intervention embedded across all four nations — the proportion of each birth cohort affected by FASD will, over time, begin to fall, meaning that each successive generation entering adulthood will carry a smaller number of those who are undiagnosed (Purshouse et al., 2013; Proof Alliance, 2025). The lifetime benefit-cost ratio of 3.56:1 is not a description of what happens in five years; it is a description of what happens to the children supported in those five years as they move through adolescence, adulthood, and into later life — a trajectory that, under the current system, too often ends in crisis, custody, or permanent welfare dependency, and under the proposed system need not.

The bottom line - 0.25% is feasible – and the right thing to do

Benchmarking 0.25% of alcohol duty receipts for an FASD Prevention and Response Fund — £31 - £32 million per year — is a fraction of the £9.25 billion annual societal cost of FASD. It is also a fraction of one percent of the £12.6 billion in receipts already collected from the product whose most serious preventable harm this fund addresses. The fiscal precedent is established (Soft Drinks Industry Levy); the polluter-pays logic is direct; and the envelope is sized to deliver a fully-costed programme with headroom to absorb realistic variation.

The case for action is not whether the UK can afford a national FASD programme. The figures in this brief make clear it is the case that the UK cannot afford to continue without one.

For 0.25% of UK alcohol duty receipts — approximately £31 million a year, against a duty base of £12.65 billion (HMRC, 2025) — the United Kingdom can fund:

- A four-nation FASD Prevention and Response Programme -including a clinical network supporting a cumulative cohort of 10,400 children, young people and adults within five years in partnership with local peer support groups.
- A National FASD Linked Database/Registry that, for the first time, makes the condition visible in routine NHS data.
- A UK-wide FASD prevalence study that closes the largest evidence gap identified by the DHSC Health Needs Assessment.

- An NIHR-aligned standing research fund that turns UK research excellence into commissionable practice.
- A sentinel surveillance and data linkage function that supports the analogue-to-digital shift in the NHS.
- An independent evaluation that gives HM Treasury a real-time audit of the Invest-to-Save case.

The total five-year programme cost is £106.0 million, against a five-year envelope of £157.5 million, with £49.6 million in present-value headroom. The lifetime present-value avoided costs are £236.7 million. The lifetime benefit-cost ratio is 3.56 to 1. The model is fully aligned with the three shifts of the 10 Year Health Plan, with the strategic-commissioner role of the reformed ICBs, with the Core20PLUS5 inequalities framework, and with the SEND, maternity, and justice priorities of the wider government policy programme.

This is not a request for new money. It is a request for a fractional, ring-fenced stable, recurring DEL funding line benchmarked to be 0.25% of duty - a tax base that already exists, applied to a population that is already costing the Exchequer £9.25 billion a year. The cost of inaction has been quantified in the chapters that precede this one. The cost of action — and the return on it — is set out here.

The case is made. The decision is now a political one.

CONCLUSION

The Cost of Inaction

Seven practical next steps — the only thing missing is political will.

AT A GLANCE · CONCLUSION

The Cost of Inaction on FASD

> *"Can you live with the cost of your inaction? More than 50 years after the first FASD diagnoses, decades behind some similar countries, it is time to step up and have lasting generational impact."*
>
> **— Sandra Butcher, Chief Executive, National Organisation for FASD**

The evidence is unambiguous. The guidance exists. The legal duties are engaged. The return on investment is among the strongest in UK public health. The only thing standing between where the UK is now and where it needs to be is **political will** — and a four-nation response is both feasible and affordable.

1.4–2.8m
people in the UK have FASD — **most undiagnosed**

£9.2bn
estimated **annual cost** of inaction to the UK

3.56 : 1
lifetime **benefit–cost ratio** of the proposed programme

£31–32m
a year from **0.25% of alcohol duty** — no new tax or law

Six priority next steps — sequenced by feasibility, cost and return

Most require no new legislation and can begin within the current parliamentary and commissioning cycles.

1. **FASD impact assessments**
Require explicit FASD impact assessment in every current reform — highest return, lowest cost, removes legal exposure.
2. **Embed FASD in SEND frameworks**
Name FASD in the SEND Code of Practice and education guidance across all four nations.
3. **Strengthen prevention**
Systematic antenatal alcohol enquiry plus a national alcohol-in-pregnancy campaign at the scale of smoking campaigns.
4. **Start the programme now**
Commission FASD diagnostic pathways using existing budgets, building on proven national clinics.
5. **The 0.25% Fund**
Establish an FASD Prevention and Response Fund benchmarked at 0.25% of alcohol duty — the central ask.
6. **Build the evidence base**
Fund a UK prevalence study, a national FASD registry and an NIHR-aligned research stream.

A four-nation response is possible

Each government acts within its own competence while contributing to a shared UK framework — consistent with established practice.

ENGLAND **SCOTLAND** **WALES** **NORTHERN IRELAND**

- Each nation publishes its own consultation or discussion paper on FASD.
- Findings synthesised into a shared UK Prevention and Response Framework.
- England via a dedicated Green Paper on alcohol, pregnancy and FASD.
- Precedents: vaping regulation and post-Brexit Common Frameworks.

The cost of inaction is a choice — so is the cost of action

For a rounding error on alcohol duty, the UK can turn existing guidance into routine practice across all four nations, prevent foreseeable harm, and match the FASD investment of comparable countries. It requires no new tax and no new legislation — only the will to act.

Sources: NICE QS204; SIGN 156; DHSC FASD Health Needs Assessment (2021); PHE Maternity High Impact framework; HM Treasury alcohol duty receipts; National FASD "Not Commissioned" report (2024); Institute for Government (2023); National FASD programme model (Appendix E).

From: The Cost of Inaction on FASD (June 2026), Section 5: Conclusion. The programme model is an illustrative proof of concept — details to be agreed via four-nation consultation.

Section 5: Conclusion: The Cost of Inaction on FASD

> *"Can you live with the cost of your inaction? What would you be doing if it was your own loved one's future at risk? More than 50 years after the first FASD diagnoses, decades behind some similar countries, it is time to step up and have lasting generational impact."*
> *— Sandra Butcher, Chief Executive, National Organisation for FASD*

The evidence assembled in this report is unambiguous. FASD affects an estimated 2–4% of the UK population — between 1.4 and 2.8 million people, the overwhelming majority undiagnosed. It costs the UK an estimated £9.2 billion annually. The guidance exists — in NICE Quality Standard 204, SIGN 156, the DHSC Health Needs Assessment, and PHE's Maternity High Impact framework among other documents across the four nations — but it is not being implemented The legal duties are engaged. The return on investment is among the strongest in UK public health: a 3.56:1 lifetime benefit-cost ratio. The delivery vehicle — a FASD Prevention and Response Fund benchmarked at 0.25% alcohol duty generating approximately £31-32 million per year — requires no new legislation and no new tax rates .

The only thing standing between where the UK is now and where it needs to be is political will.

A four-nation response is possible

It is time for action. A four-nation response to FASD is both constitutionally feasible and consistent with established UK policy practice. Devolution allows Scotland, Wales and Northern Ireland to develop policy in areas such as health, education, social care and public health, while the UK Government retains responsibility for England and for reserved matters such as macro-fiscal policy. In practice, this means each government can consult and act within its own competence while still contributing to a shared UK-wide framework (HM Government, 2015; HM Government, 2016; Institute for Government, 2023).

Each government should publish its own consultation or discussion paper on FASD, framed around a shared set of core questions and supported by a common evidence base.

In practical terms, this could work in three stages.

1. The UK Government, Scottish Government, Welsh Government and Northern Ireland Executive would jointly establish a four-nations officials' group on FASD, with responsibility for agreeing the consultation scope, timetable, evidence base and common analytical questions.
2. Each government would run its own consultation process within its devolved responsibilities, enabling it to test policy options relevant to its own institutions, service model and legal context. In England, this should take the form of a dedicated Green Paper on alcohol, pregnancy and FASD, followed by full public consultation. In Scotland, Wales and Northern Ireland, equivalent government-led consultation and strategy processes should be launched to develop nation-specific FASD Prevention and Response plans, aligned with each nation's health and disability policy frameworks.
3. The four governments could synthesise the consultation findings into a shared UK FASD Prevention and Response Framework or concordat, setting common principles, minimum standards and reporting expectations, while allowing each nation to tailor delivery,

commissioning and funding arrangements to local circumstances (Civil Service, 2016; HM Government, 2016; Institute for Government, 2023; Welsh Government, n.d.).

This approach fits with established practice. Devolution guidance already expects governments to engage one another where policy proposals have implications across devolved and reserved boundaries, and the post-Brexit Common Frameworks demonstrate that the four governments can agree shared approaches in areas of intersecting competence while retaining separate decision-making powers (Food Standards Agency, n.d.; HM Government, 2015; HM Government, 2016).

Recent examples show that this kind of coordination can happen

In 2023, the UK Government and devolved administrations worked on a joint approach to vaping regulation, using consultation and policy coordination to pursue broadly aligned outcomes across the UK despite devolved responsibilities (Horsley, 2023). Likewise, the Four Nations Policy Leads Group in research governance provides an example of the four health systems agreeing UK-wide policy and standards while implementation remains rooted in each nation’s structures (Health Research Authority, 2023). Broader public health analysis has also shown that the four UK nations frequently pursue different operational models within devolved systems while learning from one another and working toward common goals (Civil Service, 2016; Association of Directors of Public Health, 2018).

For FASD Prevention and Response, this model offers three advantages. It respects devolution by allowing each nation to develop proposals suited to its own institutional and service context; it strengthens the evidence base by generating comparable consultation findings across the UK; and it creates a credible route to UK-wide coherence without requiring identical systems or legislation in all four nations (Civil Service, 2016; HM Government, 2016; Institute for Government, 2023).

AT A GLANCE · FOUR-NATION PROCESS

A four-nation response to FASD

Constitutionally feasible within UK devolution

A shared evidence base and core question set, synchronous consultations across the four nations, and a shared UK Prevention and Response Framework — within existing devolution.

4
nations,
England, Scotland, Wales, NI

4
practical
stages of work

1
shared
evidence base & question set

0
new legislation
needed to start

The four-stage process

Joint scope → parallel consultations → shared UK framework → national strategies & ongoing dialogue.

1 Convene
four-nations officials' group
UK Government, Scottish Government, Welsh Government and NI Executive jointly agree the consultation scope, timetable, evidence base and common analytical questions.

2 Consult
synchronously, in each nation
England: Green Paper on FASD Prevention and Response, followed by full public consultation. Scotland, Wales and NI: equivalent government-led consultations to develop nation-specific plans.

3 Synthesise
into a shared UK framework
Findings synthesised into a shared UK FASD Prevention and Response Framework or concordat — common principles, minimum standards, devolved delivery.

4 Decide
+ ongoing dialogue
National strategies / White Papers (or equivalents) in each nation, supported by ongoing four-nation dialogue and shared reporting against the framework.

Co-production runs through every stage

People with FASD, their families and other stakeholders — partners in scoping, consulting, framework design and decisions.

Scoping — question set · **Consulting — in each nation** · **Synthesising — the framework** · **Deciding — next steps**

Stage 2 in detail — each government, within its devolved responsibilities

England
Green Paper on FASD Prevention and Response
- Green Paper, followed by full public consultation
- Ministerial champion + unit

Scotland
Govt-led consultation
- Nation-specific FASD Prevention & Response plan
- Aligned with Scottish health & disability policy
- Ministerial champion + unit

Wales
Govt-led consultation
- Nation-specific FASD Prevention & Response plan
- Aligned with Welsh health & disability policy
- Ministerial champion + unit

Northern Ireland
Executive-led consultation
- Nation-specific FASD Prevention & Response plan
- Aligned with NI health & disability policy
- Ministerial champion + unit

What is shared, and what is devolved

Shared across all four nations
- Core consultation question set & evidence base
- Synchronous consultation timetable
- Co-production with people with FASD, families and other stakeholders
- Synthesis into a shared UK Framework / concordat

Devolved to each administration
- Document format and consultation mechanism
- Legislative, policy and service-delivery framing
- Local response analysis and engagement design
- Ministerial champion, delivery unit and targets
- Delivery, commissioning and funding arrangements

Achievable now — respects devolution, accelerates alignment

Four stages, one shared evidence base — no new legislation required to begin.
Builds on Common Frameworks and recent four-nation work (e.g. vaping; research governance).
Co-produced with people with FASD, their families and stakeholders throughout.
Ends in national strategies / White Papers and ongoing four-nation dialogue against the shared framework.

Sources: HM Government (2015, 2016); Civil Service (2016); Institute for Government (2023); Food Standards Agency (n.d.); Welsh Government (n.d.); Horsley (2023); Health Research Authority (2023); ADPH (2018); National Organisation for FASD (2025).
From: The Cost of Inaction on FASD (June 2026), Section 2 — A four-nation response is possible.

NATIONAL ORGANISATION FOR FASD · **nationalfasd.org.uk**

Priority next steps — sequenced by feasibility, cost and return

What follows sets out the priority next steps sequenced by feasibility, cost, and likely return — followed by specific actions for each of the key stakeholder groups who have the power to change trajectories.

Step 1 — Mandate FASD impact Assessments for All Current Reform Programmes

Implementation vehicle: Administrative direction — no legislation required. Deliverable within current parliamentary session.

This is the highest-return, lowest-cost action available to government. Every major reform currently underway — the independent review into mental health, ADHD and autism; SEND reform; the Youth Justice White Paper *Cutting Youth Crime, Changing Young Lives*; changes to PIP and disability benefits; the Adoption and Special Guardianship Support Fund review; and children's social care reform — has the potential to cause foreseeable, measurable harm to people with FASD if FASD is not explicitly included in impact assessment . Ministers across DHSC, DfE, the Ministry of Justice, and DWP should be directed to require their policy teams to conduct explicit FASD impact assessments for each of these programmes, drawing on the prevalence, cost, and overlap evidence in this report. This costs nothing, requires no new structures, and removes the most immediate legal risk of discrimination and systemic exclusion.

Likely return: Prevents active harm. Removes legal exposure under the Equality Act 2010 and the Human Rights Act across multiple departments simultaneously.

Step 2 — Embed FASD in the SEND Code of Practice and education frameworks across all four nations

Implementation vehicle: Statutory guidance revision — no primary legislation required. Can be enacted through a DfE/Welsh Government/Scottish Government/Northern Ireland Education Authority guidance update.

FASD is already covered by the legal architecture of the SEND Code of Practice, Wales's Additional Learning Needs Act and Northern Ireland's SEN framework — but none of these documents names FASD explicitly. A guidance revision naming FASD as a condition requiring recognition within neurodevelopmental assessment, EHCP eligibility, and behaviour and exclusion policy would cost little and immediately change how children are identified, assessed, and supported. (Scotland's coming Learning Disabilities, Autism and Neurodivergence Bill should be reviewed to ensure it spotlights FASD on par with other conditions such as autism.) This should be combined with the revision of the Relationships, Sex and Health Education (RSHE) curriculum to include age-appropriate content on alcohol and pregnancy, providing the prevention infrastructure that keeps the next cohort of children out of the education system's highest-cost placements.

Likely return: Reduces independent special school placements (averaging £61,500 per pupil per year against £23,900 in state provision), reduces exclusions, and reduces CAMHS referrals attributable to unrecognised FASD .

Step 3 — Strengthen alcohol-in-pregnancy prevention infrastructure

Implementation vehicle: NHS England commissioning direction and NICE implementation guidance — no legislation required.

Universal, consistent antenatal alcohol-history taking is mandated by SIGN 156 in Scotland and reinforced by NICE QS204, but implementation across maternity services in England, Wales, and Northern Ireland remains highly variable. Commissioners should be directed to embed systematic alcohol enquiry, accurate recording (using the three new FASD SNOMED CT codes introduced in 2024), and brief intervention as core components of antenatal care. This should be accompanied by a national public health campaigns on alcohol in pregnancy equivalent in reach to existing smoking-in-pregnancy campaigns — a direct, evidence-based, cost-effective prevention measure that no UK government has yet funded at scale. The precedent is clear: nations have responded to smoking in pregnancy with a sustained, well-resourced public health programme. Alcohol in pregnancy causes comparable and in many respects greater neurodevelopmental harm and has received a fraction of the prevention investment .

Likely return: Every case of FASD prevented saves up to £431,802 in lifetime costs. Even a marginal reduction in prevalence generates returns that dwarf the cost of the intervention many times over.

Step 4 — Begin implementing the FASD Prevention and Response Programme now, using existing foundations

Implementation vehicle: NHS England commissioning direction (England); Health Board commissioning decisions (Scotland, Wales, Northern Ireland) — no legislation required. Can begin within current commissioning cycles, ahead of the FASD Prevention and Response Fund being established.

The National FASD Clinic at Surrey and Borders Partnership NHS Foundation Trust has already demonstrated some of what a national hub/centre of excellence can do: delivering complex multidisciplinary FASD assessments, providing clinical leadership, training the wider workforce, and producing post-diagnostic management plans that reduce downstream crisis demand. That model — and the clinical expertise accumulated within it — provides the proof of concept and the practical foundation on which a full national FASD Prevention and Response Programme can now be built without starting from scratch. The Scottish FAAST team has expertise in national advice, training, and consultation. ICBs in England, and Health Boards in Scotland, Wales and Northern Ireland, should commission FASD diagnostic pathways ahead of the FASD Prevention and Response Fund being established, using existing neurodevelopmental and prevention budgets. Each national hub (one per nation, budgeted at £1.75 million per year) coordinates complex diagnostics, workforce training, prevention activity, post-diagnostic support, data contribution to the National Linked Database/ Registry, and clinical leadership. Regional centres/spokes (up to 20 across the UK, at £635,000 per year each) deliver multidisciplinary assessments for less complex presentations, local training and prevention, family-facing support including the SPECIFiC programme, and escalation routes to their national centre. The *Not Commissioned* report (National FASD, 2024) demonstrated through Freedom of Information requests that most ICBs have no FASD pathway whatsoever — commissioning action now, before the Fund is confirmed, closes that gap and establishes the local infrastructure through which Fund resources can subsequently flow.

Likely return: Reduces crisis-driven, high-cost downstream demand across CAMHS, acute mental health, social care, and justice. Generates the diagnosis-led benefit that drives the 3.56:1 BCR. Demonstrates delivery readiness to Treasury at the point the 0.25% ask is made.

Step 5 — Establish an FASD Prevention and Response Fund (the 0.25% ask)

Implementation vehicle: Establish a budget measure benchmarking a stable, recurrent FASD Prevention and Response Fund (or even a formal hypothecation) equivalent to 0.25% of existing alcohol duty receipts — no new legislation required. The Soft Drinks Industry Levy is the established UK legislative and fiscal precedent.

With £13 billion expected in alcohol duty receipts in 2025–26, a 0.25% allocation generates approximately £31-32 million per year — sufficient to fund four national hubs (one per nation), up to 20 regional centres/spokes, a National FASD Linked Database/Registry, a UK-wide prevalence study, an NIHR-aligned research fund, sentinel surveillance infrastructure, and independent evaluation: a total five-year programme cost of £106 million. This is the central ask of this report, and the one that makes all other steps sustainable and scalable. It requires no new tax rates and no new legislation — only a spending decision at the Budget direction at Spending Review. The same logical principle that underpins the Soft Drinks Industry Levy applies: the producer of the harm should fund the remedy.

Likely return: Delivers the full £9.2 billion annual cost reduction pathway. Creates the national infrastructure that turns existing guidance into routine practice across all four nations. Positions the UK on a par with comparable FASD investment in Canada, Australia, and the United States.

Step 6 — Build the national evidence base and data infrastructure

Implementation vehicle: NIHR commissioning direction; NHS Digital/NHS England data governance; DHSC cross-departmental data strategy — no legislation required.

The UK is currently a net consumer of FASD evidence, not a producer. The US NIH has invested over $600 million in FASD research since 1999; the UK has no equivalent dedicated funding stream. A UK-wide active case ascertainment prevalence study (budgeted at £7.2 million over five years), a National FASD Linked Database/Registry (£9.2 million), sentinel surveillance and data linkage (£2.9 million), and an NIHR-aligned research fund (£12 million) would, for the first time, give UK policymakers UK-specific data on prevalence, cost, and intervention effectiveness The 2024 introduction of three FASD SNOMED CT codes in primary care provides the coding infrastructure; this step funds the data system that makes those codes useful for commissioning and population health management. Weak data has been used for too long as a reason for inaction; better data must instead be treated as a core reform task.

Likely return: Converts data absence into a positive force for evidence-led investment. Enables the UK to lead, rather than follow, the international FASD field. Removes the most frequently cited objection to sustained policy commitment.

Step 7 — Embed people with FASD, families and FASD-informed professionals as partners in every stage

Implementation vehicle: Commissioning conditions, NIHR PPIE requirements, and programme governance design — no legislation required. Can be built into every step above from the outset.

Every step in this sequence will be more effective, more durable, and more equitable if people with FASD, their families and carers, and the professionals who support them are engaged as genuine partners — not consulted after decisions are made, but involved in shaping impact assessments, service design, commissioning specifications, research priorities, and programme governance. The evidence base underpinning this report is substantially built on lived-experience data gathered through National FASD surveys, the FASD UK Alliance, and years of testimony from families who have been failed by systems that did not understand FASD. That same community holds knowledge about what works, what is needed, and where current provision breaks down that no desk review can replicate.

Concretely, this means:

- **Impact assessments (Step 1):** People with FASD and family organisations must be consulted as a required input into each departmental FASD impact assessment, with accessible formats, compensation for participation, and a clear feedback loop.
- **Education and SEND reform (Step 2):** Children and young people with FASD, and the families who support them, should be represented in SEND reform consultation panels and in the co-design of revised guidance. National FASD's education survey evidence should be treated as primary source data, not anecdote.
- **FASD Prevention and Response Programme (PRP) network (Step 4):** Lived experience must be embedded in the governance structure of each national hub, with a lived-experience advisory group holding real decision-making power. The SPECIFiC programme and peer support models developed with people affected by FASD provide the template.
- **The FASD Prevention and Response Fund (Step 5):** The Fund's governance board should include representation from people with FASD, birth, adoptive, kinship and foster families, and VCSE organisations — not simply as beneficiaries but as accountable overseers of how it is spent and whether it delivers.
- **Research (Step 6):** All NIHR-funded FASD research should require funded, accessible, supported Patient and Public Involvement and Engagement (PPIE) from the point of grant application, with researchers required to demonstrate how they will address the specific participation barriers — executive functioning difficulties, sensory sensitivities, communication differences — that standard PPIE formats do not accommodate.
- **Professionals who support people with FASD:** The workforce of FASD-aware practitioners — specialist teachers, community paediatricians, educational psychologists, social workers, CAMHS clinicians, youth justice workers, and voluntary sector support workers — hold irreplaceable frontline knowledge that should be systematically captured through the national FASD Linked Database/ Registry and through implementation science evaluation.

Likely return: Programmes designed with lived experience are more likely to reach the people who need them, more likely to be sustained beyond initial funding cycles, and more likely to generate the trust required for community engagement to complement statutory provision. Co-production is not a cost — it is a quality multiplier across every other step.

What Each Stakeholder Can Do Now

For Policymakers and Legislators

The policy environment has never been more aligned with the need for FASD action — and more at risk of entrenching harm through FASD-blind reform. The following actions are available now, within current mandates, without primary legislation:

- **Immediately:** Direct all major reform teams (SEND, mental health review, youth justice, disability benefits, adoption, care, homelessness, etc) to conduct explicit FASD impact assessments before final policy positions are determined.
- **Short term (within 6 months):** Issue a joint ministerial statement confirming that FASD is within the scope of current neurodevelopmental and SEND reform programmes across all four nations.
- **Budget cycle:** Champion a 0.25% allocation of alcohol duty receipts as the FASD Prevention and Response Fund — framed as an invest-to-save measure consistent with the NHS 10 Year Plan's shift from sickness to prevention, the *Get Britain Working* workforce agenda, and the government's commitment to reducing long-term welfare dependency.
- **Legislative programme:** Each government — UK Government (for England), Scottish Government, Welsh Government and the Northern Ireland Executive — should undertake its own public consultation or discussion paper on FASD within its devolved responsibilities, coordinated through a four-nations officials' group and supported by a shared evidence review. The resulting national consultations should then be synthesised into a common UK FASD Prevention and Response framework, setting shared principles and minimum standards while allowing each nation to tailor delivery and funding to local context.
- **Ministerial champion and delivery units:** Each nation should identify a ministerial champion for the FASD Prevention and Response Programme, with a small delivery unit and a tight delivery framework with targets.
- **SEND:** Instruct DfE to revise the SEND Code of Practice to name FASD explicitly within neurodevelopmental assessment and EHCP eligibility. In Wales, revise ALN guidance. In Scotland, issue GIRFEC supplementary guidance on FASD. In Northern Ireland, update SEN framework guidance.
- **Justice:** Direct the Ministry of Justice to name FASD in the Neurodiversity Action Plan and its implementation guidance, update the CHAT tool, and require FASD-informed protocols in all Youth Intervention Courts and diversion services.
- **Workforce:** Work with Health Education England (and its devolved equivalents) to embed FASD in undergraduate, postgraduate, and CPD curricula for paediatrics, general practice, midwifery, health visiting, educational psychology, social work, and psychiatry — as called for in NICE QS204.

For Researchers and Academics

The evidence gap has been weaponised as a reason for inaction for too long. Researchers have a critical role in closing it — and in making the case that it can be closed:

- Prevalence: Design and seek funding for a new UK active case ascertainment prevalence study, building on the methodology of McCarthy et al. (2021) in Salford and extending it to representative samples across all four nations.

- Apply for NIHR funding to evaluate the cost-effectiveness of existing FASD diagnostic services — including the National FASD Clinic and NHS Grampian Hub — using Green Book-compliant methodology, to strengthen the BCR evidence base with UK-specific data.

- Use the three new FASD SNOMED CT codes (introduced 2024) to begin building primary care incidence data, working with EMIS and SystmOne data holders to establish FASD as a routinely coded condition.

- Develop and validate FASD-specific quality-of-life and health utility measures that can anchor a UK QALY-based economic evaluation, reducing the current reliance on Canadian and US cost parameters. Commission a UK-native lifetime cost study that replaces the current PPP-adjusted US estimate and can withstand Treasury scrutiny

- Data infrastructure: Work with NHS Digital, NHS England, the Health Innovation Network (England) and devolved equivalents to embed the three FASD SNOMED CT codes in routine clinical coding and link across maternity, paediatric, primary care, education and justice datasets.

- Support the design of a national FASD National Database/Registry in partnership with NHS England, devolved health departments, and the voluntary sector, integrating maternity, paediatric, primary care, education, and justice data understanding IGARD (Independent Group Advising on the Release of Data) approval.

- Prioritise translational and intervention research that moves beyond epidemiology to evidence-based support models, as the US NIH has done with its therapeutic research portfolio.

- Advocacy for funding: Join the call for an NIHR-aligned FASD research fund. The UK is currently a net consumer of FASD evidence; it is time to become a producer

- Include people with FASD and their families as genuine co-producers of research through funded, supported, accessible PPIE built into grant applications from the outset.

- Work with the third sector to help evaluate the impact of available materials, such as National FASD's Me and My toolkit, alcohol and pregnancy toolkit, university toolkit for midwives and education toolkit.

For Practitioners

The gap between national policy and daily practice is where FASD disappears. Every practitioner working with children, young people, adults, or families in health, education, social care, or justice will — statistically — be working with people affected by FASD right now, most of whom will be unidentified. Practitioners do not need to wait for new legislation, new funding, or new guidance to begin acting on what already exists. Practitioners across health, education, social care, and justice are the system's first and most important line of identification. Most people with FASD will be encountered by a practitioner before they are ever seen by a specialist:

Health

- **Advise:** ensure preconception health advice about alcohol harm.

- **Screen, ask, record:** Apply the CMOs' guidance on alcohol in pregnancy consistently in every antenatal appointment (ensuring you have training on the best practice on how to ask lifestyle questions about alcohol and pregnancy). Use the three FASD SNOMED CT codes when prenatal alcohol exposure is recorded or suspected. Refer to neurodevelopmental assessment where there is a history of prenatal exposure and developmental or behavioural concerns, as required by NICE QS204.

- **Consider FASD in differential diagnosis:** When assessing a child or adult with unexplained neurodevelopmental, behavioural, or mental health presentations — particularly where autism or ADHD have been considered but don't fully explain the picture — ask about prenatal alcohol exposure as a standard part of history-taking.

- **Provide post-diagnostic support:** A diagnosis without follow-on support is an incomplete intervention. Ensure families receive a care management plan, access to FASD-informed resources, and a named point of contact for onward support.

- **Paediatrics and CAMHS:** Ensure FASD is included in neurodevelopmental assessment pathways. Do not discharge children with complex presentations from CAMHS without considering prenatal alcohol exposure as a potential explanatory factor.

- **Seek training**

Educators

- **Reframe behaviour as disability.** When a child with FASD is non-compliant, impulsive, disruptive, or unable to follow instructions, this is neurological, not volitional. Applying behavioural sanctions to disability-driven behaviour causes harm, accelerates exclusion, and increases long-term cost. FASD-informed classrooms adapt the environment, not the child.

- **Pursue FASD recognition in EHCP and SEN support plans.** Where a child has an EHCP or is receiving SEN support, ensure that FASD or suspected FASD is named explicitly as a factor — not subsumed under ADHD, autism, or "complex needs." Vague formulations result in generic support packages that do not address the specific FASD profile (DHSC, 2021; National FASD Education Survey, 2026).

- **Use FASD-specific resources.** National FASD's *Me and My FASD* resource suite, the University of Salford's SPECIFiC evidence-informed programme and other independent FASD groups provide practical, classroom-ready tools. Share these across your team — FASD awareness in a school is only effective when it extends beyond a single informed teacher.

- **Flag at transition.** The move from primary to secondary school, and from secondary to post-16 and further education, are points of high risk for young people with FASD. Ensure that transition documentation explicitly captures the FASD profile, the adjustments that have worked, and the support needs for the next setting. Do not allow FASD to be invisible in the handover.

- **Advocate for EHCP retention under SEND reform in England.** The proposed reforms that would remove EHCPs for children not in specialist provision present a direct risk to children with FASD in mainstream settings. Educators should make representations through governors, unions, and professional associations that FASD must be explicitly named in any revised framework as a condition warranting formal support planning and emphasise the need for individualised support based on assessed needs, not prepackaged support plans (National FASD, 2026).

- **Flag FASD-consistent presentations** — executive functioning difficulties, impulsivity, emotional dysregulation, memory problems, difficulties with consequences — within SEND assessment processes rather than attributing them to behaviour, conduct, or parenting.

- **Seek training**

Social care

- **Include FASD in assessments of looked-after children and care leavers.** Research shows that between 17% and 27% of children in care may have FASD (McCarthy et al., 2021). A child whose behaviour, placement instability, or developmental presentation cannot be explained by trauma or attachment alone should be considered for FASD assessment. This is especially important at the point of care planning and statutory review.

- **Challenge trauma-only formulations.** Attachment disorder and developmental trauma are not mutually exclusive with FASD — they frequently co-occur. A formulation that attributes all difficulties to relational trauma in a child with known prenatal alcohol exposure is structurally incomplete and risks placing impossible demands on therapeutic interventions that cannot address organic neurodevelopmental impairment (Price, 2017; DHSC, 2021).

- **Support carers to access diagnosis.** Foster carers, adoptive parents, and kinship carers often know that FASD is the most plausible explanation for a child's presentation but cannot access assessment. Social workers should actively support referrals, document the functional impact in statutory reports, and use the FASD evidence to make the case to commissioners for a funded pathway (National FASD, 2025).

- **Plan transitions actively.** For every young person with FASD leaving care, a transition plan that extends beyond the age of 18 and explicitly addresses adult FASD-informed support, housing, benefits, and employment should be in place before they leave. The cliff-edge at 18 is predictable and preventable (Gault et al., 2023; National FASD, 2022).

- **Record prenatal alcohol exposure.** Where prenatal alcohol exposure is known or suspected and recorded in case files, ensure it is carried forward accurately into all subsequent assessments, court reports, and care plans. Lost history is one of the most common reasons FASD goes undiagnosed across generations of looked-after children (DHSC, 2021).

- **Seek training**

Justice system practitioners

- **Apply FASD-informed practice at every point of contact.** Police, custody sergeants, appropriate adults, solicitors, probation officers, and prison staff should treat undiagnosed neurodevelopmental disability as a baseline assumption when working with people who may acquiesce, who may confabulate and give false confession, who are unable to retain and effectively use the police caution, who are impulsive, suggestible, apparently non-compliant, or inconsistent in their accounts — FASD is likely one of the most probable undiagnosed conditions in that group (Brown et al., 2024).

- **Request neurodevelopmental screening.** Where a child or adult in the justice system shows indicators consistent with FASD — care-experience, school exclusion history, prior mental health contact, inconsistent behaviour — request a neurodevelopmental assessment that explicitly includes FASD within its scope. Do not accept referrals that default only to autism and ADHD screening (CJJI, 2021; Ministry of Justice, 2026).

- **Adapt questioning and communication.** Do not rely on verbal comprehension as evidence of understanding. Use concrete, visual, and written communications. Allow processing time. Verify understanding by asking the individual to explain back what has been said, rather than accepting a "yes" as confirmation. These adjustments are consistent with existing PACE guidelines and the intermediary scheme (Brown et al., 2024).

- **Use FASD evidence in mitigation and sentencing.** Where FASD has been diagnosed or is strongly suspected, ensure this is presented in pre-sentence reports, considered by the court as a mitigating factor, and reflected in any order or disposal that requires the individual to comply with conditions. Orders that are neurologically impossible to comply with will be breached and will increase harm (Michael Sieff Foundation, 2025; National FASD, 2026).

- **Advocate for FASD inclusion in the Neurodiversity Action Plan.** The Ministry of Justice's Neurodiversity Action Plan and the Neurodiversity Support Manager programme remain FASD-blind as of its February 2026 update (Ministry of Justice, 2026). Prison officers, probation practitioners, youth justice workers, and their professional associations should actively call for FASD to be added to the neurodiversity screening protocols, training curricula, and reasonable adjustments frameworks — in writing, through workforce consultations, and via their union representatives.

- **Seek training**

Across all settings

- **Learn about FASD:** Complete available FASD e-learning, access training resources, and share knowledge with colleagues. Professional awareness is the cheapest and most immediate lever available — and the one the *Not Commissioned* report identified as the most critical current gap.
- **Advocate for pathways:** Where no FASD diagnostic pathway exists in your ICS, raise it with commissioners. The evidence is that referrals proceed where pathways exist and are routinely denied where they do not.
- **Train and share knowledge:** Undergraduate, postgraduate and CPD curricula for paediatrics, psychiatry, general practice, midwifery, health visiting, educational psychology and social work should all include FASD. Free and accredited resources exist through National FASD and other

organisations. FASD awareness training should be treated as equivalent to safeguarding training in terms of professional obligation — not optional (DHSC, 2021).

- Support people with FASD and their families at every opportunity. Remember the “power of one”. You might change someone’s life by your caring, concern and connection.

For Commissioners

Commissioners are the structural link between policy intent and service reality. FASD has been stuck in guidance that does not translate into commissioning for over a decade:

- **ICBs in England:** Commission FASD diagnostic pathways using the hub-and-spoke model as the delivery architecture now, ahead of the FASD Prevention and Response Fund being established, using existing neurodevelopmental and prevention budgets.

- **Health Boards (Scotland, Wales, Northern Ireland):** Build on existing SIGN 156 and NICE QS204 mandates to develop or extend FASD diagnostic pathways within existing neurodevelopmental commissioning envelopes.

- **Local authorities:** Ensure FASD is included in SEND commissioning strategies, virtual school plans, and children's social care training frameworks. Use the Local Government and Social Care Ombudsman precedent — which ruled that applying restrictive criteria excluding children with FASD from assessment is unlawful — to require FASD-informed assessment across the area.

- **Integrated care partnerships:** Use population health intelligence to better identify the FASD-attributable share of demand in CAMHS, youth offending, exclusions, and looked-after children health reviews, and build that demand analysis into five-year commissioning strategies.

- **Maternity commissioning:** Direct Local Maternity and Neonatal Systems (LMNS) to implement consistent alcohol enquiry, accurate recording, and brief intervention as core maternity safety standards, aligned with PHE Maternity High Impact Area 4 and NICE QS204.

- **Cross-system commissioners:** Build FASD into joint strategic needs assessments (JSNAs) and health and wellbeing board strategies as a cross-cutting, high-cost population need that spans health, education, social care, and justice.

- **Use the business case:** Even doubling the diagnosis rate from 10% to 20% would reduce the undiagnosed-case cost premium by £5–10 million per ICS per annual cohort — more than covering the cost of the pathway. The pathway is not an additional cost; it is a cost reduction.

- **Align with ICB reform:** The FASD PRP maps directly onto the new strategic commissioner role for the reformed ICBs. A nationally funded specialist tier that ICBs can commission against, rather than build from scratch, is exactly what the restructured system requires.

- **Integrate into neurodevelopmental and other pathways:** FASD should not sit in isolation. It belongs inside mainstream neurodevelopmental, CAMHS, perinatal mental health, substance use, paediatrics, adult mental health, and learning disability pathways – adjust services that are designated for autism and learning disability to be more inclusive of FASD.

- **Track improvements in care over time:** NICE QS204 indicators should be used by England and Wales and can be adopted as best practice by Scotland and Northern Irelance.

For NICE (and Equivalent Guideline Bodies in Scotland, Wales and Northern Ireland)

NICE Quality Standard 204 was a landmark achievement — the first formal quality standard for FASD in England and Wales, published in 2022. Four years on, the evidence base has grown, diagnostic practice has developed, and the *Not Commissioned* report has demonstrated that QS204 alone has not driven the systemic change that was needed. NICE, alongside SIGN in Scotland and equivalent bodies in Wales and Northern Ireland, now has both the opportunity and the responsibility to go further. The following actions are within NICE's existing mandate and require no new legislation:

- **Revisit and strengthen NICE Quality Standard 204.** QS204 should be reviewed and updated to reflect the evidence accumulated since 2022 — including the Salford prevalence data, the three new FASD SNOMED CT codes, the *Not Commissioned* findings on implementation failure, and the growing international literature on cost-effective intervention. The revised standard and its measurable implementation indicators that ICBs are expected to report against, should be further highlighted so it moves to an accountable commissioning standard.

- **Develop new NICE guidance on FASD diagnosis in adults.** Current diagnostic guidance in both NICE QS204 and SIGN 156 is focused primarily on children and young people. Yet the majority of people with undiagnosed FASD are adults cycling through mental health, substance misuse, criminal justice, and employment support services without an explanatory diagnosis. New adult diagnostic guidance would enable commissioners to build adult FASD pathways into mental health, liaison psychiatry, and learning disability services, and give adult clinicians the framework they currently lack.

- **Develop a NICE clinical guideline on FASD care management.** NICE has published detailed care management guidelines for autism (NG228), ADHD (NG87), and other neurodevelopmental conditions — covering post-diagnostic support, transition to adult services, and the role of education and social care. No equivalent guideline exists for FASD. The absence of care management guidance means that what happens after diagnosis is left entirely to local discretion, producing the postcode lottery that lived-experience surveys consistently describe. A NICE care management guideline covering the full lifespan — from diagnosis through to adult services — would place FASD on the same statutory guidance footing as the neurodevelopmental conditions it most commonly co-occurs with.

- **SIGN (Scotland):** SIGN 156 has been updated to include the new SNOMED CT codes. Further updates to SIGN 156 could reflect developments since 2019, advances in adult diagnosis, and evidence on post-diagnostic support interventions. Consider supplementary guidance on FASD within the criminal justice system and within looked-after children health assessment frameworks. Consider adding a section on how it translates to England and Wales. Consider how Scotland might reflect ways to track measurable improvements in quality of care put forward in NICE QS 204.

- **Wales and Northern Ireland:** NICE QS204 applies in Wales; the Welsh Government should direct NHS Wales to implement it as an accountable commissioning standard and consider a Wales-specific FASD care pathway document aligned with the ALN Act. In Northern Ireland, the Public Health Agency and Health and Social Care Board should commission FASD-specific guidance aligned with NICE and SIGN standards.

Likely return: Every expansion of NICE guidance that brings FASD into scope — adult diagnosis, care management, lifespan planning — reduces the proportion of people with FASD assessed and treated under frameworks designed for other conditions, and increases the proportion receiving interventions calibrated to their actual needs.

For the alcohol industry

Industry has responsibility for point-of-sale prevention and public awareness. This is not a request to fund lobbying, brand campaigns, or industry-led "responsible drinking" programmes of the kind that public health researchers have found to omit, distort or dilute health risk information. It is a request for independently governed, evidence-based prevention investment — at the point where alcohol is sold, at the point where the harm begins, and at the population scale where it can make a difference.

- **Fund a comprehensive point-of-sale FASD prevention campaign** — immediately, without legislation: The point of sale — supermarkets, off-licences, pubs, restaurants, and online alcohol retailers — is the highest-reach contact point between alcohol products and the public. It is also the point furthest from clinical guidance and farthest from any existing FASD prevention infrastructure. A well-funded, independently designed, and consistently deployed point-of-sale campaign — covering pregnancy warning messaging, no-alcohol-in-pregnancy advice, and signposting to support services — would reach populations that antenatal services alone cannot. This does not require legislation. It can be negotiated through a voluntary cross-industry commitment to an agreed national standard. However, the evidence is clear that voluntary action without independent oversight and accountability consistently underdelivers. Any industry commitment should therefore be independently governed, externally evaluated, and reported publicly — not managed by the industry itself. National FASD has a model on-trade prevention project ready to scale up should needed, stable funding be secured.

- **Support and implement mandatory pregnancy warning labels:** The UK Government's 10 Year Health Plan has pledged to introduce mandatory health warning labels. The alcohol industry should support the rapid implementation of that commitment – including a new alcohol and pregnancy warning image to replace the crossed out pregnant woman and including accompanying language to emphasise why it’s important to avoid alcohol in pregnancy.

- **Apply the polluter-pays principle in corporate reporting and ESG commitments:** Major drinks companies publish environmental, social and governance (ESG) reports and health and wellbeing strategies. FASD is almost entirely absent from these documents. Given that FASD is a direct consequence of prenatal alcohol exposure, and that the industry's marketing strategies, pricing decisions, and product availability all influence rates of consumption during pregnancy, its absence from corporate social responsibility frameworks is a material omission.

For Advocates and Families

The lived experience of people with FASD and their families is not a footnote to this report. It is its moral and evidential foundation. The voices collected across National FASD surveys, the FASD UK Alliance surveys, and the UK FASD Manifesto have driven every policy ask in these pages. Advocates and families are the people who have held this field together in the absence of government investment. There are specific, practical things they can do now to drive the change this report calls for:

- **Keep telling your stories:** Parliamentary evidence sessions, select committee inquiries, consultation responses, and media coverage are all shaped by the power of lived experience. Your accounts of missed diagnoses, closed doors, and lives transformed by support are irreplaceable.

- **Use this report.** Share its key findings — the £9.2 billion annual cost, the 3.56:1 BCR, the 0.25% ask, the comparison with Canada, Australia, and the US — directly with local MPs, ICB executives, local authority SEND leads, and health and wellbeing board members.

- **Request FASD impact assessments.** Write to MPs, ICBs, local authorities, and devolved governments asking them to confirm that FASD has been included in impact assessments for SEND reform, the mental health review, PIP changes, and care reform. If they cannot confirm it, that is a Parliamentary question, a Freedom of Information request, and a media story**:** FASD is discussed 13 times less often in Parliament than autism, despite comparable prevalence. Every letter, every surgery, every parliamentary question changes that ratio

- **Document and report.** Every refused diagnosis, every FASD-related exclusion without recognition, every adult processed through a justice system that does not understand them — report it to National FASD. It builds the evidence base that drives policy change.

- **Engage with consultation processes.** The national consultations proposed in this report will only reflect lived experience if people with FASD and their families submit responses. National FASD will support families to engage — but families must claim their place in those processes.

- **Champion the UK FASD Manifesto.** The Manifesto — written by people with FASD — is a policy document as much as a personal statement. Its demands are measurable, achievable, and directly addressable by government. Share it, quote it, and use it in every conversation with a decision-maker.

- **Support peer networks – engage with local independent groups in the FASD UK Alliance.** The isolation described repeatedly in lived-experience surveys — *"FASD is a very, very lonely disability"* — is itself a policy failure. Peer support and FASD community groups are both a response to that isolation and a vehicle for the collective advocacy that changes systems.

For the Media

The visibility gap documented in this report is not only parliamentary — it extends into public understanding. FASD is the largest neurodevelopmental disability most people have never heard of. The media has a specific and powerful role to play in closing the awareness gap and holding government to account:

- **The numbers are the story.** An estimated 1.4–2.8 million people in the UK may have FASD. The annual cost to the public purse is £9.2 billion. FASD is mentioned 131 times less frequently in Hansard than autism, despite comparable or greater prevalence. These are not niche statistics — they are a national scandal.

- **The reform risk is the story.** Every major reform currently being debated — SEND, mental health, youth justice, disability benefits, adoption — will be shaped by whether FASD is included. Scrutinising whether FASD has been considered in impact assessments is a concrete, verifiable, and urgent accountability question.

- **The prevention story is the story.** England funds smoking-in-pregnancy campaigns. It does not fund equivalent alcohol-in-pregnancy campaigns. That is a policy choice that costs billions in downstream harm.
- **The lived experience is the story.** A child told they won't be diagnosed because "nothing can be done." A parent waiting five years for assessment. An adult with FASD asking why their disability is "being swept under the carpet". These are human stories that the public understands and that decision-makers respond to.
- **The international comparison is the story.** Canada, Australia, and the United States have all invested in national FASD strategies, prevalence research, and funded clinical networks. The UK has not. Asking why the UK is so far behind comparable countries on a condition costing £9.2 billion a year is a legitimate and important question.
- **Tell the human story accurately:** FASD is not a story about blame. It is a story about a brain-based disability that is misunderstood, misdiagnosed, and systematically underfunded. The person with FASD who was excluded from school, the family waiting five years for a diagnosis, the birth mother told "there is nothing that can be done" — these are stories of systemic failure, not individual failing.
- **Challenge the reform gap:** Every major UK reform programme announced over the past five years — mental health, SEND, children's social care, benefits — has either excluded FASD or mentioned it only in passing. Asking Ministers why is legitimate, urgent journalism.
- **Support the 100 experts:** More than 100 UK experts publicly called for action at the University of Salford in June 2025. Their call has not yet been answered. That is a story.
- **Signpost!** Be sure to include information about the risks of alcohol in pregnancy and provide support links in stories or at the end of the programme when showing a pregnant women drinking or touching on FASD.

A final word: the voices that cannot wait

Throughout this report, a single consistent message has emerged from the people who live with FASD every day. It is not a message asking for pity. It is not a message asking for special treatment. It is a message asking for what already exists in law, in clinical guidance, and in government policy to actually happen.

- *"Why isn't FASD made more public? I just can't believe how many people don't know about it — it's like it's being swept under the carpet."* — Person with FASD, National FASD Impact Survey, 2025
- *"FASD is a lifelong disability and severe impairment of short-term memory. Please see the child that can't rather than the child that is not willing."* — Carer, National FASD Education Survey, 2026
- *"What parents need is practical support, not sheets of paper. We need support groups, physical advocates to support us all in challenging professionals... living with and catering for FASD children is a lonely, challenging, sometimes violent place and there is nothing out there to physically and emotionally support us."* — Parent, National FASD Impact Survey, 2025
- *"We don't have any care management plan, strategies. In fact we have no help at all... We cry for help and meet a series of closed doors."* — Family, FASD UK Alliance Survey, 2023

- *"Early diagnosis helps shape ongoing care and educational support. That can make a vast difference to the total outcome for that young person."* — Respondent, National FASD Improving Quality of Care Survey, 2019

These are not hypothetical people. They are not edge cases. They are the human reality behind the £9.2 billion annual cost figure - behind the 13:1 ratio of autism to FASD mentions in Hansard, behind the 27% of looked-after children who had FASD in one Peterborough study and the 2-4% in the Salford study, while none had previously been identified.

The UK FASD Manifesto says it plainly: *"We are sick of people saying they understand, or that they are trying to help, but they do nothing... just because you can't see our disability doesn't mean we don't have one. Never give up on people with FASD"*.

More than fifty years after the first FASD diagnosis. Decades behind comparable countries. Billions of pounds lost annually to crisis, exclusion, and misdiagnosis. Millions of people — children, young people, adults — living without the diagnosis and support that could transform their trajectories and reduce the burden on every system that touches them.

The transformative impact of action is not speculative. Every case of FASD prevented saves up to £431,802 in lifetime costs. Every child correctly diagnosed and supported stays in education, avoids the care system, reduces pressure on CAMHS, and has a better chance of contributing to the workforce and to society. Every family that receives proper support stays intact rather than fragmenting into crisis, placement instability, and cost. Every adult finally given a diagnosis gains access to the explanatory framework, the reasonable adjustments, and the post-diagnostic support that can change the course of a life.

The cost of inaction has been counted.

The cost of action has been costed.

The choice is now a political one — and it belongs to every person who reads this report and has the power to act.

The question is not whether the UK can afford a national FASD prevention and response programme.

The evidence is unambiguous: the UK cannot afford to continue without one.

APPENDICES

Evidence & Methodology

Cost-model methods, the mental health review gap, and a US funding case study.

AT A GLANCE · APPENDIX A

UK FASD cost model methodology summary

How the UK lifetime and annual cost estimates were derived — the source data, the two-step PPP conversion, the parameters and the limitations researchers should cite.

£359.8k
lifetime cost per
diagnosed FASD case

£431.8k
lifetime cost per
undiagnosed case (+20%)

2.7%
central prevalence
(Salford midpoint)

3.5%
HM Treasury Green Book
social discount rate

How $596,000 becomes £359,835 — the two-step PPP transfer

Per Shemilt et al. (BMJ, 2010): GDP PPP for the whole, plus healthcare price ratio on the healthcare slice only.

US source
$596,000
Greenmyer 2018, Popova/Klug/Burd

Step 1: GDP PPP
× 0.69
OECD/World Bank 2023–24

GDP-PPP value
£411,240
general price-level adjusted

Step 2: healthcare 0.50
£359,835
applied to medical slice only

Undiagnosed cases carry a +20% premium → £431,802 lifetime cost (working assumption, pending UK evidence).

Model parameters and methodological choices

Standard NICE / OECD / WHO-CHOICE practice for cross-country cost-of-illness transfer.

Why not market FX?

FX rates reflect tradable goods and capital flows — not what a pound buys inside the NHS. Using FX overstates UK burden, especially on the medical slice.

Prevalence: 1.8–3.6% (2.7% central)

Salford School-Based Study (McCarthy et al., 2021). Sensitivity sheet tests 1%–5% to span the full UK evidence including Lange 2017 (3.2%).

Population: 672,000 live births

ONS 2024: 594,677 England & Wales plus Scotland and Northern Ireland. Diagnosis rate set at 10% — Salford found 0/8 previously identified.

Discount and inflation

HM Treasury Green Book social time preference rate of 3.5% (sensitivity 2–5%). Cost inflation 1.0% real p.a. tracking health and social care unit cost growth.

Component split logic

Healthcare price ratio applies only to medical care. Productivity, special education, social services, justice and housing/benefits retain GDP PPP only.

Annual headline

Lifetime cost ÷ 75 years for the headline annual figure. Model also distributes costs across age bands — concentrated in school years (6–17) and working age.

A smaller but defensible number wins the argument

PPP-adjusted £359.8k per case vs simple-FX £429k — 16% lower but materially more credible to NICE, ONS and Treasury.
Cite as: PPP-adjusted estimates derived from Greenmyer (2018), using GDP PPP plus healthcare ratio per Shemilt (2010).
Limitations: US-derived proxy; FASD heterogeneity not modelled separately; +20% undiagnosed premium is a working assumption.
A bottom-up UK costing remains the priority research need — funded directly through the proposed 0.25% allocation.

Sources: Greenmyer et al. (2018); Shemilt et al. (BMJ, 2010); McCarthy et al. (2021) Salford prevalence; OECD/World Bank PPP 2023–24; OECD Health at a Glance 2025; Anderson & Reinhardt 'It's the prices, stupid'; HM Treasury Green Book; ONS births 2024; Lange et al. (2017).
From: The Cost of Inaction on FASD (June 2026), Appendix A.

Appendix A: UK FASD Cost Model

Purpose of this summary

This summary explains, for researchers and reviewers, how the lifetime and annual cost estimates of Fetal Alcohol Spectrum Disorder (FASD) in the UK were derived in the financial model generated by Perplexity AI. It sets out the source data, the conversion methodology, the rationale for each adjustment, and the limitations researchers should bear in mind when citing the figures.

Starting point — the source estimate

The model anchors on the most widely cited US lifetime cost estimate for an individual with FASD: USD $596,000 per case (Greenmyer et al., 2018, drawing on Popova/Klug/Burd). This figure represents the cumulative direct and indirect societal cost of one FASD case from birth to death, expressed in 2018 US dollars.

UK-specific lifetime cost data does not exist at comparable granularity, so transferring the US estimate is unavoidable. The methodological question is how to transfer it. Earlier drafts of the model used a simple market-rate FX conversion (USD ÷ 1.32 × small adjustment). That approach is rejected here in favour of the two-step purchasing power parity method that NICE, the OECD, WHO-CHOICE and most healthcare insurers and governments use when porting international cost-of-illness data.

Why simple FX conversion is the wrong tool

Market exchange rates reflect tradable-goods flows, capital movements and short-term sentiment. They do not reflect what a pound or a dollar actually buys inside a domestic health and social-care system. Two specific problems:

> **General price-level differences.** A pound in the UK buys a different real basket of goods than a dollar in the US. FX rates ignore this.
>
> **Sectoral price differences.** Even after correcting for general price levels, US healthcare is dramatically more expensive than UK healthcare for equivalent services. US per-capita health spending in 2024 was $14,775 vs ~$5,800 in the UK on a PPP-adjusted basis — a ratio of roughly 2.5× that no FX rate captures.

Applying market FX to a US healthcare cost and calling the result a UK cost therefore overstates UK system burden, particularly for the medical-care components.

The two-step adjustment used in the model

The methodology follows Shemilt et al. (BMJ, 2010), the foundational NICE/HTA paper on cross-country cost transfer.

Step 1 — GDP PPP conversion

The US dollar cost is first converted to GBP using the OECD GDP Purchasing Power Parity factor of approximately 0.69 GBP per international dollar (OECD/World Bank, 2023–24). PPPs are constructed by pricing a representative basket of goods and services in each country and computing the conversion rate that equalises real purchasing power. This removes the general price-level distortion that FX rates carry. $596,000 × 0.69 = £411,240 — the GDP-PPP-equivalent UK cost.

Step 2 — Healthcare-specific price ratio on the healthcare slice only

GDP PPP corrects for *average* price differences across the whole economy, but US healthcare prices are an outlier: hospital, physician, drug and device prices are roughly twice UK NHS prices for clinically equivalent services (OECD Health at a Glance 2025; Anderson & Reinhardt's "It's the prices, stupid"). To capture this, the model applies a healthcare price ratio of 0.50 — i.e. the healthcare slice of the lifetime cost is scaled to half its GDP-PPP value, reflecting the lower NHS unit cost.

Crucially, this ratio is applied only to the healthcare component. Productivity loss, special education, social services, criminal justice and housing/benefits do not exhibit the same UK/US price gap as medical care, so they retain the GDP PPP conversion only. This component-weighted approach is what distinguishes a defensible cost transfer from a blunt one.

Resulting build-up

Component (% of lifetime cost)	US cost (USD)	After GDP PPP (£)	Final UK (£)	Adjustment
Healthcare (25%)	149,000	102,810	51,405	× 0.50
Productivity loss (30%)	178,800	123,372	123,372	GDP PPP only
Special education & SEND (15%)	89,400	61,686	61,686	GDP PPP only
Social services & out-of-home care (18%)	107,280	74,023	74,023	GDP PPP only
Criminal justice (8%)	47,680	32,899	32,899	GDP PPP only
Other (housing, benefits, family support) (4%)	23,840	16,450	16,450	GDP PPP only
TOTAL diagnosed lifetime cost	596,000	411,240	359,835	

The undiagnosed lifetime cost is then derived by applying a 20% premium to the diagnosed figure (£431,802), reflecting the higher long-run societal cost of cases that miss early intervention — a working assumption pending UK-specific evidence.

4. Other model assumptions

- **Prevalence (central case 2.7%)** is the midpoint of the Salford School-Based Study (McCarthy et al., 2021) range of 1.8%–3.6%. The sensitivity sheet tests 1%–5% to span the full UK evidence base, including the Lange et al. 2017 modelled estimate of 3.2%.
- **UK live births** are set at 672,000 (ONS 2024: 594,677 in England & Wales, plus Scotland and Northern Ireland).
- **Diagnosis rate** is 10% — Salford found 0/8 children previously identified, suggesting UK diagnosis is severely under-realised.
- **Discount rate** is the HM Treasury Green Book Social Time Preference Rate of 3.5%, with sensitivity tested between 2% and 5%.
- **Cost inflation** is set to 1.0% real per annum in line with long-run growth in health and social-care unit costs.
- **Annual cost** is approximated as lifetime cost ÷ 75 years for the headline figure; the model also shows a non-flat age-band distribution in which costs concentrate during school years (6–17) and working age.

5. Headline outputs and how they should be cited

Metric	Central-case figure
Lifetime cost per diagnosed UK case	£359,835
Lifetime cost per undiagnosed UK case	£431,802
New UK FASD cases per year	~18,100
Annual UK societal cost	£9.2 billion
30-year cumulative cost (PV at 3.5%)	£160 billion

When citing these figures, researchers should describe them as "PPP-adjusted estimates derived from Greenmyer et al. (2018), using the GDP PPP plus healthcare-specific price ratio method per Shemilt et al. (2010)" rather than as primary UK measurements.

6. Limitations

- The US-derived per-case cost is a proxy. A bottom-up UK costing remains the priority research need.
- FASD heterogeneity (FAS, partial FAS, ARND, ARBD) is not modelled separately; the cost figure represents an average across the spectrum.
- Caregiver productivity loss and family-level economic impact are only partially captured by the productivity component.

- The 20% undiagnosed premium is a working assumption, not an empirical estimate; it is a candidate for future calibration as UK longitudinal data emerges.
- Prevention savings and early-intervention cost-benefit are not modelled here — see Greenmyer et al. (2020) for that analysis.
- The healthcare price ratio of 0.50 is itself an estimate; sensitivity testing on this parameter (Sensitivity sheet, Table 3) is recommended before any policy-facing citation.

7. Why this matters for advocacy and policy

The PPP-based methodology is more conservative than the simple-FX method (£360k vs £429k per case, a 16% reduction), but it is also more credible. Government statisticians, NICE evaluators and Treasury analysts will recognise the methodology as standard practice; figures derived this way are more defensible in consultation responses, parliamentary submissions and grant applications. Where the goal is to influence policy or unlock funding, a smaller but rigorously derived number is materially more persuasive than a larger but methodologically vulnerable one.

AT A GLANCE · APPENDIX B

FASD invisible in the MH / ADHD / Autism Review

The Independent Review (interim, March 2026) does not name FASD — yet FASD sits inside the exact populations it aims to reach. Omission is substantive, not minor.

2–4%
may have FASD —
more prevalent than autism

1.4–2.8m
people in the UK
likely living with FASD

117–234k
young adults 18–24
entering adulthood with FASD

27%
of children in care
in Peterborough had FASD

The Review's own aims map directly onto the FASD evidence

Four stated objectives of the Independent Review — each one is where FASD belongs.

Understand drivers of rising diagnoses
Prenatal alcohol exposure is a major aetiological pathway behind ADHD- and autism-like presentations — currently missing from the explanatory frame.

Address co-occurring conditions
FASD is heavily comorbid with ADHD, autism, anxiety, depression and substance use. Mislabelled as attachment disorder, trauma, or 'complex' cases.

Reach those with greatest impairment
FASD is concentrated among care-experienced, justice-involved and multiply-excluded children — the highest-need cohort in the system.

Build a fairer, more proportionate system
Equity test: care-experienced children with FASD get punitive responses for a brain-based disability. The Review must integrate them, not lose them.

Why omitting FASD is a substantive flaw, not a minor gap

The Review contradicts existing NHS, DHSC, NICE QS204 and SIGN 156 commitments by not naming FASD.

Prevalence is hidden in plain sight
FASD affects more people than autism, yet most live undiagnosed inside NHS mental health, ADHD and autism services.

Mislabelling drives wrong interventions
FASD presents as 'complex ADHD', 'complex autism' or attachment disorder. Standard interventions then fail — wasting resource and time.

Brain-based disability misread as defiance
Without diagnosis, services interpret disability as wilful behaviour — leading to exclusion, family stress and justice contact.

Equity test fails for care-experienced
The very children most likely to have FASD — care-experienced, traumatised, multiply-excluded — are treated as noise rather than a defined need.

Existing frameworks already require it
NHS Long Term Plan, NICE QS204, SIGN 156 and DHSC FASD HNA already commit the system to recognise FASD. The Review contradicts these.

'There is no mild FASD' — DHSC
Lifelong brain-based condition. Early FASD-informed support reduces secondary disabilities: school failure, offending, substance use.

Invisibility is a deliberate choice — and a costly one

National FASD wrote to the Review urging inclusion of FASD and lived experience. The offers were declined.
Lord Adebowale put the question to the Government (April 2026). Baroness Merron deferred to the chair.
A review that ignores prenatal alcohol exposure misses a key driver of the rising distress it was set up to address.
Mainstreaming FASD via QS204, SIGN 156 and the DHSC HNA delivers the 10-year strategy's goals.

Sources: DHSC Independent Review into Mental Health Conditions, ADHD and Autism — Interim Report (March 2026); McCarthy et al. (2021) Salford; Peterborough LAC FASD study; NICE QS204; SIGN 156; DHSC FASD Health Needs Assessment; UK FASD Manifesto (2023); Hansard, 24 April 2026.
From: The Cost of Inaction on FASD (June 2026), Appendix B.

NATIONAL ORGANISATION FOR FASD · nationalfasd.org.uk

Appendix B: The Impact of Failing to Include FASD in the Independent Review into Mental Health Conditions, ADHD and Autism[3]

The Department of Health and Social Care has published the “Independent Review into Mental Health Conditions, ADHD and Autism: Interim Report” (March 2026). This report does not yet name FASD (Fetal Alcohol Spectrum Disorder) as a driver or lens for the identified “rising distress” and “growing difficulty” in the related services, and that is a material gap. The Independent Review will miss some of the most vulnerable children and young people if it does not explicitly consider FASD. People with FASD and their families have a right to be heard in policy discussions that affect their lives.

Overview

FASD is more common than autism and is heavily over-represented among care-experienced, traumatized, justice-involved young people and those with extensive school exclusion histories. Yet, FASD is rarely diagnosed and is often mislabelled as ADHD, autism, “behavioural problems” or attachment issues. A sizeable fraction of those presenting with “complex ADHD”, “complex autism”, emotional dysregulation or multiple psychiatric diagnoses have underlying FASD. Even when it is diagnosed, appropriate professionals are unaware of the import of that diagnosis. In fact, failure to recognise and address FASD can increase risk for mental health challenges among some of society’s most vulnerable.

Ignoring FASD means that a biologically driven, preventable contributor to ADHD- and autism-like presentations is left out of the explanatory framework, and the highest-need subgroup inside today’s ADHD/autism/mental health caseloads is treated as invisible.

If the review wants to understand why some people with similar diagnoses have much worse outcomes, and if it aims to design a fair, proportionate system that reaches those with the greatest impairment, it must build FASD into its analysis of prevalence, comorbidity, risk, and service design.

The situation is not static. More than 100 experts (June 2025) expressed concern that planned changes to benefits and education mean that people with FASD are now facing a more uncertain and risky future than ever.

Given the review’s own aims of understanding drivers, dealing with complexity, and creating a fairer, more proportionate system, not considering FASD would leave the review’s analysis and recommendations incomplete and skewed:

  - *Scientifically*, because it excludes a large, high-comorbidity neurodevelopmental group integral to ADHD/autism/mental-health intersections.

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[3] Reprinted from National FASD Policy Brief, The Impact of Failing to Include FASD in the Independent Review into Mental Health Conditions, ADHD and Autism, April 2026. https://nationalfasd.org.uk/fasd-cannot-be-ignored. This policy brief was written by Sandra Butcher, Chief Executive, with thanks to Prof Raja Mukherjee MBE, Clinical Lead, FASD national specialist clinic, in Surrey. Registered Charity 1101935. info@nationalfasd.org.uk.

  - *Ethically and in equity terms*, because it overlooks a key explanatory factor for the worst outcomes among care-experienced and disadvantaged children.

Overview chart

Dimension	**Review focus**	**What FASD evidence adds**	**Why omission matters**
Scope	Prevalence and support for mental health, ADHD, autism	FASD is common, with prevalence rate higher than autism	A major neurodevelopmental condition is absent
Drivers of rising diagnoses	Distress, awareness, thresholds, service pressures	Prenatal alcohol exposure as an aetiological driver for some cases	Misses preventable, biologically rooted contributors
Comorbidity	Plans to look at multiple conditions in next phase	FASD commonly co-occurs with ADHD, ASD, mental illness	High-need subgroup inside cohorts is unrecognised
Equity focus	Children, young people, those out of education/work	FASD concentrated in care-experienced and justice-involved groups	Most vulnerable children fall through analytic and policy gaps
System design	Earlier, better-matched, proportionate support	FASD requires adapted assessment, formulation and intervention	Risk of designing pathways that don't work for those with FASD

This chart summarises why the Independent Review on Mental Health Conditions, ADHD and Autism will be incomplete without considering FASD.

FASD prevalence

FASD is a highly prevalent common neurodevelopmental disability caused by prenatal alcohol exposure that affects more people than autism. FASD is preventable.

- 2–4% of children may have FASD (McCarthy et al., 2021) according to a UK prevalence study, based on gold-standard active case-ascertainment research in Greater Manchester. This is considered a conservative estimate by the researchers, as some of those most at risk were not included in the study. This rate is consistent with wider studies done in other countries.
- 1.4–2.8 million people in the UK may have FASD using 2024 population figures. Most are in NHS services, undiagnosed and not receiving appropriate care.

- 117,340–234,680 18–24 year olds in the UK are likely entering adulthood with FASD. Most are undiagnosed. They have a hidden brain-based neurodevelopmental condition, and are likely accessing multiple mental health, ADHD and autism services but not receiving FASD-informed support.

The Independent Review and the FASD evidence overlap conceptually

The independent review was commissioned to address “rising distress” and “growing difficulty” in obtaining timely, appropriate and proportionate support for mental health, ADHD and autism. It explicitly aims to:

- Understand trends in prevalence and distress.
- Examine drivers behind rising diagnoses of autism and ADHD.
- Identify where people “are not getting the support they need as quickly or as early as they need it”.
- Inform recommendations for a “fairer and better system of treatment and support”, including for people who have more than one mental health or neurodevelopmental condition.
- The interim report says the next phase will focus on co-occurring conditions, better alignment across health, education and other public services, and more equitable access, “ensuring that those with the greatest levels of distress and functional impact receive timely and appropriate help”.
- The review’s own framing is: multi-diagnostic, concerned with comorbidity, and focused on children and young people who are falling through the gaps. That is exactly where FASD sits.

Please note: The evidence base has weaknesses due to the lack of funding for further research. Much of the literature comes from specialist clinics, foster care, justice settings or other high-risk samples, so percentages may overstate prevalence in community FASD populations. Definitions vary across studies. That said, the evidence is overwhelming that FASD overlaps significantly with mental health, ADHD and autism.

People with FASD ask to be heard in policy discussions

Lee is an adult with FASD who has spoken widely about his experiences leaving school, running away, becoming addicted to alcohol, attempting suicide, ending up in jail. It wasn’t until his FASD diagnosis as an adult that things changed for him.

“There is nothing worse than knowing you can't do anything right due to behaviours out of your control, and not knowing the why behind it. Life growing up can become very isolated. But there is a strength or gift in every individual with FASD, and that is what must be focused on, to help build a good self worth, and a reason not to isolate themselves. That isolation makes life very lonely, and that loneliness can put them on a path they never need to walk.”

People with FASD combined their voices in the UK FASD Manifesto. They ask to be treated “with the same respect as others.” That means including FASD in relevant policy documents and discussions.

“My first primary school teacher described me as being lazy, defiant, obstructive and evil when I was in Year 1. My GP knew nothing about FASD, even though it was suggested at my adoption medical…I saw CAMHS last week and they really told me that it's not really their job to support people with my conditions….I want people who understand the effects of FASD on minds and mental health… Mental health services who recognise and have services for those affected… Not to be blamed for my conditions." — Georgia (quoted in DHSC, 2021).

The intersect of FASD, ADHD, autism and mental health

Condition	Statistics	Policy point
ADHD is the single most frequent co-occurring diagnosis in FASD.	FASD is present in around half of ADHD cases (Peadon and Elliot, 2010). The national FASD service in Surrey currently shows that 75% of those they diagnose with FASD also have ADHD.	ADHD policy that ignores FASD risks assuming a more typical ADHD profile, overlooking differences in neurocognition, support need and treatment response.
Autism-spectrum conditions similarly have high rates of overlap.	There are no solid estimates yet on the exact rate of overlap. The national FASD clinic currently shows that about 75% of those they diagnose with FASD also have autism.	Autism services will include a subgroup whose autism-like presentation is linked to FASD and who may need different assessment histories, communication approaches and family support.
Over 90% of individuals with FASD experience mental health difficulties.	One study states that, compared to the general population, individuals with FASD are reported to be 10 times more likely to have ADHD, 20 times more likely to have substance use problems, and 25 times more likely to be diagnosed with a psychotic disorder. Mental health challenges include anxiety, depression, suicidality and psychosis.	Undiagnosed FASD is associated with misdiagnosis, poorly fitting interventions, repeated service failure, and delayed access to supports, all of which impact mental health. Ignoring FASD can create more demand on services by worsening anxiety, depression, suicidality and substance-related harm.
FASD is heavily over-represented among care-experienced, excluded and justice-involved young people.	FASD impacts precisely the "most vulnerable" groups the review is concerned with. Around 34% to 46% with FASD score four or more Adverse Childhood Experiences, compared with around 10% to 16% in the general population.	FASD and trauma often co-occur. Most services focus on trauma alone. This does not remove the need to identify FASD; rather, both need to be addressed together. The review should take account of FASD when considering trauma.

A major aetiological pathway is invisible

- The interim report talks about the "drivers behind rising diagnoses of autism and ADHD" but frames these largely in terms of diagnostic culture and thresholds, awareness and expectations, social and service pressures, and broader trends in distress.
- The FASD evidence adds another, qualitatively different driver: prenatal alcohol exposure as a cause of a significant subset of ADHD- and autism-like presentations.

Not diagnosing FASD increases mental health risk

Poor professional training and weak service pathways mean opportunities for diagnosis are frequently missed, increasing stigma.

When FASD is not recognised, services may interpret brain-based disability as wilful behaviour, poor motivation or non-compliance. In practice this can mean exclusionary school responses, ineffective behavioural plans, poor fit with standard mental health interventions, family stress, escalating crises and contact with the criminal justice system.

When FASD is ignored, some of the most vulnerable in society are met with ineffective punitive responses for a brain-based disability. This compounds the mental health problems this population faces.

"There is no 'mild' FASD." — DHSC.

If the review does not explicitly consider FASD, it will fail an equity test

The very children and young people most likely to have FASD, care-experienced, traumatised, multiply-excluded, will be treated as noise in the data rather than a defined population whose needs can be addressed.

The interim report highlights links between mental health, neurodevelopmental conditions and not being in education, employment or training, and acknowledges that distress is especially high among children and young people.

The FASD evidence shows that:

- FASD is much more prevalent among children in care, adopted from care and those with high ACE scores, and is often mislabelled as attachment disorder or trauma alone. One study in Peterborough showed 27% of those in care had FASD. It also noted that 75% of adoption reports indicated prenatal alcohol exposure.[file:1]
- Care-experienced children with unrecognised FASD are at increased risk of exclusion, justice involvement and severe mental-health crises.
- Early diagnosis and FASD-informed support can reduce "secondary disabilities" such as school failure, offending and substance use.

Omission of FASD in the Independent Review is a substantive flaw, not a minor gap, and fails to incorporate standing NHS, DHSC and NICE policies and guidance

Taken together, the NHS Long Term Plan, NICE Quality Standard 204, SIGN 156, and the DHSC FASD Health Needs Assessment already commit the system to recognising FASD as:

- A common, high-need neurodevelopmental condition.
- Heavily entangled with mental health, ADHD and autism in both presentation and service use.
- Particularly concentrated in care-experienced, marginalised and justice-involved populations.

A mental health/ADHD/autism policy review that fails to integrate FASD would:

- Contradict these existing frameworks' logic on early identification, equity and integrated care.
- Systematically under-estimate the complexity and support requirements of the "rising prevalence" groups.
- Miss a critical opportunity to reduce avoidable downstream harm, including exclusions, crises and criminalisation, in one of the highest-need child and youth populations in the UK.

A review that instead mainstreams FASD, using QS204, SIGN 156 and the DHSC Health Needs Assessment as its foundation, will be far better placed to achieve the 10-year strategy's goals: earlier, fairer, more proportionate support for children and young people whose lives are currently shaped by unrecognised neurodevelopmental disability and preventable secondary mental-health problems.

Summary

The direction of evidence is consistent: FASD is heavily over-represented in mental health, ADHD and autism pathways, and policy that does not take this into account is likely to be clinically and economically inefficient.

People with FASD and their families, some of society's most vulnerable, will be further failed.

If the Independent Review into Mental Health Conditions, ADHD and Autism is serious about understanding why some children and adults with ADHD, autism and mental health diagnoses struggle so profoundly despite contact with services, and if the point of the review is to design equitable, joined-up support, then FASD cannot be ignored.

The invisibility of FASD in the Independent Review into Mental Health Conditions, ADHD and Autism is a deliberate choice

- National FASD contacted the Independent Review urging them to include FASD on more than one occasion. We also asked they include FASD lived experience. These offers were declined.
- Lord Adebowale asked the Government "whether the final report of the Review will address the evidence on Fetal Alcohol Spectrum Disorder and the neurodevelopmental consequences of prenatal exposure to alcohol and other substances, including the misidentification of these conditions as ADHD or autism; and if not, why not." The response from Baroness Merron (24 April 2026) stated "The review is independent of the Government, and it is for the chair and vice chairs to determine the specific issues the review considers." She added it will make recommendations on how the Government, the health system, and wider public services can

respond to increasing demand for support more fairly and effectively so that people receive the right support, at the right time, in the right place."

- Any review of the challenges confronting mental health, ADHD and autism, SEND and other services that ignores prenatal alcohol exposure and FASD will be inadequate and incomplete as it will miss a key driver for the current challenges the systems face. This oversight will have profound impact on the lives of many and will waste precious Government resources.

AT A GLANCE · APPENDIX C

Case study:
US FASD research funding

The NIH has a multi-million-dollar, multi-institute FASD research portfolio. The UK has no ring-fenced FASD research line — it imports the evidence base instead of building one.

$729.6m
NIH FASD spend
1999–2026 (RePORTER)

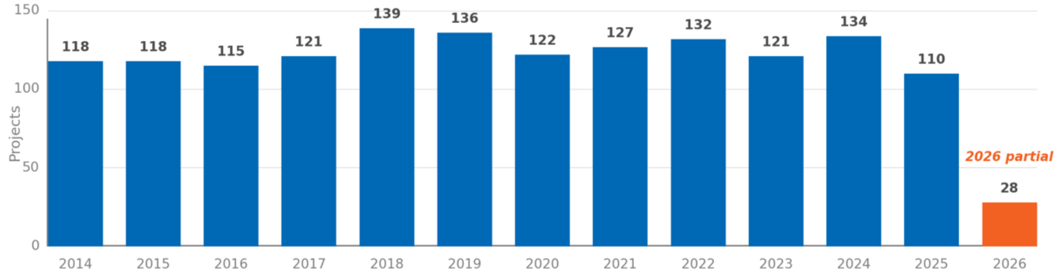
2,449
NIH-funded FASD
research projects since 1999

$49.2m
NIH spent on FASD research
in 2025 (110 projects)

£0
ring-fenced UK
FASD research budget

NIH-funded FASD research projects per year

A sustained portfolio across NIAAA, NICHD, NIMH and NINDS. Source: reporter.nih.gov.



What US investment is producing — and the UK currently borrows

NIH's 'Bench to Bedside' programme and broader portfolio span prevention to intervention.

Prevention trials

Native CHOICES and other alcohol-exposed pregnancy programmes — culturally adapted, economically evaluated.

Schwartz et al. 2024; O'Connor et al. 2023

Screening & cost-effectiveness

Screening and brief-intervention linked to economic models. UK has minimal FASD-specific adaptation.

Purshouse et al. 2013; Reid et al. 2024

Neurodevelopmental outcomes

Cohorts and neuroimaging clarify FASD's overlap and divergence with ADHD and autism — underpins UK service planning.

Greenmyer et al. 2020

Intervention & support trials

School-age executive-function training, caregiver coaching, family support models — the post-diagnostic toolbox UK families ask for.

Reid et al. 2024; NIH FASD summary 2026

The UK is a consumer, not a producer, of FASD evidence

US taxpayers are subsidising the evidence base UK policymakers rely on — not sustainable for UK systems.
Key UK cost-of-illness, prevalence and intervention work is funded by US and Canadian sources (Popova, Greenmyer, Cook).
A 0.25% allocation funds UK prevention trials, NHS screening models, longitudinal cohorts and intervention research.
Building a domestic FASD research pipeline is morally justified — and strategically necessary for sovereign policy.

Sources: NIH RePORTER (reporter.nih.gov) FASD search 1999–2026; NIH Bench to Bedside PAR on FASD (2025); DHSC FASD Health Needs Assessment (2021); McCarthy et al. (2021); McQuire et al. (2019); NICE QS204; SIGN 156; Popova et al. (2016); Greenmyer et al. (2020); Thanh et al. (2015); Cook et al. (2016).
From: The Cost of Inaction on FASD (June 2026), Appendix C.

Appendix C: Case study: US research funding on FASD

The reporter.nih.gov database shows a substantial, sustained stream of US federal investment in FASD research over many years, with millions of dollars committed in the most recent years alone, while the UK has had no comparable, dedicated research funding line. This US investment is already helping to drive some of the only sustained FASD research involving UK populations, and it illustrates the kind of progress that becomes possible when a system takes FASD seriously as a research and public-health priority.

NIH’s FASD research calls (e.g. the current “Bench to Bedside” PAR on FASD therapeutic development; National Institutes of Health, 2025).

There is a large, multi-year US portfolio of FASD projects.

The ALL-years export runs to thousands of project-year rows, covering basic science, neuroimaging, prevention, screening, intervention trials, and health-services research. This is not a one-off grant; it is a sustained portfolio across multiple NIH institutes (NIAAA, NICHD, NIMH, NINDS and others) (NIH FASD research summary, 2026; National Institutes of Health, 2025).

Total US spending on research listed in the NIH database 1999-2026

Combined total from NIH database when searched for FASD showed 2,449 FASD-funded research projects for a total of $729,637,722 between 1999 – 2026.

Yearly number of US funded research projects listed in the reporter.nih.gov database:

- 2026(28)
- 2025(110)
- 2024(134)
- 2023(121)
- 2022(132)
- 2021(127)
- 2020(122)
- 2019(136)
- 2018(139)
- 2017(121)
- 2016(115)
- 2015(118)
- 2014(118)
- 2013(114)
- 2012(112)
- 2011(135)
- 2010(150)
- 2009(155)
- 2008(130)
- 2007(50)
- 2006(21)
- 2005(30)
- 2004(15)
- 2003(13)
- 2000(2)
- 1999(1)

2024-2026 totals for funded research projects:

- 2026(28 projects so far) – $9,948,004
- 2025(110) – $49,234,796
- 2024(134) – $40,019,007

NIH is now explicitly investing in translational and therapeutic work, not just descriptive epidemiology.

The current “Bench to bedside: Advancing therapeutic development for fetal alcohol spectrum disorders (R61/R33)” call is explicitly designed to move from understanding FASD to testing interventions and supports (National Institutes of Health, 2025). That sits alongside continuing investment in prevention (e.g. alcohol-exposed pregnancy interventions), screening, and service models (Schwartz et al., 2024).

Even if exact totals per year vary with exchange rates and project timing, the direction and scale are clear: the US has a dedicated, multi-million-dollar FASD research effort, including in the last 2–3 years.

Comparison with the UK: a near-absence of dedicated FASD research funding

In the UK, there is no equivalent, ring-fenced FASD research programme. The DHSC FASD Health Needs Assessment explicitly highlighted “limited UK research evidence” and the absence of routine funding mechanisms to address key gaps (Department of Health and Social Care [DHSC], 2021). Recent UK prevalence studies in Manchester and Wales have relied on individual grants and one-off NIHR or charity funding, not on a standing FASD programme (McCarthy et al., 2021; McQuire et al., 2019).

There is also no UK analogue to the NIH “Bench to Bedside” funding call specifically focused on therapeutic development for FASD (National Institutes of Health, 2025). While FASD may appear occasionally as a subtopic in broader alcohol, neurodevelopmental, or children’s research calls, there is no consistently resourced UK stream that matches:

- the scale of NIH’s cross-institute portfolio;
- the explicit FASD labelling of the US grants; or
- the emphasis on multi-stage prevention, diagnosis, and intervention research.

Against that backdrop, the NIH portfolio your exports capture is a stark contrast: it shows what it looks like when a system decides that FASD is worth a dedicated research line, rather than relying on ad-hoc, one-off projects.

What this level of US research investment allows – and why it matters for prevention and response

NIH’s spending is already producing work that directly informs better prevention and response, including areas that the UK urgently needs but has not funded at scale:

- **Prevention interventions**
  NIH-funded trials like Native CHOICES and other alcohol-exposed pregnancy programmes are testing culturally adapted, economically evaluated interventions to reduce alcohol use before

and during pregnancy (Schwartz et al., 2024). That evidence base can guide UK prevention strategies beyond generic “don’t drink” messaging.

- **Screening, brief intervention, and cost-effectiveness**
  US-funded work links screening and brief interventions to economic models (Purshouse et al., 2013; Reid et al., 2024). The UK has some alcohol SBI cost-effectiveness work, but very limited FASD-specific adaptation; robust US evidence makes it easier to argue that investing 0.25% in FASD prevention can be cost-effective.

- **Neurodevelopmental and mental-health outcomes**
  NIH has funded multiple cohorts and neuroimaging studies that clarify how FASD overlaps and diverges from ADHD and autism, and how different patterns of prenatal exposure shape trajectories (e.g., Greenmyer et al., 2020). That knowledge underpins the argument that FASD is a distinct, identifiable neurodevelopmental condition that UK services should plan for, rather than an amorphous subcategory of “behavioural problems.”

- **Intervention and support trials**
  More recent NIH funding is supporting school-age interventions and family supports, including trials looking at executive-function training, caregiver coaching, and service models (Reid et al., 2024; NIH FASD research summary, 2026). This goes exactly to the heart of the UK lived-experience call for post-diagnostic support rather than diagnosis alone.

In other words, NIH’s multi-million-dollar investment is building the toolbox that allows systems to move from “FASD is a problem” to “here are tested ways to prevent, identify and support it.” The UK currently benefits from that toolbox as a borrower, not as a co-author.

US funding is underwriting some of the only sustained UK FASD research

Ironically, the NIH portfolio has already helped sustain important FASD work involving UK researchers and populations. Several patterns stand out:

- **Collaborative projects where UK investigators are co-investigators or collaborators on US-funded studies**
  For example, some neurodevelopmental and cost-of-illness projects that include UK data or UK-based co-authors have been supported by NIH or other North American funding, not by UK research councils or DHSC.

- **Methodological and economic work that UK teams rely on**
  Key cost-of-illness and prevention-economics studies (Popova et al., 2016; Greenmyer et al., 2020; Thanh et al., 2015) are Canadian/US-funded but are now being used to argue for UK FASD investment, including in National FASD’s cost model and advocacy materials. Without that foreign funding, UK policy would have even less to stand on.

- **Translational science that informs UK guidelines**
  Elements of SIGN 156 and NICE QS204 draw on NIH-funded basic and clinical research (e.g., Cook et al., 2016), including diagnostic guidelines and neurodevelopmental outcome studies. The UK has effectively “imported” the evidence base while not investing equivalently in its own FASD research pipeline (NICE, 2022; SIGN, 2019; Cook et al., 2016).

The result is that US taxpayers are subsidising part of the evidence base that UK policy makers now rely on. That is not sustainable if the UK wants to tailor prevention, diagnosis and support to its own population, systems, and inequalities.

How this comparison supports the 0.25% proposal

1. **The US shows what dedicated FASD research funding looks like**
   A multi-million-dollar annual NIH portfolio has generated prevention trials, screening tools, diagnostic guidelines and intervention studies that move FASD policy beyond rhetoric to action (National Institutes of Health, 2025; Schwartz et al., 2024; Reid et al., 2024). The UK has no comparable, sustained, FASD-labelled research line.

2. **The UK is currently a net consumer, not a producer, of FASD evidence**
   Key prevalence, cost and intervention evidence used in UK policy debates is funded from US and Canadian sources (Popova et al., 2016; Greenmyer et al., 2020; Thanh et al., 2015; Cook et al., 2016). NIH funding has even underpinned collaborative work involving UK researchers and settings, because there has been so little UK-specific investment.

3. **A 0.25% FASD funding allocation would allow the UK to build its own evidence base and implementation science**
   With a dedicated 0.25% allocation, the UK could:

   - Fund UK-specific prevention trials (e.g., culturally tailored alcohol-in-pregnancy programmes integrated with NHS maternity and public health);
   - Develop and test FASD screening and care-management models in NHS, education and social care settings;
   - Support longitudinal and service-use studies that quantify UK costs, inequalities and outcomes; and
   - Build FASD-informed intervention research (e.g., UK trials of school-based and family-based supports) rather than relying on US and Canadian analogues.

This comparison is powerful because it shows both what is possible when a system invests in FASD research (the NIH portfolio) and what is missing in the UK.

It supports the argument that a UK FASD Prevention and Response Fund equivalent to 0.25% of the alcohol duty allocation for FASD prevention, diagnosis and post-diagnostic support is not only morally justified by lived experience and need, but also strategically necessary if the UK is to stop depending on other countries' research to shape its own policy and practice.

AT A GLANCE · APPENDIX D

Soft Drinks Industry Levy as precedent for the FASD Prevention and Response Fund

The SDIL shows that the UK can legislate a product-specific health levy and hypothecate receipts to a targeted programme — the proven model for a 0.25% alcohol duty allocation.

£2.2bn
raised by SDIL since
April 2018

47%
average sugar cut
in some drink categories

£286m/yr
to children's health
PE, breakfast, sport facilities

0.25%
of alcohol duty is
the FASD ask — 100% less

How the Soft Drinks Industry Levy works — and where its receipts go

Announced March 2016 (Budget), in force April 2018, legislated via Finance Act 2017 — a standard Budget measure.

Tiered levy

Paid by producers and importers

- 18p/L on 5–8g sugar/100ml
- 24p/L on 8g+ sugar/100ml
- Two-year lead-in drove reformulation

→

Revenue raised

£240m/yr forecast; £2.2bn to date

- Extends to milk-based drinks 2028
- April 2025 consultation
- to strengthen levy scope

→

Hypothecated to children

England's share → children's health

- +£160m/yr Primary PE Premium
- £26m National School Breakfast
- £100m Healthy Pupils Capital

Five structural parallels between the SDIL and the FASD Prevention and Response Fund

The parallel is structural, not rhetorical — the FASD ask is more modest at every level.

1. Producer of harm funds the remedy

Sugar producers fund childhood obesity programmes — alcohol producers fund prevention, diagnosis and support for prenatal alcohol harms.

2. No new tax, no new rate

SDIL was itself a new levy. The FASD ask redirects only 0.25% of existing alcohol duty — 100% smaller in scope and easier to enact.

3. Already established in UK practice

Finance Act 2017 set the precedent. A 0.25% direction needs no new primary legislation — a Budget measure or statutory instrument suffices.

4. Dual mechanism: behaviour + revenue

SDIL drove a 47% sugar cut and funded children's health. FASD allocation signals priority — shaping industry behaviour and funding the response.

5. Targets inequality where harm is highest

SDIL's biggest predicted life-expectancy gains are in the most deprived areas. FASD follows the same socioeconomic gradient — same equity logic.

⚠ Lesson: hypothecation must be protected

Institute for Government (2025): SDIL revenue has been gradually subsumed into general spending. The FASD Prevention and Response Fund must be ring-fenced in statute, with independent oversight — political commitment alone is not enough.

The UK has done this before — and it works

Mechanism, legislation and political acceptance are established — the FASD ask is proportionally negligible.
Statute or Treasury direction with independent oversight prevents the SDIL's gradual erosion of hypothecation.
A cross-departmental FASD board, transparent annual reporting and external evaluation protect the ring-fence.
0.25% of one existing duty stream — the smallest possible ask, against the largest possible evidence and need.

Sources: Institute for Government (2025); HM Government (2018, 2025); British Heart Foundation (2026); Recipe for Change (2018); Pell et al. (BMJ 2021); Briggs et al. (Lancet Public Health 2017); LSHTM (2024); WHO Europe (2019); DHSC FASD HNA (2021).
From: The Cost of Inaction on FASD (June 2026), Appendix D.

Appendix D: The Soft Drinks Industry Levy as precedent

What the Soft Drinks Industry Levy is and how it works

The Soft Drinks Industry Levy (SDIL) was announced in the March 2016 Budget and came into force in April 2018, legislated through the Finance Act 2017 and the Soft Drinks Industry Levy Regulations 2018 (Institute for Government, 2025). It is paid directly to HMRC by UK producers or importers at tiered rates: 18p per litre on drinks containing 5–8g of sugar per 100ml, and 24p per litre on drinks exceeding 8g per 100ml (Institute for Government, 2025). Manufacturers were given a two-year lead-in period between announcement and implementation to reformulate products; by the time the levy came into effect, over 50% of manufacturers had already reduced sugar content (HM Government, 2018). The total sugar sold in soft drinks by retailers and manufacturers decreased by 35.4% between 2015 and 2019, and the sales-weighted average sugar content fell by 43.7% (Institute for Government, 2025).

On introduction, the levy was forecast to raise £240 million per year (HM Government, 2018). It has since raised more than £2.2 billion in total since 2018 (British Heart Foundation, 2026). From 2028 it will be extended to sugary milk-based drinks, and in April 2025 the UK Government opened a consultation on further strengthening the levy's scope (HM Government, 2025).

How the receipts were calculated

When announcing the SDIL, the Government pledged that "every penny of England's share of the spending raised by the Levy will go towards improving children's health" (Recipe for Change, 2018). The revenue was directed to three specific programmes:

- **Doubling the Primary PE and Sport Premium** — an additional £160 million per year to schools for physical activity (HM Government, 2018; Recipe for Change, 2018)
- **A National School Breakfast Programme** — initially £26 million over two years, subsequently extended (Recipe for Change, 2018)
- **A Healthy Pupils Capital Fund** — £100 million in a single year (2018–19) for school sports facilities upgrades (Recipe for Change, 2018)

This is the defining feature of the SDIL: it established a direct, publicly announced causal chain between a levy on a harmful product and investment in a programme specifically designed to reduce the health harm associated with that product — in this case, childhood obesity driven by excess sugar consumption (HM Government, 2018). The link between cause and remedy was explicit, proportionate, and publicly legible.

However, the Institute for Government (2025) has found that, since its first year, SDIL revenue has been "gradually subsumed into the general tax pot," with the amount set aside becoming less rigorous over time. This is a known weakness of non-statutory hypothecation and is directly relevant to the FASD proposal: any alcohol duty allocation should be ringfenced in statute or Treasury direction — not merely announced as a political commitment — to avoid the same erosion. The proposed cross-departmental FASD board and independent evaluation function described in Section 5 of this report are precisely the governance structures that would prevent this.

In strict Treasury terms the Soft Drinks Industry Levy (SDIL) is more of a “soft” or political hypothecation than a hard, legally earmarked one.

- When the SDIL ("sugar tax") was announced, ministers explicitly linked it to funding school sport and programmes to tackle childhood obesity, and it is frequently cited in tax commentary as an example of a hypothecated health levy.
- However, like most UK taxes, SDIL receipts go into the Consolidated Fund, and spending on school sport and obesity programmes is then allocated through normal departmental budgets and Spending Reviews, not via a rigid, formulaic earmark tied pound-for-pound to levy revenue.

So:

- In everyday political language, SDIL is treated as a hypothecated health tax.
- In fiscal reality, it is better described as soft hypothecation or earmarking: there is a strong narrative and policy link, but no strict legal requirement that every pound raised is spent on the named programmes.

That is exactly the kind of model that serves as a precedent for an FASD Prevention and Response Fund.

Why this is the direct precedent for the FASD proposal

The parallel between the SDIL and the proposed FASD Prevention and Response Fund is structural, not merely rhetorical. It operates on five levels.

1. The same logical principle: the producer of the harm funds the remedy

The SDIL uses revenue from the production of a health-damaging product — high-sugar drinks — to fund interventions that reduce the health harm that product causes (Institute for Government, 2025; WHO Regional Office for Europe, 2019). The proposed FASD Prevention and Response Fund uses a fraction of alcohol duty — revenue generated from the production and sale of alcohol — to fund prevention, diagnosis, and support for the most serious preventable consequence of alcohol consumption during pregnancy (National FASD, 2026). The polluter-pays logic is identical in both cases.

2. No new tax and no new rates

The SDIL was itself a new levy. The FASD proposal is more modest still: it does not create any new levy. It asks only for 0.25% of existing alcohol duty receipts — which already flow to the Treasury — to be directed to a specific programme (National FASD, 2026). The SDIL redirects 100% of its receipts to health programmes; the FASD proposal redirects 0.25% of one existing revenue stream. By comparison, the ask is proportionally negligible.

3. The mechanism is established in UK law and practice

The SDIL was legislated through the Finance Act 2017 — a standard Budget measure — demonstrating that product-specific health levies and hypothecated spending directions are fully within conventional Treasury and parliamentary practice (Institute for Government, 2025). A 0.25% direction of alcohol duty receipts requires no new primary legislation: it can be achieved through a Budget measure or statutory instrument under existing alcohol duty reform machinery (National FASD, 2026). The SDIL established this type of mechanism as a viable and accepted precedent in UK fiscal policy.

4. The dual mechanism — behaviour change and revenue generation

The SDIL generated two types of public health benefit simultaneously: manufacturers reformulated their products (with sugar content falling by 47% on average in some categories; British Heart Foundation, 2026), and the revenue funded health programmes (London School of Hygiene and Tropical Medicine [LSHTM], 2024). The FASD proposal creates an analogous dual effect: an explicit benchmarking to 0.25% of the alcohol duty signals that alcohol's prenatal harms are a government priority — which itself shapes industry behaviour, public understanding, and commissioning decisions — while the revenue funds the infrastructure to address those harms directly.

5. The health inequality dimension

Research shows that the SDIL's greatest predicted improvements in life expectancy are in children from the most deprived areas, where obesity rates are highest (Briggs et al., 2017; Pell et al., 2021). FASD follows the same socioeconomic gradient: it is more prevalent in more deprived populations, more common among children in care and care-experienced young people, and more concentrated in communities least likely to access services (Department of Health and Social Care [DHSC], 2021; National FASD, 2026). Both interventions are therefore progressive in impact — directing more of their benefit toward those who bear the highest burden of the harm being addressed, and thereby contributing to the Core20PLUS5 and health inequalities agendas (NHS England, n.d.).

The key lesson: the amount ring-fenced must be protected

The SDIL precedent also illustrates a risk that the FASD proposal must address directly. Despite the Government's initial pledge, the Institute for Government (2025) concluded that SDIL revenues have over time been "subsumed into general departmental spending" rather than remaining tightly tied to the three named programmes. This erosion of formal and informal hypothecation is a known pattern in UK fiscal policy and must not be repeated with the FASD Prevention and Response Fund.

The solution, as set out in Section 5 of this report, is to establish the Fund through a formal Treasury direction or statutory instrument with transparent annual reporting, independent oversight via a cross-departmental FASD board, and external evaluation of programme outcomes. Political commitment alone is insufficient; the governance architecture must protect the ring-fence.

Summary

The Soft Drinks Industry Levy demonstrates that the United Kingdom is willing and institutionally capable of linking revenue from a harmful product to a targeted, evidence-based public health programme through a Budget measure; that such a levy can be effective in reducing harm at population level; that the financial mechanism is legally and practically straightforward; and that public and parliamentary acceptability is achievable (British Heart Foundation, 2026; Institute for Government, 2025; Pell et al., 2021). Every one of those conditions applies equally to the proposed FASD Prevention and Response Fund — at a fraction of the financial scale.

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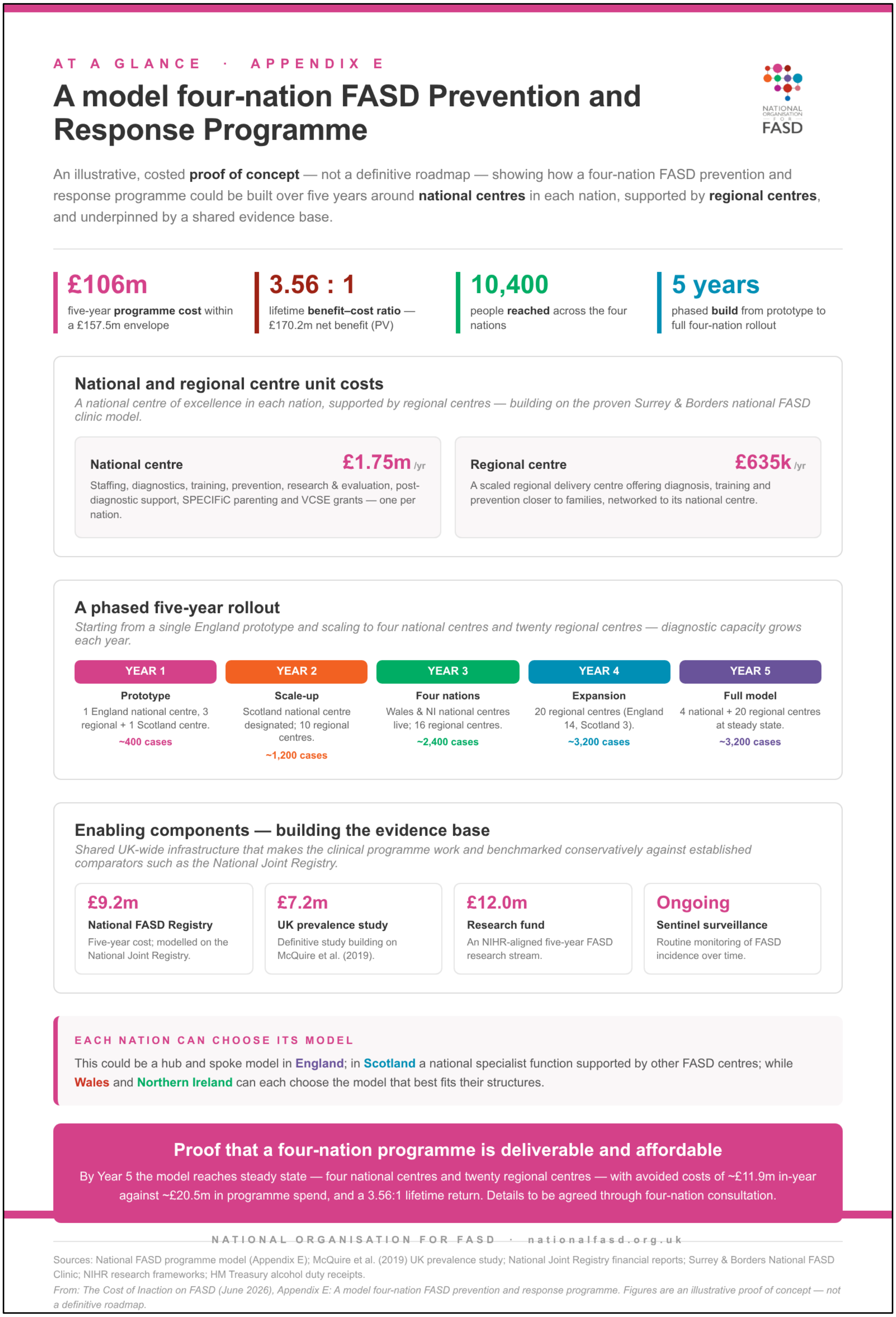

AT A GLANCE · APPENDIX E

A model four-nation FASD Prevention and Response Programme

NATIONAL ORGANISATION FOR FASD

An illustrative, costed **proof of concept** — not a definitive roadmap — showing how a four-nation FASD prevention and response programme could be built over five years around **national centres** in each nation, supported by **regional centres**, and underpinned by a shared evidence base.

£106m
five-year **programme cost** within a £157.5m envelope

3.56 : 1
lifetime **benefit–cost ratio** — £170.2m net benefit (PV)

10,400
people **reached** across the four nations

5 years
phased **build** from prototype to full four-nation rollout

National and regional centre unit costs

A national centre of excellence in each nation, supported by regional centres — building on the proven Surrey & Borders national FASD clinic model.

National centre **£1.75m** /yr
Staffing, diagnostics, training, prevention, research & evaluation, post-diagnostic support, SPECIFiC parenting and VCSE grants — one per nation.

Regional centre **£635k** /yr
A scaled regional delivery centre offering diagnosis, training and prevention closer to families, networked to its national centre.

A phased five-year rollout

Starting from a single England prototype and scaling to four national centres and twenty regional centres — diagnostic capacity grows each year.

YEAR 1	YEAR 2	YEAR 3	YEAR 4	YEAR 5
Prototype	**Scale-up**	**Four nations**	**Expansion**	**Full model**
1 England national centre, 3 regional + 1 Scotland centre.	Scotland national centre designated; 10 regional centres.	Wales & NI national centres live; 16 regional centres.	20 regional centres (England 14, Scotland 3).	4 national + 20 regional centres at steady state.
~400 cases	**~1,200 cases**	**~2,400 cases**	**~3,200 cases**	**~3,200 cases**

Enabling components — building the evidence base

Shared UK-wide infrastructure that makes the clinical programme work and benchmarked conservatively against established comparators such as the National Joint Registry.

£9.2m
National FASD Registry
Five-year cost; modelled on the National Joint Registry.

£7.2m
UK prevalence study
Definitive study building on McQuire et al. (2019).

£12.0m
Research fund
An NIHR-aligned five-year FASD research stream.

Ongoing
Sentinel surveillance
Routine monitoring of FASD incidence over time.

EACH NATION CAN CHOOSE ITS MODEL

This could be a hub and spoke model in **England**; in **Scotland** a national specialist function supported by other FASD centres; while **Wales** and **Northern Ireland** can each choose the model that best fits their structures.

Proof that a four-nation programme is deliverable and affordable

By Year 5 the model reaches steady state — four national centres and twenty regional centres — with avoided costs of ~£11.9m in-year against ~£20.5m in programme spend, and a 3.56:1 lifetime return. Details to be agreed through four-nation consultation.

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Sources: National FASD programme model (Appendix E); McQuire et al. (2019) UK prevalence study; National Joint Registry financial reports; Surrey & Borders National FASD Clinic; NIHR research frameworks; HM Treasury alcohol duty receipts.

From: The Cost of Inaction on FASD (June 2026), Appendix E: A model four-nation FASD prevention and response programme. Figures are an illustrative proof of concept — not a definitive roadmap.

Appendix E: model four-nation FASD Prevention and Response Programme

As mentioned in the *Cost of Inaction* report, this model is put forward for discussion, based on the idea that over 5 years, each nation would have a national FASD centre of excellence, supported by additional regional centres. These would support ongoing more diffuse FASD prevention, diagnosis, research and support at local levels.

This appendix provides some details to show just how comprehensive the plan could be, if political will and funding were available. To our knowledge, no such comprehensive plan has ever been mapped out.

In England, this could be best described as a 'hub and spoke' model as references in the DHSC FASD Health Needs Assessment. In Scotland this could be a national specialist function supported by other FASD centres. Wales and Northern Ireland could decide which model. How it is set up in each nation will be determined via national consultations. This is just one example of how it might roll out.

For this exercise, each national centre in this model is costed out as a multidisciplinary FASD service with a common core offer (diagnosis, training, prevention, post-diagnostic support, grants to VCSE partners), scaled differently at national and regional/local levels (in England hub/spoke levels) and rolled out across the four nations over five years.

It includes all four nations as a thought exercise. The systems are different. The details are not the point for this exercise. The intention is to show that all nations could have improved FASD prevention/diagnosis/post-diagnostic support on a scale hitherto unimagined under this model of scale of invest-to-save modelling.

This is a model to start discussion – not a definitive roadmap

The FASD Prevention and Response programme suggested below (and further outlined in Appendix E) is put forward as a proof of concept. It is not meant to be definitive. It is meant to show that with a rounding error on the alcohol duty, a funded, comprehensive four-nation FASD Prevention and Response Programme is feasible. The details can and should be worked out, possibly through synchronous national consultations which should engage a wide range of people with FASD and their families and other stakeholders. There are differences in how this would roll out in each of the four nations and differences in how the Programme should like. Our purpose is to show it is possible to fund a truly comprehensive national response at the scalen needed across the four-nations. We reemphasise, if we can produce a vision like this as a small charity, imagine what could be done with the four national Governments putting their considerable expertise and resources to the task. All that is missing is political will.

What a national centre (national hub) does – an illustrative example

Each national centre is a fully-fledged, national Multi-Disciplinary Team (MDT) FASD centre of excellence with responsibility for: clinical leadership, complex diagnostics, national or nation-wide training and prevention campaigns, data and evaluation, digital platforms, and holding/overseeing grants to voluntary sector.

The unit cost per hub per year at Y1 prices is £1.75m, broken down across:

- Staffing (clinical, admin, coordination): £850k per hub per year – paediatrician, psychologist, SLT, OT, family support, coordination, management.
- Diagnostics (assessment, neuropsychology, imaging etc.): £180k – covering multidisciplinary assessments at higher complexity and throughput than regional centres (spokes).
- Training (workforce, GP, midwifery, education): £140k – design and delivery of CPD and awareness across large geographies.
- Prevention (alcohol in pregnancy, public campaigns): £120k –campaigns, materials, and coordination.
- Research and evaluation: £95k – contributing to registries, linked datasets, and formal evaluation of outcomes.
- Estates and overheads: £110k – premises, IT, governance, HR/finance overhead.
- Post-diagnostic support (Me and My FASD, workshops, SEND toolkit): £85k – licence and platform costs plus national coordination.
- SPECIFiC parenting programme: £60k – train-the-trainer, multiple cohorts per year.
- Grants to charities/VSCE: £110k – national-level grants to adoption/fostering, lived experience and prevention partners.

So operationally, each national centre is both a direct clinical service and the coordinating centre for its part of the network, responsible for standards, pathways, training content, data, and VCSE partnerships.

What a regional centre (spoke) does – an illustrative example

Each regionally-based FASD centre is typically embedded in an NHS trust/health board or equivalent, delivering the core model locally with stronger emphasis on day-to-day clinical work, local training and prevention activity.

The unit cost per regional centre (spoke) per year is £635k, with the same headings scaled down:

- Staffing: £320k – local multi-disciplinary assessment or team (often part-time across existing staff) plus admin and coordination.
- Diagnostics: £90k – local multidisciplinary assessments, often for less complex cases with complex ones escalated to the hub.
- Training: £45k – local CPD for GPs, midwives, schools, social workers.
- Prevention: £35k – local outreach, maternity pathway work, place-based campaigns.
- Research & evaluation: £20k – data entry/quality, service audits, contributing to national studies led by hubs.
- Estates & overheads: £40k – local premises and operational overhead.
- Post-diagnostic support: £32k – running groups, workshops, and community support using the shared tools.
- SPECIFiC parenting: £28k – delivering local groups with fidelity to the evidence-based model.

- Grants to charities/VCSE: £25k – commissioning small local VCSE partners to deliver peer support, mentoring, or targeted prevention.

Regional centres (spokes) work to the same national specification, but tailored to local systems (ICSs/health boards, LA SEND teams, schools and social care) and are the main interface for families and professionals.

How the FASD PRP network builds over five years

Year 1 – prototype and proof of concept

- One England national hub is established with three England spokes and one Scottish regional centre, reaching around 400 new cases per year.
- Priority is to stand up the core MDT at the hub, pilot diagnostic pathways, begin national-level training content, and test prevention messaging with early adopter areas.
- Governance arrangements, data standards and evaluation frameworks are designed and agreed, ready to scale.

Year 2 – dual-hub network and rapid regional/spoke growth

- The national centre is designated in Scotland, and the total regional centres/spokes increase to 10 (7 England, 2 Scotland, 1 Wales).
- With 1,200 new cases per year reached, networked training and prevention become more systematic, and early avoided-cost effects begin to appear in the model.

Year 3 – full 4-nation coverage

- National centres for Wales and Northern Ireland go live, giving four national hubs/centres in total, and regional centres/spokes increase to 16 (including a first spoke in NI).
- Cohort reach doubles again to 2,400 new cases per year; this is where economies of scale in training, digital platforms and evaluation really start to operate.
- A genuinely four-nation structure with shared standards but devolved implementation.

Year 4 – consolidation to near-steady state

- The regional centres/ spokes grow to 20, with England reaching 14 and Scotland 3
- Cohort reach reaches 3,200 new cases a year and the within-cohort avoided-cost rates for each component (healthcare, SEND, social care, CJS, productivity, housing/benefits) ramp up further in the attribution schedule.
- Attention moves from basic capacity building to quality improvement, advanced training, and more sophisticated multi-agency integration (e.g. youth justice, employment support).

Year 5 – full delivery and optimisation

- The network configuration is held at 4 national centres and 20 regional centres/spokes, again reaching 3,200 new cases, but with the highest attribution rates to avoided costs (for example healthcare at 25%, SEND at 20%, social care at 22% for those reached).
- By this point the programme has fully embedded prevention components, post-diagnostic support pathways, and a maturing evidence base; programme-level avoided costs rise to nearly £11.9m in-year against about £20.5m in programme spend.

- The network is positioned for a subsequent phase either to deepen intensity (more cases per centre (spoke), more complex support) or broaden reach (more centres or satellite clinics) while keeping the same hub infrastructure.

Network layout by year

The model ramps from a single proto-national hub and 4 regional centres (spokes) to a 4-nation hub network with 20 centres (spokes) over five years.

The planned configuration is:

Year	National centres of excellence (UK total)	Regional centres (UK total)	England hubs	England spokes	Scotland National centre of excellence	Scotland FASD centres	Wales national centre of excellence	Wales spokes	NI national centre of excellence	NI spokes
Y1	1	4	1	3	0	1	0	0	0	0
Y2	2	10	1	7	1	2	0	1	0	0
Y3	4	16	1	11	1	2	1	2	1	1
Y4	4	20	1	14	1	3	1	2	1	1
Y5	4	20	1	14	1	3	1	2	1	1

By Y4–5 there would be one hub per nation, with England holding a single national hub and the majority of spokes (14), and the devolved nations each hosting their own national hub and a smaller number of regional centres/spokes. The cohort reached for intensive support grows from 400 new cases per year in Y1 to 3,200 per year from Y4 onwards.

The FASD PRP model fits into existing services

In England (as in other nations) the PRP plugs into existing neurodevelopmental and mental health systems rather than sitting alongside them. They give ICSs and health boards a way to make FASD business-as-usual inside community paediatrics and CAMHS, instead of a niche, ad-hoc add-on. In England there used to be 14 regions – the proposed 14 hubs might for example map onto that system.

Core idea – as an illustration

- National Centres of Excellence = national, higher-tier specialist FASD teams (multidisciplinary, with strongest diagnostic expertise, research/data, supervision and training functions).
- Regional Centres = local/regional FASD-capable centres (spokes) embedded in existing neurodevelopmental, community paediatrics and CAMHS pathways, drawing on the hub for complex cases and support.
- That lets FASD slot into pathways that already exist for autism/ADHD and complex neurodevelopmental need, rather than having to build a parallel system.

Within neurodevelopmental pathways

Most ICSs and health boards across the UK are moving toward integrated neurodevelopmental assessment pathways (single front door for ASD, ADHD, LD, tic disorders, etc.), typically coordinated between community paediatrics and CAMHS.

In that context:

- Regional centres (spokes) could be designated centres with FASD leads inside those integrated pathways.
- They sit in the same MDT structures that already assess ASD/ADHD – paediatrics, psychology, SLT, OT, education – but with added FASD competence and a clear protocol for prenatal alcohol history, differential diagnosis, and comorbidity.
- Referral criteria simply add “suspected prenatal alcohol exposure and neurodevelopmental/ behavioural profile consistent with FASD” to existing neurodevelopmental flags, so no new referral route is needed.
- National centres of excellence provide the top tier for complex or contested cases.
- When the local ND team is uncertain (multiple labels, atypical profile, safeguarding concerns, significant legal/medico-legal implications), the case is escalated to the next tier
- National centres of excellence set the clinical standards, tools, and documentation used across the integrated ND pathway, and host case-discussion/concordance meetings.

Operationally:

- FASD is listed explicitly in ND pathway guidance alongside autism and ADHD, with red-flag combinations (care-experienced, adoption/SGO, maternal substance misuse, etc.).
- Existing ND triage meetings gain an FASD-trained clinician; the pathway diagrams show FASD as one of the core ND outcomes, not an “add-on diagnosis.”

Within community paediatrics

- Community paediatrics already holds much of the ND work – developmental delay, LD, ASD/ADHD, LAC/adoption health, SEND medical advice.

Regional centres (spokes) in community paediatrics would:

- Community paediatricians lead on medical history, growth, physical anomalies, neurological exam and investigations, and coordinate the MDT.
- The “community paediatrics” box in local FASD diagrams (e.g. SIGN 156) becomes formally hooked into the FASD PRP rather than operating in isolation.
- Embed FASD into existing clinics, not create new silos.
- LAC/adoption clinics, “neurodisability” clinics and school-age ND clinics adopt a standard FASD screen and scripted questions about prenatal alcohol exposure.
- Where FASD is suspected, the same team uses assessment protocol (standardised neuropsychology profile, functional assessment, caregiver history) with support from the regional and national centres.
- Use the national centre for escalation and training.
- National hubs and regional centres deliver regular teaching, joint clinics and case supervision to community paeds, using a model similar to epilepsy or neuromuscular networks.
- Borderline cases (e.g. trauma vs FASD vs ASD) can be brought to a national centre rather than bounced between services.
- The idea is to keep ownership of child FASD diagnosis with services that already hold ND and SEND medical responsibility, while giving them the tiered FASD specialist support they currently lack.

Within CAMHS and CYP mental health

CAMHS are already the commissioned home for many ND assessments and for co-occurring mental health conditions.

In the FASD PRP model:

- Regional centres (spokes) could be based inside CAMHS handle FASD where mental health is the presenting problem.
- ND CAMHS teams add FASD to their assessment menu, with a standard approach to taking prenatal histories, using brief FASD screens, and knowing when to involve the hub.
- Where CAMHS holds the lead (e.g. severe mood disorders, self-harm, complex trauma), the FASD clinicians ensure the formulation explicitly includes or rules out FASD and flags educational/SEND implications.
- National and regional centres support CAMHS clinicians to “open the FASD box”.
- Recent qualitative work shows CAMHS clinicians often feel unsure how to explore FASD or where to refer, which leads to avoidance and missed diagnosis.
- The National (hubs) and regional centres (spokes) provide clear referral criteria, consultation slots, and shared-care protocols, so FASD is a recognised part of CAMHS ND and complex-case work, not something clinicians feel they cannot touch.
- Interface with early-support / open-access hubs.
- As “Young Futures” / early-support hubs expand (no-referral walk-in mental health hubs for 11–25s), FASD-trained staff in regional centres (spokes) can offer brief screening and signpost into ND and paediatric pathways, preventing repeated low-yield presentations without a diagnosis.

How other services engage with the FASD PRP

General practice

General practice is the most consistent point of contact for individuals with FASD across the life course, yet it is currently one of the least equipped parts of the health system to identify or coordinate care for the condition. Referrals to FASD assessment proceed where a pathway exists and are routinely denied where one does not — making GP awareness a prerequisite for the whole network to function (Mukherjee et al., 2025). Workforce training delivered by PRP centres creates the referral readiness that makes this possible.

- Identification and referral of children and young people. GPs and practice nurses should refer children showing developmental delay, behavioural profiles inconsistent with chronological age, combined ADHD and autism features unresolved by standard intervention, care-experienced or adopted status, or known prenatal alcohol exposure. (Mukherjee et al., 2025; National FASD, 2026).

- Preconception and antenatal advice. All GPs and practice nurses should provide consistent advice that no level of alcohol in pregnancy has been established as safe, in line with the UK Chief Medical Officers' low-risk drinking guidelines (Department of Health, 2016). AUDIT-C screening should be normalised within pre-pregnancy and early antenatal consultations as designated by NICE QS204 (NICE, 2022) and OHID Maternity High Impact Area 4 (Public Health England, 2020).

- Assessment and care management for adults. Where FASD is suspected in an adult patient — particularly where there is a care-experienced background, school exclusion history, repeated mental health contacts, or a pattern of difficulties inconsistent with other diagnoses — GPs should refer for adult assessment and, following diagnosis, coordinate care across mental health, social care, housing, and employment support (Department of Health and Social Care, 2021; National FASD, 2026).

- SNOMED CT coding. GPs should apply the relevant SNOMED CT codes — introduced in 2024 across EMIS and SystmOne — to the records of all patients with a confirmed or working FASD diagnosis. Consistent use of these codes is the foundational layer of the national data infrastructure: it enables caseload visibility at practice and ICB level, supports appropriate care planning, and ensures individuals are not lost when they move between services or transition to adult care (Mukherjee et al., 2025; Harding et al., 2024).

- Links to disability and wider services. GPs should support access to Personal Independence Payment and other disability benefits by providing clear clinical evidence of the neurodevelopmental basis of an individual's difficulties, and facilitate referrals to adult social care, learning disability services where appropriate, employment support through Access to Work, housing services, and local FASD peer support networks. Where patients have children who may themselves be at risk, standard safeguarding processes apply, informed by FASD awareness (National FASD, 2022; Department of Health and Social Care, 2021).

How it all fits together in practice

National Centres of Excellence:

- sit at national level, usually hosted in a tertiary paediatric ND or academic centre, and:
- hold the heaviest cases,
- set standards,
- own the national registry and linked data work,
- train, supervise and QA the regional centres (spokes).

Regional Centres (Spokes) are:

- embedded in integrated ND pathways (single front door) so FASD is assessed alongside ASD/ADHD rather than after years of failed support;
- spread across community paediatrics (LAC/adoption, developmental, neurodisability clinics) where they can catch high-risk groups early;
- present in CAMHS ND/complex teams so that children and young people presenting with mental health crises are screened and, where appropriate, streamed into FASD-informed care.

The net effect is:

- no new stand-alone service tier the system cannot afford;
- a clear “who does what where” for FASD inside structures commissioners and providers already understand; and
- a realistic way to move from today’s “FASD is nobody’s job” to tomorrow’s “FASD is a routine part of ND, paediatrics and CAMHS”.

Five key evidence-infrastructure components of the FASD PRP

The remainder of this Appendix sets out each of the five components in turn: what it does, why it matters, what it costs, and how it interacts with the FASD PRP.

1. A National FASD Linked Database/ Registry – an illustrative example

Component	**National FASD Registry**
Five-year cost	£9.2m (Y1 £1.2m · Y2 £1.6m · Y3 £2.0m · Y4 £2.2m · Y5 £2.2m)
Build phase	Years 1–2: data architecture, governance, SNOMED CT integration, consent framework
Operating phase	Years 3–5: full registry operation at ~£2.0–2.2m/yr (NJR benchmark £3.95m/yr)
Comparator	National Joint Registry (NJR) — £3.95m expenditure, £3.5m subscription income in 2023/24

Hosted by	Open competition — likely HQIP, NHS England Specialised Commissioning, or a UK Research and Innovation–funded academic consortium

A national clinical registry is the single largest evidence-infrastructure gap in UK FASD. Diagnoses are made — increasingly so, since SIGN 156 and NICE Quality Standard 204. Despite the introduction of FASD SNOMED CT codes in 2024 (Mukherjee et al., 2025) — but there is no national-level dataset that allows the NHS to count them, to follow patients longitudinally, or to audit the implementation of NICE Quality Standard QS204 (NICE, 2022). The registry is, in effect, the FASD field's equivalent of the *National Joint Registry* (NJR) for orthopaedic implants, the National Cancer Registration and Analysis Service (NCRAS) for oncology, or the National Diabetes Audit for diabetes care. Dr Cheryl McQuire and researchers at the University of Bristol (Harding et al., 2024) have mapped out a plan for a national linked FASD database. The following is based loosely on that idea but extrapolated to demonstrate the possible scale if funding were available through an FASD Prevention and Response Fund.

Build phase (Years 1–2): £2.8m

- Data architecture: relational dataset designed against the NHS England Information Standard, with the FASD SNOMED CT codes (sentinel facial features; without sentinel facial features; at increased risk) as the spine.
- Governance: registry steering committee with patient and family representation; Confidentiality Advisory Group (CAG) Section 251 approval; ICO registration; alignment with the DSPT (Data Security and Protection Toolkit).
- Consent: tiered consent model with explicit opt-in for research use, opt-out for routine audit use, drawing on NJR practice and the IGARD precedent for population-scale clinical datasets.
- Integration: bidirectional feed with the four national hubs and twenty regional centres (spokes) via NHS Digital APIs; passive linkage to HES, ECDS and the National Pupil Database via the ONS Secure Research Service.

Operating phase (Years 3–5): £6.4m

- Annual reporting: published audit of NICE QS204 implementation, broken down by ICB footprint (England/Wales).
- Quality assurance: case-completeness benchmarking against the prevalence study (see component 2) and the sentinel surveillance function (see component 4).
- Research access: ISO 27001–compliant safe haven for accredited researchers, modelled on the NHS Digital Data Access Request Service.
- Public dashboard: anonymised, aggregated quarterly publication for use by ICBs, devolved governments, and the third sector.

The £9.2m cost is sized conservatively against published NJR financial statements (NJR, 2025), which show an annual operating cost of approximately £3.95m and an income base of £3.5m in clinician subscriptions. The FASD national linked database is unlikely to be subscription-funded in the same way; the figure here assumes full Exchequer-funded operation, with a stretch ambition to develop a partial subscription model (NHS Trusts, ICBs, devolved governments) in Years 4–5.

2. A definitive UK-wide FASD prevalence study – an illustrative example

Component	**UK-wide FASD prevalence study**
Five-year cost	£7.2m (Y1 £0.8m · Y2 £2.2m · Y3 £2.4m · Y4 £1.4m · Y5 £0.4m)
Design	Four-nation, three-cohort active case ascertainment (ADD-GM Salford method, scaled)
Comparator	ADD-GM (Greater Manchester): McCarthy et al., 2021 — methodology proof of concept
Gap addressed	DHSC FASD HNA identified the absence of a UK prevalence estimate as the single largest evidence gap (DHSC, 2021)
Outputs	Peer-reviewed central UK prevalence estimate; nation-level breakdowns; subgroup estimates for looked-after and adopted children

The DHSC Health Needs Assessment for FASD was unambiguous: the single largest evidence gap in the field is the absence of a definitive UK prevalence estimate (DHSC, 2021). The closest the UK has come to one is the screening prevalence study by McQuire et al. (2019), and the Greater Manchester active-case-ascertainment study by McCarthy et al. (2021). Neither is a definitive UK figure. This component funds one. Researchers at the University of Salford have put forward a proposal for a national prevalence study. Again, the following is based loosely on that idea but extrapolated to demonstrate the possible scale if funding were available through an FASD Prevention and Response Fund.

Design (Years 1–2): £3.0m

- Active case ascertainment using the McCarthy et al. (2021) Greater Manchester (ADD-GM) protocol — a three-stage screen (developmental questionnaire → parent interview → multidisciplinary diagnostic assessment) — scaled to four nations.
- Three cohorts: 5–7 years (early-years population), 10–12 years (school-age population), and 15–17 years (transition-to-adulthood population). The three-cohort design lets the study estimate both prevalence and the secondary-disability lag.
- Recruitment frame: GP-registered population samples in 12 sites (5 England, 3 Scotland, 2 Wales, 2 Northern Ireland), weighted to ensure ethnic, socioeconomic and rural-urban representativeness.

- Embedded sub-study of looked-after and adopted children, where prevalence estimates run an order of magnitude above the general population (DHSC, 2021).

Fieldwork and analysis (Years 2–4): £3.6m

- Approximately 18,000 children screened, 2,700 followed through to interview, 900 through to full diagnostic assessment, against a target precision of ±0.3 percentage points on the central estimate.
- Diagnostic assessment delivered by the network hubs (built-in capacity-building dividend) under standardised SIGN 156 and NICE QS204 protocols.
- Quality assurance through double-blind diagnostic review on a 10% sample, against the Canadian Guidelines (Cook et al., 2016) and the upcoming DSM-5-TR FASD criteria.

Publication and translation (Year 5): £0.6m

- Peer-reviewed publication of central UK prevalence estimate, nation-level breakdowns, and looked-after/adopted children subgroup.
- Policy translation: working papers for HM Treasury, DHSC, the devolved administrations, and the SEND review; lay summary for the third sector.
- Methods archive deposited with the UK Data Service for replication and longitudinal extension.

3. An NIHR-aligned FASD research fund – an illustrative example

Component	**NIHR-aligned FASD research fund**
Five-year cost	£12.0m (Y1 £1.5m · Y2 £2.2m · Y3 £2.5m · Y4 £2.8m · Y5 £3.0m)
Structure	Standing pot, commissioned in partnership with NIHR / MRC / ESRC
Comparator	NIH/NIAAA R61/R33 envelope for FASD intervention research (NIH, 2025)
Award types	Intervention trials, biomarker development, lifecourse epidemiology, implementation science, lived-experience research
Independent review	Annual call, expert peer review, parent/lived-experience panel, publication of awarded portfolio

The UK has produced FASD prevalence epidemiology (McQuire et al., 2019, McCarthy et al., 2021) and the primary-care SNOMED implementation evidence base (Mukherjee et al., 2025) — on a shoestring. Most UK FASD research is grant-funded one project at a time, with no standing infrastructure and no commissioning pathway into routine practice. This component creates that pathway.

Award portfolio (illustrative, over five years)

- Intervention trials (~£5m, ~4 awards): randomised trials of FASD-specific parenting, educational, and post-diagnostic support interventions, prioritising the SPECIFiC programme (University of Salford) and the Me and My FASD resources for scaled UK evaluation.
- Biomarker development (~£2.5m, ~3 awards): meconium and dried-blood-spot biomarker work to refine antenatal alcohol-exposure measurement, with translational potential into routine maternity screening.
- Lifecourse epidemiology (~£2m, ~2 awards): linked-data studies using the linked database/registry (component 1) and surveillance (component 4) to track secondary disability, education trajectory, justice contact, and employment over the lifecourse.
- Implementation science (~£1.5m, ~3 awards): studies of how the FASD PRP is taken up across the four nations, with attention to equity, workforce, and digital infrastructure.
- Lived-experience research (~£1m, ~5 awards): patient, parent and carer–led research, including studies of diagnostic experience, transition to adulthood, and the parental advocacy pathway.

The fund is sized against the equivalent NIH/NIAAA envelope, which commissions FASD R61/R33 translational research at $4–6m per cycle in the US (NIH, 2025). Per-capita parity with NIH would suggest a UK ask of approximately £1m per cohort year; the £2–3m profile here reflects a deliberate front-loaded investment to clear the backlog of unfunded FASD intervention trials accumulated over the past two decades.

4. Sentinel surveillance and data linkage – an illustrative example

Component	Sentinel surveillance and data linkage
Five-year cost	£2.9m (Y1 £0.4m · Y2 £0.5m · Y3 £0.6m · Y4 £0.7m · Y5 £0.7m)
Sites	20 NHS sentinel sites contributing standardised data to the registry
Data spine	FASD SNOMED CT codes (introduced 2024); EMIS/SystmOne primary-care extracts
Linkage targets	Maternity (CMACE/MBRRACE), paediatric (CYPHS), primary care, ECDS, National Pupil Database, Justice Data Lab
Use cases	Early-warning indicators, ICB-level population health management, registry quality assurance

Sentinel surveillance is the lightweight complement to the full registry. Where the registry captures every diagnosed case in the country, sentinel surveillance commissions a representative network of NHS sites to contribute richer, standardised, linked data that fills the gaps the registry cannot reach — particularly antenatal exposure data, primary-care presentation patterns before formal diagnosis, and the educational and justice trajectories that follow diagnosis.

What the network does

- Twenty NHS sentinel sites, commissioning standardised data extracts on FASD-related presentations using the new SNOMED CT codes.
- Quarterly data submission to the registry safe haven; quality assurance against case-completeness benchmarks; annual publication of population health management dashboards by ICB footprint.
- Linkage to maternity datasets (MBRRACE-UK), paediatric community datasets (CYPHS), primary care (CPRD/Aurum), emergency care (ECDS), education (National Pupil Database), and youth justice (Justice Data Lab) under standing IGARD approval.
- Early-warning function: identification of geographical or demographic clusters of new FASD diagnoses, with rapid feedback to commissioners and Directors of Public Health.

The £2.9m budget is modest because the sentinel sites are leveraging the infrastructure funded under the main network — no new clinical workforce is required. The cost is in the data infrastructure: extract, linkage, governance, and the population health management analytics capability.

5. Implementation science and independent evaluation – an illustrative example

Component	Implementation science and independent evaluation
Five-year cost	£2.2m (Y1 £0.3m · Y2 £0.4m · Y3 £0.5m · Y4 £0.5m · Y5 £0.5m)
Independence	Contracted to an external academic partner via open competition (e.g. NIHR PRU)
Methods	Realist evaluation; process tracing; cost-utility modelling against the Green Book; equity audit
Deliverables	Annual public reports; mid-term review (Y3); final five-year evaluation (Y5)
Audience	HM Treasury, DHSC, NHS England, devolved governments, ICBs, the Public Accounts Committee

It is the smallest line in the £33.5m programme of evidence-led components, and the most important.

Evaluation design

- Realist evaluation: what works, for whom, under what circumstances, across the four-nation rollout — drawing on the Pawson and Tilley framework standard in NIHR-commissioned health systems research.
- Process tracing: how the network is taken up by ICBs, by devolved health boards, and by the third-sector and family-led organisations that have historically held the field together.
- Cost-utility modelling: refinement of the Invest-to-Save BCR against actual cohort outcomes, using the Green Book 3.5% discount rate and the most recent QALY estimates from the FASD intervention literature.
- Equity audit: distributional analysis of network access and outcomes against Core20PLUS5 PLUS groups (NHS England, n.d.), with particular attention to looked-after children, ethnic minority communities, and inclusion health groups.
- Mid-term review at Year 3 with formal advice to HM Treasury; full evaluation at Year 5 timed to inform the next Spending Review.

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