NATIONAL ORGANISATION FOR FASD

The Cost of Inaction on FASD:

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

June 2026

Quick summary in 12 charts

AT A GLANCE · UNDERSTANDING FASD

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).

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.

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.

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.

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.

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.

AT A GLANCE · CONCLUSION

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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.

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.

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.

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)

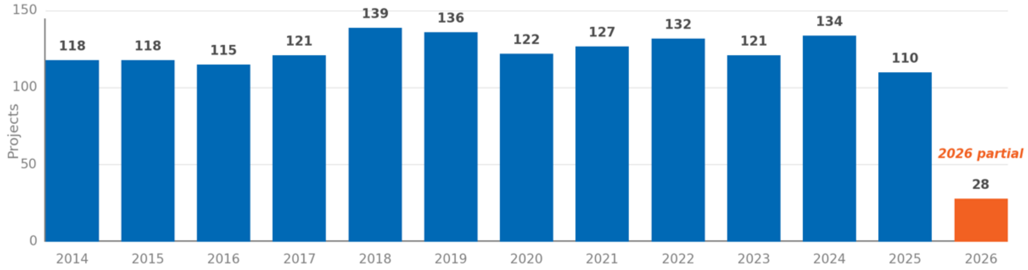
2,449
NIH-funded FASD
research projects since 1999

$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.

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.

AT A GLANCE · APPENDIX E

A model four-nation FASD Prevention and Response Programme

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.

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.