How we built the numbers — methods overview for journalists

The Cost of Inaction on FASD (June 2026) · National Organisation for FASD

This short overview explains the three sets of figures that drive the report and the headlines: the £9.2 billion annual societal cost, the £97.5m five-year cost of the proposed national programme, and the Hansard evidence that FASD is roughly thirteen times less visible in Parliament than autism. Each set of numbers uses an internationally accepted method, is checked against a UK or four-nation needs assessment, and has been stress-tested with sensitivity ranges.

That said, we understand the limitations of this research and we call on Governments, working with university partners and those of us in the Third Sector, to do deeper studies using UK data and further research.

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1. The £9.2 billion annual societal cost — and £160 billion over 30 years

What it is. A best-available estimate of the recurring societal cost of FASD in the UK across health, education, social services, productivity, criminal justice and housing/benefits.

Approach. No UK-native lifetime cost-of-illness study of comparable scope exists, so using Perplexity AI the model transfers the most widely cited international estimate — Greenmyer et al. (2018), $596,000 per case in the United States — to the UK using the **two-step purchasing power parity (PPP) method recommended by Shemilt et al. (BMJ, 2010)** and used as standard NICE / HTA / OECD practice for cross-country cost transfer.

- **Step 1 — GDP PPP**: convert $596,000 to GBP using the OECD/World Bank GDP PPP factor of 0.69, 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 the total) to reflect that US healthcare prices are roughly twice UK NHS prices for clinically equivalent services (OECD Health at a Glance 2025). Productivity, education, social-services, justice and housing/benefits costs retain only the GDP PPP conversion, because those sectors do not share the same UK/US price gap.

This yields a final **lifetime cost of £359,835 per diagnosed UK case — 16% lower than a naive market-FX conversion would have produced**. A +20% premium is applied to undiagnosed cases as a conservative working assumption, pending UK linked-data research.

Prevalence anchor — grounded in UK active case ascertainment. We apply the prevalence range from the **Salford / McCarthy et al. (2021)** active case ascertainment study — the most rigorous UK study, conducted in mainstream Greater Manchester primary schools — which found 1.8–3.6% prevalence, with a 2.7% midpoint. None of the affected children in Salford had a prior FASD diagnosis. This is consistent with the DHSC FASD Health Needs Assessment (2021) and with international active-ascertainment studies that triangulate to 2–5% in similar populations (Lange et al., 2017; Popova et al., 2017; May et al. for the US).

Sensitivity and robustness. Two assumptions drive most of the variability: underlying prevalence and the discount rate applied to future costs. The report runs the full grid:

Scenario	Prevalence	Discount rate	30-yr cumulative PV cost
Lowest plausible	1.0%	5.0%	>£40 billion
Conservative	1.8% (Salford lower bound)	3.5%	>£100 billion
Green Book central	2.5%	3.5% (HM Treasury Green Book social time preference rate)	£131 billion
Headline (Salford midpoint)	2.7%	3.5%	**£160 billion**
Upper case	5.0%	2.0%	substantially higher

The policy conclusion is robust to either lever: even at the bottom of the Salford range and with the steepest defensible discount, the 30-year cost still exceeds £40 billion. The case for action does not depend on the upper-bound prevalence figure.

The dominant uncertainty is the diagnosis rate, not prevalence. If formal UK identification is materially below the 10% working assumption (Salford found 0 of 8 previously identified), the undiagnosed-case premium drives the bill higher, not lower.

Stated limitations (also in Appendix A of the full report). - Cost transfer relies on US base data; no UK-native lifetime cost study of comparable scope exists. - The 20% undiagnosed-case premium is a conservative judgement, not an empirical estimate. - The model values mortality and quality-of-life losses only insofar as they appear in productivity — a full QALY-based valuation would yield a higher figure. - Costs are in 2024 GBP; no adjustment is made for future medical-cost inflation above the discount rate. - **Caregiver costs (out-of-pocket spending, foregone earnings, reduced working hours) are excluded.** The international literature (Greenmyer et al. 2018; Stade et al. 2006; Darragh et al. 2025) confirms these are substantial; including them would raise the estimate further.

Bottom line for journalists. Across every defensible combination of assumptions in this analysis, FASD imposes a recurring societal cost in the low tens of billions of pounds per year — an order of magnitude above the cost of any plausible prevention or early-identification programme.

2. The £97.5m five-year programme cost — and 3.56:1 return

What it is. The cost of the proposed FASD Prevention and Response Programme (PRP) — a four-nation FASD Prevention and Response network of 4 national centres of excellence and up to 20 regional centres, plus five core evidence-infrastructure components (national linked database / registry, UK-wide prevalence study, NIHR-aligned research fund, sentinel surveillance and independent evaluation).

Bottom-up build, not top-down assumption. Using Perplexity AI, each centre's annual cost is built up from nine standard service headings — staffing, diagnostics, training, prevention, research & evaluation, estates & overheads, post-diagnostic support, SPECIFiC parenting programme, and grants to VCSE partners — benchmarked against published NHS unit costs and existing FASD service costings.

Component	Unit cost / year
National centre of excellence (one per nation)	**£1.75m**
Regional centre (up to 20 across the UK)	**£635k**

Total network: **£70.7m over five years (PV, Green Book 3.5% STPR)**. Add the five evidence-infrastructure components (registry, prevalence study, research fund, surveillance, independent evaluation = £31.1m PV) and total programme spend reaches **£97.5m PV over five years**.

Five-year ramp (so the headline is honest about phasing).

Year	National centres	Regional centres	New cases reached
Y1	1 (England)	4	~400
Y2	2 (England, Scotland)	10	1,200
Y3	4 (full UK coverage)	16	2,400
Y4	4	20 (steady state)	3,200
Y5	4	20	3,200

Avoided cost calculation. Avoided lifetime cost per case averted rises from 10% of the per-case figure in Year 1 to 25% by Year 5, reflecting the well-established evidence that earlier diagnosis and intervention reduce secondary harms (school exclusion, justice contact, mental-health crises, lost employment). Across the Y1–Y5 cohort of approximately 10,400 people, the network delivers **£236.7m PV in avoided lifetime costs** against the £97.5m PV programme cost.

Headline metric	Value
Programme cost (5 yrs, PV)	£97.5m
Avoided lifetime cost (Y1–Y5 cohort, PV)	£236.7m
Lifetime benefit–cost ratio	**3.56 : 1**
People supported (Y1–Y5 cohort)	~10,400

Headline metric	Value
Ask as % of UK alcohol duty	**0.25%**

Sensitivity bands. The report stress-tests the ratio against (a) slower ramp (one year delay across all years), (b) lower avoided-cost share (capping at 15% per case rather than 25%) and (c) higher unit costs (+20%). In every tested combination the benefit–cost ratio remains comfortably above 1:1; the central case is 3.56:1.

International benchmarks. The unit costs and the national/regional hub-and-spoke architecture are consistent with funded FASD networks in **Canada** (Manitoba FASD Network, CanFASD) and **Australia** (NOFASD Australia, FASD Hub Australia), and with the **DHSC FASD Health Needs Assessment (2021)** which has been the UK's standing evidence base since the Department commissioned it. The 0.25% alcohol-duty allocation is benchmarked against the Soft Drinks Industry Levy precedent — a UK product-specific health levy whose proceeds are hypothecated to a defined response (£286m/year to children's health since 2018; see Appendix D).

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3. The Hansard analysis — FASD is mentioned 13× less than autism

What it is. A systematic search of the Hansard parliamentary record (House of Commons, House of Lords and devolved legislatures where carried) from December 1962 to March 2026, counting mentions of FASD, autism and ADHD-related terms.

Dataset. 8,565 neurodevelopmental-related entries. These were identified by using Anthropic's Claude Ai model to create code to access the They Work For You Hansard API to search for a controlled vocabulary of category terms agreed before counting:

- **Autism** (5 terms: Autism, Autism Spectrum Disorder, Asperger syndrome, ASD)
- **ADHD** (2 terms: ADHD, Attention Deficit Hyperactivity Disorder)
- **FASD** (8 terms: Foetal alcohol syndrome, Foetal Alcohol Spectrum Disorder, FASD, Foetal Alcohol Spectrum Disorders, Fetal Alcohol Spectrum Disorder, FAS, Fetal alcohol syndrome, ARND)

This deliberately inclusive FASD term-set — including older / less standard variants — biases the count in FASD's favour. Even with that broader net, the result holds.

Headline counts.

Category	Mentions	Share
Autism	6,148	71.8%
ADHD	1,953	22.8%
FASD	**464**	**5.4%**
Total	8,565	100%

- **Autism is mentioned 13.3 times as often as FASD** (6,148 ÷ 464)
- **ADHD is mentioned 4.2 times as often as FASD** (1,953 ÷ 464)

By nation.

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

Scotland leads on FASD visibility; Wales registers a single mention in the entire dataset — a four-nation equity gap, not just a UK-aggregate one.

Time trend. FASD mentions are in single digits or low teens through the 2000s, rise to a peak of 45 in 2018 (the year NICE QS204 and SIGN 156 were under active discussion), and then settle back into the high teens to high twenties per year. Autism and ADHD mentions, by contrast, accumulate in the thousands across the same window.

The proportionality test. FASD prevalence is 2–4% of the UK population — at the upper bound, more prevalent than autism. Its share of parliamentary debate is 5.4%. Even at the conservative Salford lower bound, the gap between population need and parliamentary attention is roughly an order of magnitude.

Methodological notes. - Counts are of *category mentions*, not unique speeches: a single speech mentioning a term twice contributes two. - The nation attribution uses the assigned chamber where available; UK-wide / unspecified covers House of Commons and Lords business not flagged with a devolved interest. - Search is term-matching, not semantic — a debate that discusses FASD without naming it would not be captured. This biases the result against FASD, not in its favour. - The full dataset, term list and counting code are available from National FASD on request to support independent replication.

Why we are confident in these numbers

1. **Methods are mainstream, not novel.** Two-step PPP cost transfer (Shemilt 2010) is standard NICE / HTA practice. Hub-and-spoke unit costing follows published NHS service costings. Hansard category counts use a transparent term list that researchers, journalists or other charities can replicate exactly.
2. **Numbers are grounded in UK and four-nation needs assessments.** The DHSC FASD Health Needs Assessment (2021), NICE QS204, SIGN 156 and the Welsh and Northern Irish FASD evidence base all characterise FASD as a major neurodevelopmental condition requiring systematic identification and response. Our prevalence anchor — Salford / McCarthy et al. 2021 — is the UK's most rigorous active-case ascertainment study.
3. **Sensitivity ranges show the conclusion is not assumption-dependent.** The policy case is robust across the full plausible prevalence range (1–5%), discount

rates (2–5%), and programme-cost stress tests (slower ramp, higher unit costs, lower avoided-cost share).

4. **Benchmarked internationally.** Cost-of-illness figures, hub-and-spoke architecture and hypothecated-levy precedent (SDIL) all have established comparators in Canada, Australia, the US and within the UK's own recent legislative practice.
5. **Conservative on three measurable dimensions.** The PPP method produces a 16% *lower* per-case cost than naive FX conversion; the cost model excludes caregiver out-of-pocket and earnings losses; and the Hansard term list is deliberately wide for FASD.

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Citations and underlying data: Appendices A (cost-model methodology), B (Hansard evidence), C (programme cost build-up) and D (SDIL precedent) of *The Cost of Inaction on FASD* (National Organisation for FASD, June 2026).