



Family action pack: using the Cost of Inaction on FASD report

For families across England, Scotland, Wales and Northern Ireland

This guide explains the report in plain language and gives practical ways to use it with politicians, health bodies and local media.

What this report says

The report's message is simple: the UK is already paying a very high price for not acting on FASD.

It says:

- FASD is a lifelong neurodevelopmental condition caused by alcohol-exposed pregnancies.
- FASD is common, but many people are still undiagnosed.
- 2–4% of children in mainstream primary schools may meet criteria for FASD or possible FASD.
- The annual societal cost is about £9.2 billion.
- The 30-year burden is about £160 billion.
- A four-nation FASD Prevention and Response Programme could be funded through an amount equivalent to 0.25% of alcohol duty receipts.
- The proposed five-year programme would cost £106 million inside a £157.5 million funding envelope.
- The lifetime benefit-cost ratio is estimated at 3.56 to 1.

Key takeaways for families

- FASD is real, common and too often missed.
- Many children, young people and adults are misunderstood because services do not recognise FASD early enough.
- The report says the “hidden majority” of people with FASD are likely to be living with birth families, in mainstream schools and in ordinary communities, without recognition or support.
- Guidance already exists, but it is not being implemented consistently.

- Major reforms in SEND, mental health, justice, benefits and maternity care will fail people with FASD unless FASD is included clearly.
- The report calls for action now, to create an FASD Prevention and Response Programme now, not after more years of delay.

What families can ask for now

You do not need to explain the whole report. Pick one or two local asks and repeat them clearly.

Good asks include:

- Recognise FASD explicitly in local health, education and social care planning.
- Improve diagnosis and post-diagnostic support pathways.
- Make sure maternity services give clear advice that the safest option in pregnancy is not to drink alcohol, and record prenatal alcohol exposure properly.
- Include FASD in SEND, ALN, ASL, justice and mental health reforms.
- Support the proposed four-nation FASD Prevention and Response Programme.

Find your representatives and local health body

England

Find your MP

- UK Parliament MPs directory: <https://www.parliament.uk/mps-lords-and-offices/mps/>
- TheyWorkForYou postcode tool: <https://www.theyworkforyou.com/mp/>

Find your local ICB

- NHS England ICB contacts: <https://www.england.nhs.uk/contact-us/about-nhs-services/contact-your-local-integrated-care-board-icb/>

Scotland

Find your MSPs

- Scottish Parliament postcode tool: <https://www.parliament.scot/msps/current-and-previous-msps/find-your-msp>

Find your local NHS Board

- NHS Scotland service directory: <https://www.scot.nhs.uk/organisations/>

Wales

Find your MSs

- Senedd member search: <https://senedd.wales/find-a-member-of-the-senedd/>
- Senedd information about Members: <https://senedd.wales/how-we-work/about-members-of-the-senedd/>

Find your local Health Board

- NHS Wales Health Boards:
<https://111.wales.nhs.uk/localservices/?s=HealthBoards&pc=n&sort=default>

Northern Ireland

Find your MLA

- Northern Ireland Assembly MLA locator: <https://www.niassembly.gov.uk/your-mlas/locate-your-mla2/>
- Electoral Office “find my elected representatives”: <https://www.eoni.org.uk/results-data/find-my-elected-representatives/>

Find your local Health and Social Care Trust

- HSCNI trusts directory: <https://online.hscni.net/our-work/performance-and-service-improvement/hsc-trusts/>

Contacting local media

You can also contact:

- Your local newspaper
- Your local radio station
- BBC local or regional news
- Community news websites

- Local digital news outlets

A short email with a personal story, one local fact and one clear ask is more likely to be used than a long policy note.

Tips for contacting people

- Keep it short: one page or one screen is enough.
- Use plain language and one or two facts from the report.
- Add your own family experience if you are comfortable doing so.
- Ask for one concrete action.
- Give a deadline for reply if you want one.
- Keep a copy of what you send.
- Include your full name and postcode when writing to an elected representative.

Sample email or letter template to an elected representative

Subject: Please act on the Cost of Inaction on FASD report

Dear [MP/MSP/MS/MLA name],

I am writing as a constituent and [as a person with FASD or family member of a person with FASD].

National Organisation for FASD's *Cost of Inaction on FASD* report shows that FASD is common, under-recognised and costly, with an estimated annual societal cost of about £9.2 billion in the UK. The report also says many people with FASD are still missed, especially those living with birth families and in mainstream services.

This matters to my family because [add 2–3 sentences in your own words].

I am asking you to:

1. Read the report and raise FASD with the relevant minister or service lead.
2. Support action to improve diagnosis and post-diagnostic support.
3. Support explicit inclusion of FASD in current reforms in health, education and social care.
4. Support the four-nation FASD Prevention and Response Programme with funding as proposed in the report.

Please let me know what action you will take.

Yours sincerely,

[Your name]

[Your address/postcode]

[Your email]

[Your phone number]

Sample email to a local health board, ICB or Trust

Subject: Request for action on FASD in local services

Dear [ICB/Health Board/Trust name],

I am writing as a local [person with FASD or family member] concerned about support for people with FASD.

The *Cost of Inaction on FASD* report says that many people remain undiagnosed or unsupported and that better prevention, diagnosis and post-diagnostic support would improve outcomes and reduce later crisis. It also says guidance already exists, but implementation is uneven.

Please tell me:

- What FASD diagnostic pathway exists locally and what steps you are taking to improve this.
- What post-diagnostic support is available and what steps you are taking to improve this.
- How local maternity services record prenatal alcohol exposure and give advice on alcohol in pregnancy and what steps you are taking to improve this.
- What plans you have to improve FASD-informed training and support.

I would be grateful for a written reply.

Yours sincerely,

[Your name]

[Your address/postcode]

[Your email]

Sample email to local media

Subject: Local families need action on FASD

Dear [journalist/newsdesk name],

A new UK report, *Cost of Inaction on FASD*, says FASD is common, under-recognised and costs society about £9.2 billion each year. It says many families are still left without diagnosis, support or understanding.

This is a local issue because [add your local example here].

I would like to encourage coverage of what the report means for families in [area]. I would be happy to speak further / I can put you in touch with National Organisation for FASD.

Best wishes,

[Your name]

[Your contact details]

One-sentence summary lines families can use

- “Families are paying the price for a system that still misses FASD too often.”
- “The report shows the UK cannot afford to keep ignoring FASD.”
- “This is about earlier recognition, better support and fewer families reaching crisis point.”
- “The cost of action is small compared with the cost of doing nothing.”