

For immediate release:  
11 June 2025

**Following death of BBC RATW star Sam Gardiner, 100 leading FASD experts, practitioners and advocates call for action so people with FASD are not left more vulnerable following government changes**



The National Organisation for FASD has released a call for national leadership on alcohol, pregnancy and FASD from more than 100 of the country's leading practitioners, researchers and people with FASD and their families who attended the FASD in the UK conference at the University of Salford on 10 June 2025. The letter was signed following a moment of silence for Sam Gardiner, the former Race Across the World star whose family have been seeking to raise awareness of FASD after his death and to raise funds for National FASD. The unprecedented call for action says, "planned changes to benefits and education mean that people with FASD are now facing a more uncertain and risky future than ever." It calls for funding via an FASD Prevention and Response fund.

Jonny Gray, Sam Gardiner's uncle, said, "We are pleased to see the national response following Sam's death. This call from 100 leading experts shows that there is a need for urgent action."

National FASD's Chief Executive Sandra Butcher said, "These signatures represent the tip of the iceberg of people all across the country who are trying to get their local, regional and national leaders to do the right thing, to implement the improvements called for by DHSC and the National Institute for Health and Care Excellence. This the time for leaders to bury their heads in the ground on alcohol, pregnancy and FASD at a time when the nation is reevaluating its priorities."

Joanna Buckard, Director of Innovation for National FASD said, "This letter is timely and important. FASD is preventable and more should be done at statutory level to raise awareness of this common, lifelong condition. Amazing young people with FASD are being left vulnerable without the supports that we have a duty to provide. Funding appropriate support can reduce the risk of people with FASD being over represented in criminal justice, homeless, mental health and substance misuse populations. This is essential work, there is no justification to fail to act."

ENDS

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## **BACKGROUND INFORMATION: The letter**

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.**

- Dr Toby Aarons, University of Salford
- Zahra Alijah, Parent
- Professor Clare Allely, University of Salford Researcher
- Mrs Tracy Allen, Shared lives carer
- Elijah Arodiogbu, University of Salford
- Dr Vidhya Sampath Arutperumselvi, Consultant Community Paediatrician
- Mrs Rachel Beckford, Parent and Clinical Psychologist
- Katie Brewin, Adoptive parent
- Jenny Brightman, Adoptive parent
- Mrs Aliy Brown, Parent of three young people with FASD
- Rich Brown, Parent / carer
- Joanna Buckard, The National Organisation for FASD

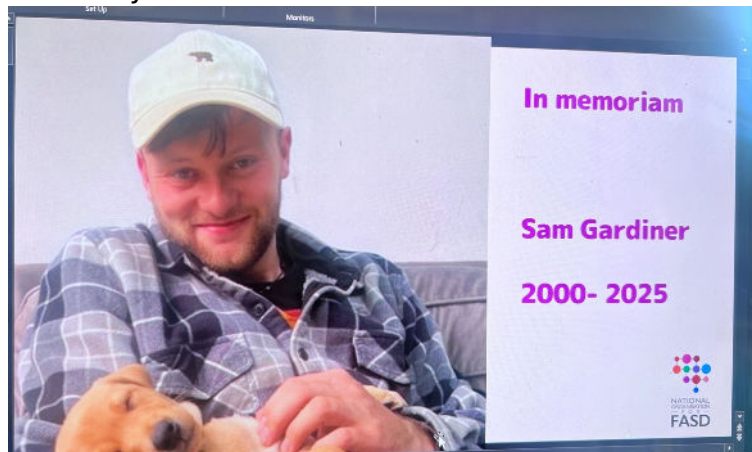
- Mr. Phillip Burgess, University of Salford
- Catherine Burke, Carer
- Ms Morag Burns, Speech and Language Therapist
- Sandra Butcher, The National Organisation for FASD
- Mrs Melanie Campbell, HCPC occupational therapist
- Dr Alexandra Carlisle, UK FASD Clinic Lead, Surrey and Borders NHS Trust
- Dr Jamie Carter MBBS, BSc, FRCPCH, DTM&H, LFFLM, NHS & PDTSAS
- Martin Clarke, Adoptive Parent & FASD trainer
- Professor Penny Cook, University of Salford
- Toni Cooper, CAMHS
- Rachel Cottrell, Cheshire and Wirral partnership
- Mandy Craig, Sheffield Children Safeguarding Partnership
- Gillian Croft, Parent
- Dr Jaya Dixit, Barnsley NHSFT
- Geoff Dunbar, Parent
- Paul Earl, Member of the public
- Lorraine Egan, Foster carer and FASD Network family advocate
- Miranda Eodanable, University of Edinburgh
- Mrs Denise Farrow, Charity - health operations manager health
- Dr Claire Farrow, Focus Mental Health Solutions
- Miss Alice Foote, Individual with FASD and advocate
- Louise Fox, Speech and language therapist
- Mrs J E Garofalo, Parent
- Anita Gibbs, Carer
- Tania Goddard, Researcher
- Janet May Griffin, Road2FASD, parent carer advocate
- Rossino Elia Griffin, Road2FASD
- Anna Hamlet, Occupational Therapist, Professional
- Jasmin Hernon BSc, Speech and language therapist working with children with FASD
- Hamish Hill (CPsychol), Clinical Psychologist working with families affected by FASD, Beacon House, Anna Freud Centre
- Dr Helen Howlett, Nurse, midwife, commissioner, researcher and advocate for women and FASD
- Miss Hollie Hughes, Assistant Educational Psychologist
- Mrs Audrey Johnson, Parent
- Steve Johnson, Parent
- Jane Jones, Healthcare clinician
- Lucy Kamau, FASD Lead in RAA
- Maria Kanaris, Parent
- Harrison Lee, Clinical Associate Psychologist, Meadows Psychology Service
- Dr Alexandra Livesey, SABP NHS trust
- Dr Lorraine Lockhart, Clinical Psychologist, FASD Hub, Adoption UK
- Dr Charlotte Mackinnon, Bolton NHSFT and GM ICB
- Dr Elaine McCullough, Clinical Psychologist
- Mrs Suzanne McDermott, Parent
- Dr. Stewart McDougall, University of Edinburgh

- Helen McGlashan
- Dr Cheryl McQuire, University of Bristol
- Danielle Miles, Speech and Language Therapist seconded to Sheffield Youth Justice Service
- Dr Sarah Mills, MBBS, FRCPCH, Diagnosing Paediatric Consultant
- Freya Morris, Assistant Psychologist, Surrey and Borders Partnership NHS Foundation Trust
- Prof Raja Mukherjee MBE, National FASD Clinic Surrey
- Dr Christiane Nitsch, Lewisham and Greenwich NHS Trust and Kent and Medway ICB
- Jayne O'Neil, Parent carer
- Barbara Ogston, Adoption UK
- Dr Angela Oliver, Barnsley Hospital NHS Trust
- Cathy Parkinson, Parent
- Mrs Michelle Paterson, Parent
- Dr Jasmine Peris, Clinical Psychologist and FASD Assessment Clinician
- Cindy Perkins, Elucidate Training and parent
- Dr Katherine Perryman, University of Salford
- Dr Alan Price, University of Salford
- Mrs Hazel Purfield, Parent
- Prof Lisa Redfern, Honorary Professor University of Salford
- Nazia Rehman, NHSGM
- Roisin Reynolds, Strategic Lead GM NHS ICB Professional
- Brian Roberts, The National Organisation for FASD\*
- Dr Eleanor Salter-Jones, Sheffield City Council, Adoption UK
- Filipa dos Santos Ramos, Trainee Clinical Psychologist, Trainee Clinical Psychologist - FASD SABP
- Dr Ruth Seed, Clinical Psychologist working for CWP NHS Trust
- Alice Sewell, The National Organisation for FASD\*
- Dr Emma Sheffield, Educational Psychologist
- Ellie Shepherd, Trainee Clinical Psychologist, Lancaster University
- Lesley Small, Parent
- MRD Samantha Steadman, Cheshire and Wirral Partnership Mental Health Trust
- Nicola Swan NHS
- Dr Inyang Takon, Paediatrician and FASD specialist
- Professor David Tappin, Glasgow University
- Mrs Nikki Taylor, Parent
- Mike Taylor, FASD Ireland
- Anthea Tinsley, Parent
- Sophie Trees, Trainee Clinical Psychologist working in the Specialist FASD Clinic in Surrey and Borders Partnership NHS Foundation Trust
- Katie Watts, The National Organisation for FASD\*
- Ms Anna Webster, Neurowise & parent
- Dr Kathryn Whyte, Clinical Psychologist
- Dr Carrie Williams, UCL & North East London Foundation Trust
- Mrs Helen Worth, Adoptive parent
- Matthew Worth, Adoptive parent of 2 children with FASD

- Stacey, Healthcare clinician
- Anonymous, Parent and advisory teacher
- Researcher, University of Salford
- Practitioner, Focus Mental Health
- Anonymous, Parent
- Clinical Psychologist, Chrysalis Associates

#### Photos:

A moment of silence was held for Sam Gardiner at the FASD in the UK Conference at the University of Salford on 10 June 2025.



Joanna Buckard and Sandra Butcher from The National Organisation for FASD led the moment of silence for Sam Gardiner



**For more information about Sam Gardiner's fund:**

<https://www.justgiving.com/page/sam-gardiner>

[https://nationalfasd.org.uk/in\\_memory\\_of\\_sam\\_gardiner/](https://nationalfasd.org.uk/in_memory_of_sam_gardiner/)

# Background information

## What is FASD?

“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.” (Source: [FASD: Preferred UK Language Guide](#), Seashell Trust/National FASD, 2020)

## How many people have FASD?

A recent [gold-standard study](#) by the University of Salford showed that 2-4% have FASD. That’s a higher rate than autism. Most people with FASD are unrecognised, undiagnosed or misdiagnosed.

## How is FASD diagnosed?

The [SIGN 156](#) guideline is the guidance now across Scotland, England and Wales. It says that to have a diagnosis you need to have “Pervasive and long-standing brain dysfunction, which is defined by severe impairment...in three or more of the following neurodevelopmental areas of assessment”: motor skills; cognition; memory; neuroanatomy/ neurophysiology; academic achievement; language; attention; executive function, including impulse control and hyperactivity; affect regulation; or adaptive behaviour, social skills or social communication.

## Alcohol in pregnancy in the UK

Over [40% of women](#) in the UK use alcohol during pregnancy, making the UK the [4<sup>th</sup> highest rate](#) of alcohol exposed pregnancies in the world.

## What is the NICE Quality Standard?

[NICE Quality Standard 204](#) (2022) identifies areas for improving quality of care regarding: advice on avoiding alcohol in pregnancy; prenatal alcohol exposure; referral for assessment; neurodevelopmental assessment; and management plan. Unlike guidance, local areas in England and Wales have to ‘have regard’ for Quality Standards and report on progress in improving care.

# Key official quotes

“There is no known safe level of alcohol consumption during pregnancy. NICE, [Fetal Alcohol Spectrum Disorder Quality Standard 204](#) (2022).

“Drinking any alcohol can cause difficulties in pregnancy and can result in Fetal Alcohol Spectrum Disorder (FASD), causing lifelong disabilities for children. There is no safe time or safe amount of alcohol to drink during pregnancy.” Public Health England, “[Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy](#)” (2020)

“There is no known safe level of alcohol consumption in pregnancy. Even low to moderate levels of PAE [prenatal alcohol exposure] can negatively impact a fetus and these adverse consequences can persist into adulthood.” SIGN 156, “[Children and Young People Prenatally Exposed to Alcohol](#)” (2019)

“The government recognises the importance of FASD.” Department of Health and Social Care, “[FASD Health Needs Assessment for England](#)” (2021)

“There is no ‘mild’ FASD.” “[FASD Health Needs Assessment for England](#)” (2021)

“Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay.” SIGN 156, “[Children and Young People Prenatally Exposed to Alcohol](#)” (2019)

“The needs identified for this population group focus on: a lack of robust prevalence estimates in England; the importance of multi-sector working to support individuals through the life course; better training and awareness for health professionals; better organisation of services to improve accessibility; a need to develop innovative approaches to support those living with the condition.” “[FASD Health Needs Assessment for England](#)” (2021)

“[W. Sussex] appears to be gatekeeping access to its services ... The council has a duty to ensure there is sufficient educational provision available in its area to meet demand. The lack of suitable placements for the boy in the council’s SEN schools suggests it is not meeting this duty.” [Local Government and Social Care Ombudsman ruling](#) (2021) that a local area couldn’t exclude someone with FASD from services for those with ‘autism and learning disability.’

“No specific public health messaging on fetal alcohol spectrum disorder (FASD) has been undertaken in the last five years.” Maggie Throup, Parliamentary Under-Secretary for Health and Social Care, [Hansard, 21 Sept 2021](#) (Note this coincides with the 2016 release of the CMOs’ guidance)

“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.” [Chief Medical Officers guidance](#) (2016)

“The Government take alcohol concerns, across the board, very seriously and even more so when they relate to pregnancy. We are making progress—I hope—to prevent future FASD cases, and trying to change the landscape on prevention and treatment for those affected. But there is not an ounce of complacency in us—there certainly is not in me. We will continue to work towards improvements in the area.” Steve Brine, then Health Minister, [Hansard, 17 Jan 2019](#)