

# Summary

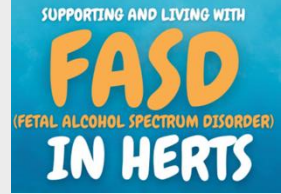
Sandra Butcher, Chief Executive  
The National Organisation for FASD  
[sandra.butcher@nationalfasd.org.uk](mailto:sandra.butcher@nationalfasd.org.uk)

Sue Sharp, Treasurer  
Hertfordshire FASD Support Network  
[support@hertsfasd.org.uk](mailto:support@hertsfasd.org.uk)



# Thank you for joining us!

This is a brief summary of key points with links to some of the policy documents, research and resources mentioned.



With a special thanks to ASDA for supporting this event and volunteers from the Hoddesdon Mockingbird Fostering HUB for helping out!

# Topics covered



On 11 February 2025 approximately 50 people from across services joined us for an open house at The Priory in Ware.

The session was opened by Martin Butcher, Mayor of Ware who is also co-founder of Herts FASD and dad to a young adult with FASD.

There was a 'taster' session on FASD provided by Dr Inyang Takon, a local community paediatrician who is one of the country's leading experts on FASD.

Sandra Butcher, National FASD provided an overview of the local ICB and Trust responses to National FASD's Freedom of Information requests about NICE QS 204.

Jacob a young adult with FASD and his parents Zoe and Alan gave some personal insights into living with FASD in Herts.

These were followed by an overview of the work of the two organisations. Katie Liddle and Sandra Butcher talked about National FASD's resources and Sue and Tony Sharp described the work of Herts FASD.

# The facts



**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](#))

**How many people have FASD?** A gold-standard study by the University of Salford showed that 2-4% have FASD. The rates are higher for children in care (27%) and among those who are adopted. This rate is higher than autism (1%).

**How many in Hertfordshire have FASD?** In Hertfordshire 7,599 - 15,197 children and young people under 19 likely to have FASD and 64,495 people (all ages) are using services in Herts and West Essex ICB. **Most are undiagnosed.**

A 2021 DHSC [FASD Health Needs Assessment for England](#) called ‘better organisation of services to improve accessibility’ and identified a ‘need to develop innovative approaches to support those living with the condition.’

McCarthy et al. <https://onlinelibrary.wiley.com/doi/full/10.1111/acer.14705>

Herts figures based on 2-4% of 379,927 under 19. For of a population of 1,612,358, 32,247 - 64,495 people (all ages) could have FASD. Source NHS England, Populations by GP practice and ICB – November 2021 to October 2022.

WHO, 2023. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>

National Autistic Society. <https://www.autism.org.uk/advice-and-guidance/what-is-autism>

Gregory, 2016 <https://journals.sagepub.com/doi/abs/10.1177/0308575915594985>



Hertfordshire  
FASD Support Network

# 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.

According to SIGN 156, “Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay.”

Children and young people should be referred to a paediatrician for a neurodevelopmental assessment and further investigation. For adults, the GP would make referrals for the assessments.

<https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol>

[nationalfasd.org.uk](http://nationalfasd.org.uk) • [hertsfasd.org.uk](http://hertsfasd.org.uk)



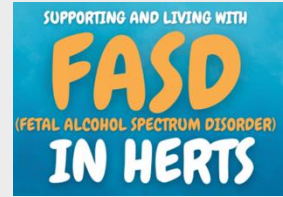
# NICE Quality Standard 204?

## What is the NICE Quality Standard 204?

[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. It also calls for cross sector training.

Unlike guidance, local areas in England and Wales have to 'have regard' for Quality Standards and report on progress in improving care using indicators provided.

For more information: <https://nationalfasd.org.uk/learn-more/policy/nice/>



**NOT COMMISSIONED**

**Systemic confusion  
in NHS services for  
alcohol, pregnancy  
and FASD**

## KEY FINDINGS

National FASD produced a report based on Freedom of Information requests to see what progress has been made 2 years after the NICE QS 204. The national picture showed the majority of Integrated Care Boards (ICBs) and Trusts are not taking action on NICE Quality Standard 204 and the vast majority of ICBs are not commissioning for FASD diagnosis. It also showed unclear lines of responsibility between ICBs/ Health Boards and Trusts on FASD; Systemic confusion within services in NHS Trusts on FASD; Nearly universal failure to track improvements in services over time on FASD; Failure to provide FASD training across the workforce. People with lived experience say this failure to act has terrible impact. This is true in Hertfordshire as well.

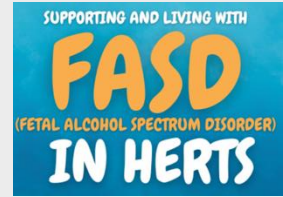
We feel like  
we are  
almost invisible.

-22-year old  
with FASD

We don't have  
any care management  
plan, strategies. In  
fact we have no help  
at all with our little  
one. We cry for help  
and meet a series of  
closed doors.

-Response to  
FASD UK Alliance  
questionnaire

# Local responses to Freedom of Information requests



**Herts and West Essex ICB** – is not commissioning for FASD diagnosis and management; while their response said safeguarding and CLA teams doing some work, ICB hasn't taken action to fully respond to NICE Quality Standard 204.

**East and N Herts** – hasn't responded in breach of legal duty to respond.

**Hertfordshire Community Trust** – says assessments happen but patients are referred to tertiary clinic for diagnosis.

**Herts Partnership University Trust** – despite being a mental health and learning disability services, says NICE QS 204 is for acute trusts.

**West Hertfordshire Teaching Hospitals NHS Trust** – says NICE QS 204 sits with community paediatrics (despite having maternity services, OT and other related services)

Responses received can be seen by following the links in the report:  
<https://nationalfasd.org.uk/not-commissioned-report/>



# Why this is an issue for Herts

**Dr Inyang Takon identified challenges for FASD in Herts to include:** NHS referrals, pathways and multidisciplinary assessments (especially access to psychologists trained in analysing neurodevelopmental assessments for FASD diagnosis)

**Consequences of inaction include:** Longer patient journey; Multiple labels; Lack of adequate support; Out of school; Placement breakdown; Child/Family Impact.

**This can have impact over the long-term** in multiple areas including on: Academics, Family; Mental Health; and Social Relations.



# About Herts FASD



Herts FASD is now helping 100 families with FASD. 2024 was a great year. We held 7 Coffee Mornings; 12 Information Awareness Sessions; 4 Awareness Stalls; set up a WhatsApp group and had 8.4k Views on single Facebook Post (Asda). We also held a FASD YP Event at Community Orchard; registered as charity with HMRC for Tax Purposes; fostering Service 'FASD Buddy Hub' launched; set up a Herts FASD Online Shop; Go Fund Me Page & Eventbrite Account Started; Joined Herts Partnership; Attended Community Alliance Funding Fayre; Made links with CAMHS Radlett.

We stand ready to assist in developing local pathways that meet the needs of some of our community's most vulnerable people.



Please contact us for more information or for training:

[support@hertsfasd.org.uk](mailto:support@hertsfasd.org.uk)

Sign up for updates on our website:

<https://hertsfasd.org.uk>

Merch shop:

[nationalfasd.org.uk](http://nationalfasd.org.uk) • [hertsfasd.org.uk](http://hertsfasd.org.uk)



Please visit our Online Shop selling motivational items or to make a donation

<https://hertsfasd.org.uk/shop/>



# National FASD resources

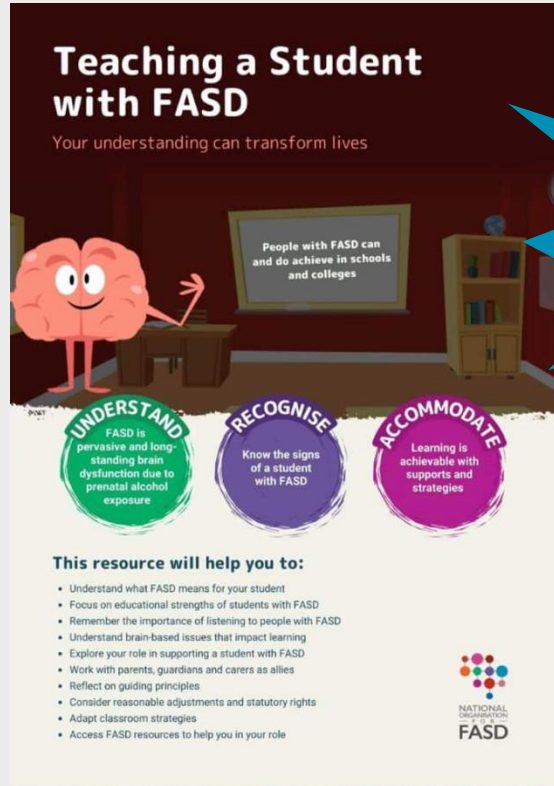
National FASD is based at The Priory in Ware and is available to assist.



- National FASD - Adults with FASD, families, practitioners [www.nationalfasd.org.uk](http://www.nationalfasd.org.uk)
- Me and My FASD – [www.fasd.me](http://www.fasd.me)
- National FASD eschool - <https://eschool.nationalfasd.org.uk>
- Prevent FASD (for 15-25 year olds) - <https://preventfasd.info>
- National FASD training: <https://nationalfasd.org.uk/learn-more/training/>
- Manifesto: <https://nationalfasd.org.uk/the-uk-fasd-manifesto/>
- Alcohol and pregnancy resources: <http://alcoholandpregnancy.info>
- SEND toolkit: <https://nationalfasd.org.uk/merch/>
- FASD Preferred UK Language Guide: <https://nationalfasd.org.uk/languageguide/>
- Best practice in FASD training guide: [https://nationalfasd.org.uk/wp-content/uploads/2020/11/Seashell\\_NationalFASD\\_BestPracticeFASDTraining.pdf](https://nationalfasd.org.uk/wp-content/uploads/2020/11/Seashell_NationalFASD_BestPracticeFASDTraining.pdf)
- Raja and Neil's FASD Book Club (15 minute free videos and easy access summaries from world's leading experts):  
<https://nationalfasd.org.uk/learn-more/resources/raja-and-neils-fasd-book-club/>



# TEACHING A STUDENT WITH FASD



Newly updated resource for schools

- Based on earlier research project
- Updated to include links to resources

Hard copy – <https://nationalfasd.org.uk/product/teaching-a-student-with-fasd-hard-copy/>  
PDF for whole school - <https://nationalfasd.org.uk/product/teaching-a-student-with-fasd-whole-school-access/>

THE TIME IS NOW,  
ARE YOU READY?

Best practices  
for those  
looking to ramp  
up services

Funded by  
Sylvia Adams  
Charitable Trust

<https://nationalfasd.org.uk/learn-more/policy/innovation-best-practice/>



“As a Paediatrician I hope that this is the start of the paediatric workforce being better informed and trained in FASD recognition and support.”

--Dr Patricia Jackson

- 140-page report highlighting UK best practice
- Based on 9 roundtables with 60 leading paediatricians, psychiatrists, GPs, commissioners, public health experts, researchers and leaders from the Third Sector & those with lived experience