

Fetal Alcohol Spectrum Disorders (FASD) Awareness

Brian & Georgia Roberts February 26th 2025

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NATIONAL
ORGANISATION
— FOR —
FASD



Support
those affected by

FASD

Our Children are

But its not just Children & Young People

Probably some of the most vulnerable children and young people in the UK.

Especially those without any easily visible disability.

Have an acquired hidden disability significantly influenced by the relationship that our society has with alcohol.

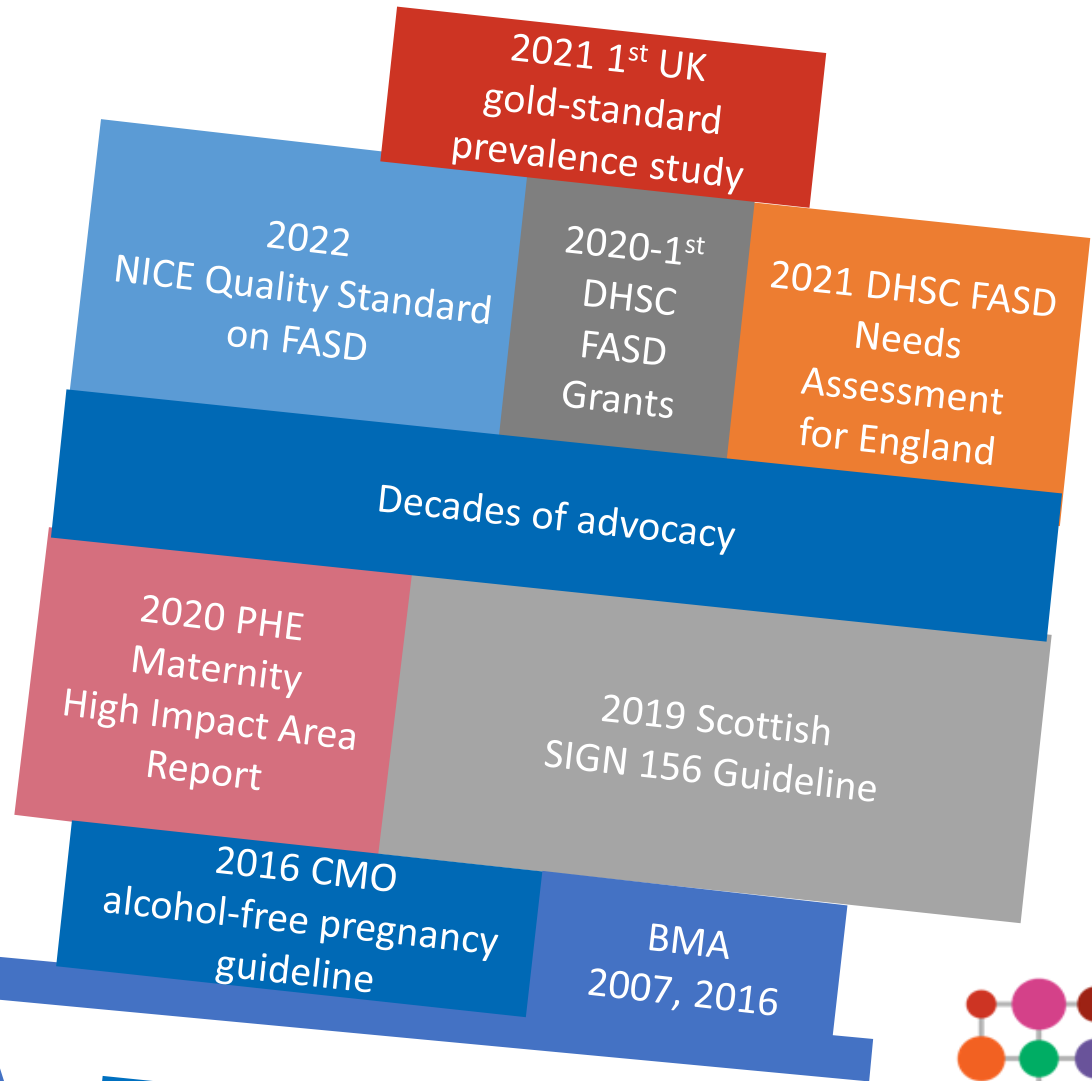
Many are suffering from a hidden / unrecognised disability and as a country where professionals are unaware of how many families are affected.

Why its important for Professionals to know about FASD

<https://www.youtube.com/watch?v=JGq00UYSWsU>

The Time is Now

Decades of
official indifference



Tipping point



DHSC FASD Needs Analysis England

September 9th 2021

- ▶ ‘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’

NICE FASD Quality Standard England & Wales

March 16th 2022

- ▶ Five key areas that all ICB's need to improve on:
 - **Advice** on avoiding alcohol in pregnancy
 - Fetal alcohol **exposure**
 - **Referral** for assessment
 - Neurodevelopmental **assessment**
 - **Multiagency management plan**
- Emphasis on FASD Awareness and training and Multiagency working for children and young people

Prevalence

Communities / School - Gold standard Mainstream Primary school prevalence study Manchester 2021

2% to 4 % (University of Salford)

In Care - Gold Standard Research Peterborough 2015 Looked after Children

27% (Department of Health & Social Care 2021)

Care Experienced - Gold Standard Research Peterborough 2015 Children Adopted exposed to alcohol in the womb

75% (Coram / BAAF)

What is the issue?

To get a diagnosis there needs to be confirmation of an Alcohol exposed pregnancy and

Evidence of **pervasive and long-standing** brain dysfunction, which is defined by **severe impairment**...in three or more of the following neurodevelopmental areas of assessment

For some facial features (Less than 10%)

Neurodevelopmental areas of assessment

- Motor skills
- Cognition
- Memory
- Neuroanatomy/neurophysiology
- Academic achievement
- Language
- Attention
- Executive function, including impulse control and hyperactivity
- Affect regulation, adaptive behaviour, social skills or social communication

Some behavioural challenges

- Working memory
- Short term memory
- Planning and organisation
- Receptive language
- Obsessions
- Hyperactivity, fidgeting
- Inattention
- Lack of social understanding
- Impulsivity
- Can't learn from negative experience
- Lack of judgment
- No understanding of consequences
- Central nervous system damage - pain, hunger, temperature, toileting
- Concepts - time, money, maths, ownership
- Relationships - over-friendly, appearing to have attachment



Some potential physical challenges

Over 425 co-occurring conditions

- Cleft palate
- Small teeth
- Hearing problems
- Heart defects
- Kidney problems
- Genital changes
- Sacral dimple
- Unusual chest shape
- Small head
- Curved fingers
- Shorter fingers and toes
- Small nails
- Low muscle tone
- Eye problems
- Fits
- Failure to thrive / growth deficiencies

Multiple diagnoses are common

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD / ADHD	Sensory Int. Dys	Autism	Bi-Polar	RAD	Depression	ODD	Trauma	Poverty
Easily distracted by erroneous stimuli	X	X	X							
Developmental Dysmaturity	X			X						
Feel Different from other people	X				X					
Often does not follow through on instructions	X	X					X	X	X	X
Often interrupts/intrudes	X	X	X	X	X		X			X
Often engages in activities without considering possible consequences	X	X	X	X	X					X
Often has difficulty organising tasks & activities	X	X		X	X		X			X
Difficulty with transitions	X		X	X	X					
No impulse controls, acts hyperactive	X	X	X		X	X				
Sleep Disturbance	X				X		X		X	
Indiscriminately affectionate with strangers	X		X		X	X				
Lack of eye contact	X		X	X		X	X			
Not cuddly	X			X		X	X			
Lying about the obvious	X				X	X				
Learning lags: "Won't learn, some can't learn"	X		X			X			X	X
Incessant chatter or abnormal speech patterns	X		X	X	X	X				
Increased startle response	X		X						X	
Emotionally volatile, often exhibit wild mood swings	X	X	X	X	X	X	X	X	X	
Depression develops often in teen years	X	X				X			X	

Supporting individuals

It's not about fixing the person,
but facilitating them to perform
optimally

Raja Mukherjee Sept 2018

Reframing

Acting like a child ↔ Is a child
Won't ↔ Can't
Lazy and does not try ↔ Exhausted with trying
Does not care ↔ Does not understand feelings
Refuses to sit still ↔ Over stimulated /needs contact
Forgets everything ↔ Can't remember
Fussy, demanding ↔ Hypersensitive
Steals ↔ Does not understand ownership
Does not get the obvious ↔ Does not learn from experience
Calculating and sly ↔ Does not understand social norms

Pick your battles

Be consistent

De personalise & when calm make sure the consequence is understood

**Needs to be valued at the time
Use to provide alternatives to intolerable**



Attempt to minimise but expect to be repeated time and time again



Support

<https://www.youtube.com/watch?v=7rcq6-LRLqM>

Positive Behaviour Support

- External support for the challenges that they face
- Reduce situational triggers:
 - ▶ environmental,
 - ▶ communication,
 - ▶ emotional,
 - ▶ social ,
 - ▶ executive function,
 - ▶ sensory

Not easy and very tiring for everyone

Sources of support



www.nationalFASD.org.uk



www.FASD.me



www.preventFASD.info



AT THE CORE

- A new website just for young people with FASD and those who support them
- Website and all materials intentionally branded throughout with FASD – a UK first





Break it Down Board



Created in collaboration with www.ourboards.co.uk

<https://fasd.me/me-and-my-fasd/coping-resources/break-it-down-board/>



Calming cards

Created with input from more than 50 young people with FASD



Mason is so proud of having his name on some of the calming cards



<https://fasd.me/funzone/games-and-activities/calming-cards/>



We have lots more planned for the characters!



The game was suggested by Andy Jackson a young adult with FASD and its name came from our Adults and Young Adults with FASD Advisory Committee

<https://fasd.me/funzone/games-and-activities/misunderstoods-the-game/>



Everything has FASD branding



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Overwhelming response

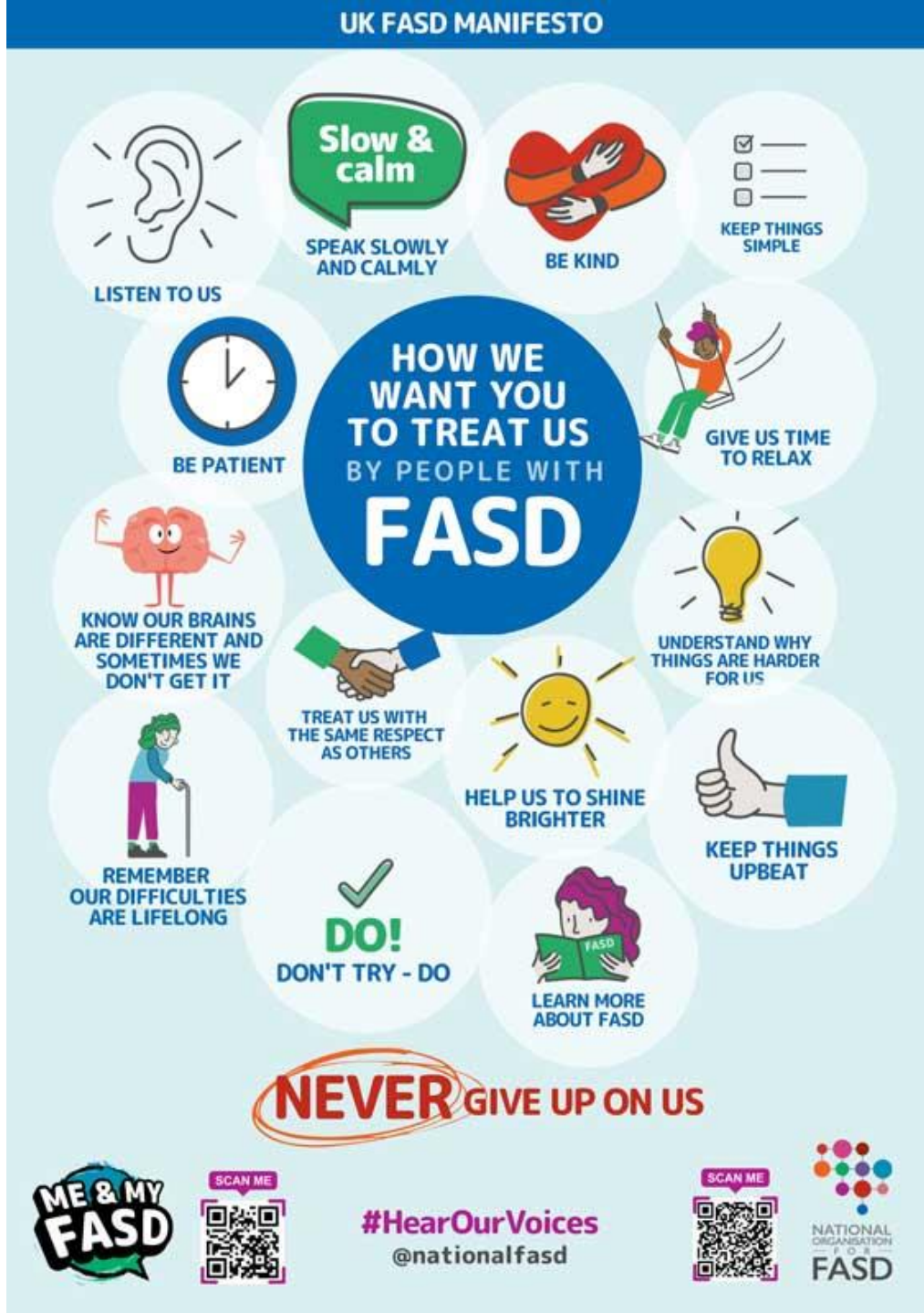
Pilot and scoping exercise funded by Pears Foundation (via Contact), as part of Government's COVID response.

Seeking funding to expand it in a sustainable manner

<https://fasd.me/club/>



UK FASD MANIFESTO




The infographic features a central blue circle with the text "HOW WE WANT YOU TO TREAT US BY PEOPLE WITH FASD". Surrounding this are 14 smaller circles, each with an icon and a message: "LISTEN TO US" (ear icon), "SLOW & calm" (green speech bubble icon), "SPEAK SLOWLY AND CALMLY" (text), "BE KIND" (hands holding a heart icon), "KEEP THINGS SIMPLE" (checkboxes icon), "BE PATIENT" (clock icon), "GIVE US TIME TO RELAX" (person on a swing icon), "KNOW OUR BRAINS ARE DIFFERENT AND SOMETIMES WE DON'T GET IT" (brain icon), "TREAT US WITH THE SAME RESPECT AS OTHERS" (handshake icon), "UNDERSTAND WHY THINGS ARE HARDER FOR US" (lightbulb icon), "HELP US TO SHINE BRIGHTER" (smiling sun icon), "KEEP THINGS UPBEAT" (thumbs up icon), "REMEMBER OUR DIFFICULTIES ARE LIFELONG" (person with cane icon), "DO! DON'T TRY - DO" (checkmark icon), and "LEARN MORE ABOUT FASD" (person reading a book icon). At the bottom, it says "NEVER GIVE UP ON US" with "NEVER" circled in red.

HOW WE WANT YOU TO TREAT US BY PEOPLE WITH FASD

- LISTEN TO US
- SLOW & calm
SPEAK SLOWLY AND CALMLY
- BE KIND
- KEEP THINGS SIMPLE
- BE PATIENT
- GIVE US TIME TO RELAX
- KNOW OUR BRAINS ARE DIFFERENT AND SOMETIMES WE DON'T GET IT
- TREAT US WITH THE SAME RESPECT AS OTHERS
- UNDERSTAND WHY THINGS ARE HARDER FOR US
- HELP US TO SHINE BRIGHTER
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- REMEMBER OUR DIFFICULTIES ARE LIFELONG
- DO!
DON'T TRY - DO
- LEARN MORE ABOUT FASD

NEVER GIVE UP ON US

ME & MY FASD  **#HearOurVoices**
@nationalfasd

NATIONAL ORGANISATION FOR FASD

UK FASD Manifesto March 2023

<https://fasd.me/uk-fasd-manifesto/>



Support

FASD UK Alliance

fasd-uk.net
fasd-uk@live.com ·
[@FASD_UK](https://twitter.com/FASD_UK)

A coalition of groups and individuals from across the UK united together for positive social change for those affected by Foetal Alcohol Spectrum Disorders (FASD). Affiliates include small local, regional and virtual groups as well as some of the country's longest standing national organisations devoted to FASD, with links to international networks.

Facebook Support Groups

- FASD UK
- FASD UK Professionals
- FASD and Gender Identity
- UK Teens & Adults with FASD

YouTube Channel

- FASD UK Resources

Affiliates

- UK & European Birth Mothers
- FASD Alliance Ireland
- FASD Awareness South East
- E. Hertfordshire and Area FASD Support Network
- FASD Dogs UK
- FASD UK London
- FASD Network UK (Tees Valley, Tyne & Wear, County Durham, North Yorkshire, Hull and East Riding, West Yorkshire)
- FASD Northwest
- FASD Scotland
- MUCH Laughter
- Peterborough and Area Family FASD Support Group
- SEND Consultancy
- South West FASD Support Group/FASD Devon and Cornwall Consultancy
- Stoke and Staffordshire FASD Support Group
- National Organisation for Foetal Alcohol Syndrome-UK

**Together we are stronger
Join us! You are not alone**





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