

For immediate release

New study: FASD affects millions in the UK The National Organisation for FASD calls for action

30 September 2021 – A <u>new study</u> from The University of Salford shows that 1.8 – 3.6% may have Fetal Alcohol Spectrum Disorder which results from alcohol-exposed pregnancies. Researchers went into schools and assessed children. All those they identified had not been previously diagnosed with a neurodevelopmental condition.

Based on the Salford figures, this means that up to a half million young people under 20 in England and Wales are careening toward their adult years with a hidden brain-based neurodevelopmental condition, undiagnosed and not receiving proper support. Nationally, the Salford figures equate to some 1.2-2.4 million in the UK who may have had FASD in 2020.

Sandra Butcher, Chief Executive of The National Organisation for FASD, said "The FASD community is delighted that the UK's first gold-standard active case-ascertainment FASD prevalence study <u>has</u> <u>been published</u>. It is now undeniable that FASD is prevalent and massively undiagnosed. What these numbers don't show is the vast impact on society from allowing this situation to continue without prioritisation from health and social care. A recent DHSC needs assessment says the financial impact can be in the billions."

This study joins the recent ground-breaking publication of the Department of Health and Social Care FASD Needs Assessment for England, the Public Health England report on alcohol harm in pregnancy and the upcoming NICE Quality Standard on FASD. Butcher said, "National FASD is encouraged that change is coming for those with FASD and their families. But to have real impact national, regional and local policy makers need to urgently come to the table with ideas and funding. While we recognise health and social care systems are under strain, investing now in proper pathways as outlined by the DHSC, NICE, SIGN, the BMA and other leading scientific bodies will stave off further strain on the systems that can arise if people with FASD are left unidentified."

National FASD is calling for funding for a UK-wide active case ascertainment FASD prevalence study so that people living with this largely hidden disability can be diagnosed and offered appropriate management plans which research has shown can change life trajectories. This will also help with planning for local needs. The organisation also believes training in FASD should be mandatory across health, social care, education, justice and associated sectors.

Butcher said, "It's critical to listen to those with FASD as these changes are made. It is a complex disability and everyone is affected differently." Nineteen-year old, Bailie said, "I want people to know that FASD is lifelong and people should take it seriously and learn more about it." Eleven-year old Michael said, "My teachers need to learn more about it." Fourteen-year old Geraldine said, "I'm neurodiverse and proud."

About National FASD

The National Organisation for FASD provides support to people affected by Foetal Alcohol Spectrum Disorder (FASD), their families and communities; campaigns to raise public awareness; and promotes relevant policies and practices. We have been proud to create new training and resources through our partnership with Seashell, funded by the Department of Health and Social Care, as well

as a new e-course with support from the Greater Manchester Health and Social Care Partnership. With Seashell, we have created a new "Me and My FASD Toolkit" that focuses on helping people with FASD to understand their diagnosis and to become self-advocates.

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 cooccur, 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.

For more information:

Comment: Sandra.butcher@nationalfasd.org.uk

Blog post and an infographic: <u>https://nationalfasd.org.uk/new-study-shows-fasd-affects-millions-in-the-uk-2021/</u>

Websites: <u>www.nationalfasd.org.uk</u> • <u>www.preventfasd.info</u> • <u>www.FASD.me</u>

National FASD is a sister organisation in the FASD UK Alliance.

