

NHS services failing to meet government policy on key neurodevelopmental disorder

National charity uses Freedom of Information requests to highlight need for parliamentary oversight on FASD services

Embargoed for release on 12.01 am 9 May 2019

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(London, 9 May 2019) -- Local Clinical Commissioning Groups (CCGs) are failing in their responsibilities as stated by government to commission services for people with widespread neurodevelopmental disorders that arise from exposure to alcohol in the womb, according to a new report from a national charity, NOFAS-UK. "Any policy maker who cares about the most vulnerable in our society should request answers to this unacceptable situation," said NOFAS-UK Chief Executive Sandra Butcher. "This is a disability rights issue. Imagine suspecting you or your loved one has organic brain damage and being unable to get a proper diagnosis or support. It's cruel."

In response to Freedom of Information requests sent to all CCGs and NHS Trusts, not one CCG said they have a policy on commissioning services for Foetal Alcohol Spectrum Disorders. Nearly 80% said they do not provide diagnosis for children with FASD and 92% said they do not provide diagnosis for adults. Only 19% of Trusts and Health Boards told NOFAS-UK that they provide post-diagnostic services for those with FASD. Similarly, these bodies indicate they are not planning to expand their services and the vast majority are not conducting training or engaging in public on FASD.

Government and leading medical experts, including the BMA, repeatedly emphasise the importance of early intervention and diagnosis for those with Foetal Alcohol Spectrum Disorders.

Lead author Martin Butcher said, "'Crisis in Commissioning' is an aid to help policy makers understand just how confused and disjointed this system is after decades of bureaucratic indifference to people on this spectrum, which research shows may affect 6% or more of the population. This report backs up anecdotal evidence that stakeholders from a range of groups in the FASD UK Alliance have been sharing with policy makers."

The issue will be addressed at a meeting of the All-Party Parliamentary Group on FASD on 9 May. Chair of the FASD APPG and adoptive parent of children with FASD, Bill Esterson MP said, "Thousands of children are born every year in the UK with entirely preventable, irreversible brain damage. The lack of support from our NHS for those with this life limiting disability is scandalous. We face a crisis of epidemic proportions and it is time for government action to end the ignorance about the risks of exposure to alcohol in the womb and to deliver the support which those living with FASD need."

Dr Raja Mukherjee who heads the National FASD Clinic said, "Despite increasing evidence that this is a common disorder, it is not often the focus or consideration of many health professionals and CCGs. For a condition that has lifelong issues for the individual and society, getting it wrong simply exacerbates the well-recognised associated disabilities. The NHS has, with the right support, the ability to change this quickly as the basic structures are in place. Without clear direction and consistent approaches, the postcode lottery highlighted in this report is likely to continue."

Despite increased attention from ministers, concrete steps are needed to overcome bureaucratic inertia. One commissioner stated, "The health minister can say, 'I expect CCGs to commission these

services', but until he or a civil servant sets it out as a Commissioning Intention or priority that CCGs are accountable for, it won't be picked up by CCGs as a 'to-do'."

"I have been trying to get a diagnosis for five years," said Nyrene Cox, a member of the National FASD Advisory Committee. "There should be no barrier or age restriction. Regardless of age I should be able to get assessed. I need a diagnosis so my employer will provide the support I need." Dr Cassie Jackson, of the new Centre for FASD in Suffolk said, "Individuals and families are struggling enough as it is without being met with the lack of awareness of professionals in this matter. FASD is more common than autism and commissioning of appropriate services needs to reflect this."

Brian Roberts, a foster carer and former virtual school head said, "Evidence is there about what works. If health services do not take the lead through commissioning diagnosis and needed support, then to be honest how will others who interact with affected individuals understand the situation and their needs? We will continue to waste millions of pounds on possibly ineffective interventions and the potential of thousands of individuals will be needlessly limited, with great impact on our society."

Consultant Paediatrician Dr Inyang Takon said, 'Paediatricians are usually the first point of contact for children with neurodevelopmental difficulties. However large number of Paediatricians seeing children with neurodevelopmental disorders do not have the appropriate skills, training and required resources needed to recognize or appropriately diagnose children with FASD. This results in many children being given inappropriate diagnostic labels for their difficulties. The lack of appropriate diagnosis results in affected children not being able to access the right resources which then results in longer term impact on the children's learning, emotional and mental health. Early diagnosis results in better outcomes for children with FASD hence there is an urgent need for commissioned services.'

The report highlights best practices in some areas, such as Scotland, the North East, Blackpool, and Manchester. Yet it also states, "In no case that NOFAS-UK is aware of is any CCG providing diagnostic services for the full number of people likely to have an FASD in their area. Even where best practices exist, the structures are not yet adequate to meet the need."

-ENDS-

Background on FASD and Policy:

1. Foetal Alcohol Spectrum Disorders are caused when exposure to alcohol in the womb damages the developing brain and other systems, leading to neurocognitive impairment and a possible range of up to 400 related conditions (1). The brain damage is lifelong and affects the individual's ability to function without support.
2. The first-ever UK estimates showed that more than 6% of the population might be affected by FASD, according to [study led by Dr Cherly McQuire](#) (2) of Bristol University and released at the end of 2018, which used data from 13,495 children from Bristol's Children of the 90s study.
3. The UK has one of the [highest rates](#) (3) of drinking alcohol during pregnancy in the world – ranking 4th (higher than in the USA) - with more than 40% of women estimated to drink during pregnancy (other studies indicate this could be higher, and in fact the McQuire study mentioned above showed up to 79% of children in the sample were exposed to alcohol in utero).
4. A recent US study (4) - an active-case ascertainment study, the gold-standard for research in the field which has not yet been conducted in the UK - found that roughly 1 in 20 first graders has an FASD but that "Of the 222 children diagnosed with FASD in the study, only two had been previously diagnosed with FASD, although many parents and guardians were aware of the children's learning and behavioural challenges." The study, which assessed 6,639 children in four different areas in the USA, was funded by an arm of the US National Institutes of Health and was released in the peer-reviewed [Journal of the American Medical Association \(JAMA\)](#). The conservative interpretation of the data says that between 1.5 and 5% of the population has FASD. This means FASD affects more people than [autism](#) (5).
5. Issues related to FASD prevention, diagnosis and support need to be better understood in the social services, care and adoption systems. In October 2015 Coram BAAF published a UK informed journal on FASD in fostering and adoption. This recorded that in a screening study in Peterborough 34% of the then looked after population were possibly affected by FASD and 75% of those who were freed for adoption due to exposure to alcohol in utero. (6) While not every child who was exposed to alcohol in the womb will have an FASD, it is not possible to know with confidence who does. We are facing what some experts have called a '[hidden epidemic](#)'. (7)
6. Scotland has recently released [SIGN 156](#) (8) guidance on "Children and young people exposed prenatally to alcohol." Which cover: identification of children at risk of FASD; criteria for diagnosis and use of FASD as a descriptor; the medical assessment; physical examination; sentinel facial features; neurodevelopmental assessment; the multidisciplinary assessment team; special considerations in the neurodevelopmental assessment; management and follow up of children and young people affected by PAE."
7. Government has been increasing its focus on FASD. In a [written reply on 19 February 2019](#) (9) Steve Brine, then-Health Minister, reinforced Government policy: "Responsibility for commissioning Fetal Alcohol Spectrum Disorders (FASD) services lies with clinical commissioning groups working together across all sectors. We know diagnosing FASD is a complex process and we have learnt from recent engagement events with FASD sufferers that diagnostic pathway should be improved. The Department is considering how we can improve access to such services and the diagnostic pathway learning from best practice. We will also ask the National Institute for Health and Care Excellence to consider the recent SIGN 156 guidelines 'Children and Young People Exposed Prenatally to Alcohol 'in Scotland to review if this guideline could be applied in England." On [17 January 2019](#) (10) Brine had stated on the floor of the House of Commons, "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. I can promise...that." Then-Deputy Chief Medical Officer Prof Gina Radford led a series of meetings in 2018 about FASD, including [one with stakeholders](#). (11) Andrew Trathen, a Public Health Registrar based with the Healthy Behaviours Team at Department of Health and Social Care, has been on secondment in the Department of Health. His discussions have helped to map out the range of

stakeholder views and to identify priorities for policy development on FASD. Children's Minister Nadhim Zahawi met with a delegation coordinated by Adoption UK and including FASD UK Alliance members in November 2018.

8. NOFAS-UK (www.nofas-uk.org) is a sister organisation in the FASD UK Alliance (www.fasd-uk.net), a coalition of groups and individuals from across the UK who are united together for positive social change for those affected by Foetal Alcohol Spectrum Disorders (FASD). Jointly these groups help administer an online support group involving more than 2200 individuals and families.

Sources:

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10. Steve Brine, Adjournment Debate, 17 January 2019 - <https://hansard.parliament.uk/commons/2019-01-17/debates/19011751000002/FoetalAlcoholSpectrumDisorder>.
11. "Foetal Alcohol Spectrum Disorders: Future policy development on issues relating to FASD," A Roundtable Discussion with FASD Stakeholders Convened and chaired by Professor Gina Radford, Deputy Chief Medical Officer National Liberal Club, London, 22 October 2018. For a report of this meeting and related roundtables: <http://www.nofas-uk.org/?cat=44>