



**Statement on behalf of the FASD UK Alliance
Meeting with Deputy Chief Medical Officer Prof. Gina Radford**

**Presented by Martin Butcher – E. Herts and Area FASD Support Network
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The FASD UK Alliance welcomes this invitation to share the views of stakeholders about the development of future policies regarding Foetal Alcohol Spectrum Disorders prevention, diagnosis and support.

The FASD UK Alliance is an informal coalition of independently organised groups and individuals who are united together for positive social change. Our affiliates include small local, regional and virtual groups as well as some of the country's longest standing national FASD organisations, with links to international networks. We collectively administer an online Facebook support group that involves more than 2,000 individuals and families. We have here today some 20 people from our network, including 6 adults and young adults with FASD, three birth mothers of children with FASD, adopters, foster carers and other support people. We stand together today and every day – representing many different backgrounds and socio-economic groups. This issue can only be fully addressed by looking at the entire community affected by FASD. We must break beyond the stigma that has stymied action for too long. Inaction and lack of appropriate support is causing devastation for individuals and families across the UK with tragic impact.

As far as we know, this current series of meetings is the first time the UK government has itself convened meetings about FASD. We deeply appreciate your invitation to share our views. As a community too long left in the shadows, we bring goodwill, urgency and a determination to ensure that yet another generation of those whose lives have been affected by FASD does not fall through the cracks.

Some things are changing. The new CMO guidance in 2016 was transformative – following on as it did from the groundbreaking work done by the BMA and others – including many FASD pioneers in this country. Government recently has on several occasions recognized FASD and the importance of early interventions. Just this week public awareness of FASD and prevention messaging hit the stratosphere as it was featured on East Enders and with Prince Harry and Meghan announcing their decision to go alcohol-free during her pregnancy.

We are, all of us, on new ground. It's beyond time for action.

We hope this meeting is the beginning of a process to comprehensively tackle this crisis that experts believe, by very conservative estimates, leaves more than more than 15,000 people born each year in the UK with life-long organic brain damage that is largely undiagnosed or misdiagnosed. We urgently need an appropriately funded active-case-ascertainment study here similar to that done in the US and in other European countries, where results have shown that FASD is one of the leading causes of development disabilities in the world. Calls

for a UK population-based prevalence study are supported by the International Charter on Prevention of FASD, the British Medical Association and the All-Party Parliamentary Group on FASD. Any such study must look at the full spectrum. Studies and statistics that look only at Foetal Alcohol Syndrome will miss up to 90% of the cases out there and can be misconstrued as a deliberate attempt to underestimate the problem.

Follow-on action needed on CMO Guidance

We need to explore how to maximise the CMO guidance. The birth mothers in our network have insights and experience to share for those seeking to shape messaging and programmes in ways that are supportive and proactive – much needs to be done because the UK has the fourth highest level of prenatal alcohol use in the world. The guidance needs to be incorporated into all public messaging, across all the NHS platforms. (Alarming, outdated guidance is still available on some NHS sites - one GP quoted it recently in support of a pregnant GP who announced on twitter that she is drinking during her pregnancy).

Midwives need appropriate training and resources. This includes initial pre-service training and continuing professional development, involving all universities and further education colleges and NHS sites where midwives are trained.

But we also need to promote the guidance more widely in society. The CMOs, ministers and other public health officials could be more visible on this issue with TV appearances and media presence, perhaps by making statements on the 9/9 international FASD awareness day. FASD messaging could be required in all pregnancy test kits – and indeed the kits could be made available at lower cost (including in pubs, as has been trialed in some places overseas.) Industry self-regulation regarding alcohol labelling is not having enough impact. More needs to be done to ensure these warnings are clearly visible on all alcohol labels. Government could explore legislation like “Sandy’s Law” in Ontario that requires awareness posters at the point of sale. We need to get the guidance into school PSHE lessons in a way that helps the next generation understand the risks of alcohol in pregnancy. But the government responsibility does not end at prevention messaging, important as that is. This is a public health problem that extends across the life span.

Need to back up Government’s statements on the importance of early intervention

The current systemic inaction has tragic consequences. Without appropriate diagnosis and lifelong support, people with FASD can face compounding secondary challenges. The rates of addiction, mental health problems, risky sexual behaviour, mental health issues, imprisonment, homeless, suicide are all exceptionally high. They tend to have low or no educational achievement although the individuals concerned are bright enough to achieve. These issues are not abstract. We have in this room and in our networks people who have been struggling for help and support in a system that does not recognise them or their needs.

And yet, with proper intervention for the individual and family, we can change trajectories, avoiding great pain for those with FASD and those who love them – but also at a great saving to society as a whole – and also to the NHS.

Early years interventions matter greatly. Health visitors, neonatal outreach teams,

paediatricians, occupational therapists, speech and language therapists all need pre-training and continuing professional development on FASD. Informed multi-professional assessment including early years professionals, teachers, educational psychologists, etc can play an important role in avoiding some of the worst-case outcomes.

Government is interested in breaking past the 'so what then' question. Individuals with FASD and their families face this apathy in ways big and small. This is in part because Government itself has not been leading on this issue. This silence creates a black hole for those with FASD to fall into.

We are asked why we want a 'label' when, we are wrongly told, there is 'nothing can be done.' One adult with FASD was supposed to be with us today but could not because of events beyond his control. His life proves how a diagnosis can change someone's path. He had been homeless, in jail, addicted to alcohol and suicidal as a young adult. Following his diagnosis, he completely turned his life around and has become a leading advocate on FASD. Even still, he has been battling for more than 18 months now to get his benefits reinstated after they were cut at short notice, leaving him in a constant state of anxiety. For the second time his appeal tribunal to reinstate his ESA (which was scheduled for last week) has been postponed. He has custody of his young daughter and his main support person, his mother, has dementia. It should not be so hard.

Please remember again the estimates. If at a minimum 15,000 per year are believed to be born with FASD, that would be 300,000 people in the past 20 years – but most of those out there are unrecognised by the NHS, schools, employers and benefits agencies as having a brain-based condition. That is not only untenable as a 'policy' – it's also unacceptable in a caring society.

With few exceptions, most professionals and practitioners we interact with have little to no understanding of FASD as a spectrum. They do not know that only about 10% of those with brain damage due to exposure to alcohol in the womb have the so-called 'facial features' associated only with exposure during a short window in early pregnancy when the face is developing. We hear time and time again that people are turned away by GPs, paediatricians and SENCOs when seeking referrals because the person doesn't have 'the face'. We hear people are told the issue is bad parenting, not that this child is unable to process information in the way it's being presented. We hear that it is the people with FASD who have to 'try harder' – which is ironic when the system has simply not yet tried to put its full expertise and weight into addressing this. Misdiagnosis or incomplete diagnoses can lead to frustrating partial solutions at best, or at worst some inappropriate therapies, medications, etc.

People are refused assessment for diagnosis. They are refused proper assessments speech and language difficulties (including receptive language problems), occupational therapy assessments (especially to identify complex sensory profiles), in-depth assessments of their cognitive and social communication profiles (including to identify their executive functioning and adaptive planning abilities), as well as other assessments related to other needs (there are 400 conditions that can co-occur with FASD). As a result, many are unable to get an Education and Health Care Plan and this then leads to tragic problems with schooling and

post-16 support. Sadly, people who have secured one of the FASD diagnoses often still struggle, because it is so little understood by most professionals.

Many with FASD have an IQ over the cut-off for an 'intellectual disability'. Because FASD diagnoses are not recognised in the same way autism is, these individuals currently are not granted full access to services for those with neuro-disabilities. This is something that could be changed relatively easily: an FASD diagnosis should allow an individual to be able access to services for those with neurodevelopmental disabilities.

We have rarely, if ever, heard of someone with FASD having a positive experience in CAMHS – and we have heard some truly tragic examples of those who are at great risk, including suicidal, who have been completely misunderstood or denied service by CAMHS – a service that is meant to help but is woefully under-trained on this issue.

We know this issue disproportionately affects those in care and those who are adopted. Special attention needs to be made to train and better support social workers, local authorities, foster carers and adopters. There are families caring for those with FASD who are seeking to educate other foster carer networks – it's essential to break the cycle of failed placements, adoption breakdowns - the devastation of dreams.

When people with FASD do have in place appropriate therapies and strategies, the whole picture can change. One young gender-non-conforming teen with FASD was spiralling out of control – running away, playing with lighters, stealing, smashing up their room regularly. When moved to a special school and with support of therapists at a local service for those with mental health and intellectual disabilities and also from Tavistock, the anxieties decreased, the behaviours receded and he's just completed an entire half-term with not one problem. There can be great successes. And yet now that he's doing better they are trying to kick him out of the service despite knowing the horrendous statistics that face someone with this mix in their teenage years. Even when things work, access to services is still needlessly precarious.

The demand on services is going to accelerate as public awareness increases and we all need to be ready. For example, in our groups we are hearing from more and more adults who believe they have FASD – and there is simply no recourse for them at the moment to get diagnosis or appropriate support. We cannot let another generation face this devastating and unacceptable situation.

The good news is we don't have to recreate the wheel. There are areas of best practice here in this country – notably the North East and Scotland. We know there are people trying to tackle this problem in major areas across the UK. We need to learn from the positive examples. Scotland's work on the SIGN guidelines could, for example, help inform urgently needed revision and inclusion of FASD in NICE guidance. The BMA Alcohol and Pregnancy Report and the Consensus Document written by dozens of UK experts provide starting points.

CCGs are not fulfilling Government's stated policy

But we also bring notice of a deep problem that families across the UK report with

consistency and great distress: The government's stated policy of leaving commissioning of FASD services to the local CCGs is failing.

NOFAS-UK has sent Freedom of Information requests to all CCGs and NHS Trusts and will be publishing these results soon. The following summary is a preliminary snapshot, with data to follow. While these may change once all the replies are processed, here is what is known so far after processing about half of the replies, as self-reported by the CCGs and Trusts. Even these preliminary results are concerning enough that Government should itself conduct its own survey of all CCGs and Trusts and policy makers should query Government's reliance on allowing this issue – where training is so sparse – to be devolved to local CCGs without national guidance:

The vast majority of CCGs do not have policies in place for commissioning services for FASD. Only one response processed so far shows a budget for FASD services and that is where the National FASD clinic is based. Responses processed so far do not indicate plans to expand services or put a budget in place. A low percentage of CCGs say they provide for diagnosis of FASD in children but diagnosis for adults is not on the radar. Of those that do provide for diagnosis, most do so only through general services or through Individual Funding Requests. As a general rule, the vast majority of CCGs are not commissioning research into FASD, nor holding public consultation on such services. Of the very few who have an FASD lead, those are maternity or children's services leads, who include FASD as part of their responsibility.

Very few of the NHS Trusts or Health Boards have reported a policy to provide specific services for those with the condition. Too many Trusts (and CCGs) echoed the Norfolk Trust that said services aren't provided as FASD is "an extremely rare condition". A very low proportion of Trusts tell us they have doctors ready to diagnose an FASD.

Even where services are provided, a large majority of Trusts say that they look at FASD diagnosis and care as a paediatric issue only, few even consider providing diagnosis and post-diagnostic services for adults with the condition. Some Trusts report diagnosing more than 100 cases per year, but most are not noting any – these numbers vary so wildly that it backs up the perception of a 'post-code lottery.'

We call for an integrated 'deep dive' incorporating all existing national policies, training and continuing education across all fields with all relevant bodies – i.e. parenting, early years, maternity, education, health, social care, justice, alcohol industry, licensing, legislative, justice, mental health, etc. We understand this is a big call, but it will be needed if we truly seek a truly effective approach to this issue.

Next steps

The first step is to put in place multiple and concurrent processes involving stakeholders to make this overview systematic. It's time for a green paper about what can be done to improve the government response to FASD. MPs can assist. The APPG on FASD should continue to assist in bringing other policy makers up to speed on these issues (and indeed a parliamentary inquiry might help bring things into focus). The National Audit Office could

review the hidden costs of inaction on these topics and could explore the impact of 'preventative spend'. Government could convene a UK-wide FASD task force to learn from best practices across the UK. Proper research could be funded concurrently (action need not wait). Identifying an FASD champion within the Department of Health and Social Services as a point of contact would be helpful. An urgent review needs to be done of the training materials used in medical and related fields – both in schools and as part of continuing professional development.

We cannot begin to solve these issues today in only 90 minutes. We hope and expect to be involved in future meetings. Stakeholder and service user experience and expertise are an integral part of addressing any public health issue. We can today begin to help frame the questions that need further exploration and renew our commitment to continuing this process.

We don't have all the answers, but we know the kinds of questions we would like asked. The most important question is this:

"How can we collectively and comprehensively work to reduce the number of children born with FASD and how can we support those with FASD throughout their lifetimes?"

As an easily achievable first step, we humbly request that you invite stakeholders to regularly scheduled quarterly meetings so we can continue this conversation and keep open this line of communication. NOFAS-UK stands ready to assist with logistics and the entire FASD UK Alliance looks forward to continued engagement.

Thank you for listening. We hope this is the first of many opportunities to work together to tackle FASD in all its complexity.

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