

First UK-Based Prevalence Study on FASD: Implications for Policy Makers

Report of the All-Party Parliamentary Group on FASD Roundtable Discussion • 13 December 2018 • Macmillan Room • Portcullis House • Houses of Parliament

KEY POLICY POINTS:

- Government must address the implications of the first ever UK prevalence study of Foetal Alcohol Spectrum Disorders, which showed that between 6-17% may have organic brain damage from exposure to alcohol in the womb. Researchers from Bristol and Cardiff Universities used data from a large-scale cohort. Results showed 79% drank alcohol while pregnant. Most who screened positive had mothers who reported low-to-moderate drinking.
- The UK should fund an active-case ascertainment study similar to those governmentally funded in other countries, using known models to go into schools and possibly prisons to test the actual number of FASD cases.
- Government was congratulated on its recent series of meetings on FASD and for seconding a health registrar to help coordinate this work.
- Government was encouraged to continue interdepartmental exploration of policy options, leading toward change and a solid commitment of resources.
- Parliament should hold further debates and possible inquiries into FASD.
- · Support for increased training for professionals is urgent.
- FASD should be recognised as a neurodevelopmental disability, enabling those with FASD to access needed services.
- Government should increase efforts to actively and prominently promote the CMO guidance on alcohol and pregnancy to reduce incidence of FASD. The long-awaited update of NICE website to reflect this guidance was noted.
- Government should assess potential cost savings to the wider health, social care and educational economy that can arise from prevention, diagnosis and appropriate support which can reduce secondary disabilities.
- Stakeholders must be included in policy making.

CHAIRED BY: Bill Esterson, MP, Chair, All-Party Parliamentary Group on FASD PRESENTATIONS BY: Dr Raja Mukherjee, Consultant Psychiatrist, National FASD Clinic; Dr Cheryl McQuire, Research Associate in Epidemiology and Alcohol Research, University of Bristol; Georgia Roberts, Young Adult with FASD; Samantha Hutt, Birth Mother of Child with FASD

Dr Raja Mukherjee

Consultant Psychiatrist, National FASD Clinic (MBBS, FRCPsych, PGDIP EPP, PhD)

Thank you for inviting me back and giving me the opportunity to present to this group. I have been asked on this occasion to talk more about service provision. In reality this may have been better to follow on from Cheryl's subsequent presentation, but I must apologise that I have to leave early for a appointment this afternoon cannot stay until the end.

FASD is a complex neurodevelopmental condition that if not diagnosed will lead to ongoing lifelong issues for those affected in terms of cognition, communication and their function. The linked secondary disabilities, such as mental health issues and criminality can be reduced by early diagnosis.

Some of you will know I have been working with FASD for over 15 years. I have been running a specialist diagnostic service since 2009. It remains the only specialist FASD service in the UK. Whilst other clinics are now beginning to establish with local specialists interest clinicians and in Scotland for example a fully funded service by central government linked to a paediatric team has been established. These services are in their infancy and need support to supervise and confirm cases, especially where cases are borderline in their presentation. Expertise remains limited.

In the last two years there have been 180 referrals to our service. Only 50% of these received funding from local Clinical Commissioning Groups. Of that remaining 50%, 40% were funded by CCGs with a third through the adoption support fund and the rest been privately funded. I would like to emphasise our clinic remains an NHS service and we do not prioritise anybody or consider a referral Private even if his funded privately although it may well be considered such. Reasons for CCGs refusing that have been passed to us include statements such as "FASD is not an important issue" or "it is not common therefore we do not need to provide services for this" yet others "it is too common and should be addressed locally". In the past people

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Dr Raja Mukherjee

have also used the lack of formal diagnostic criteria on either ICD or DSM as an excuse to rule out the referral as they do not consider the disorder valid, yet as Cheryl will highlight, if the condition is looked for it is often found.

A couple of studies to mention quickly, which I have had the pleasure to be involved with, highlight why FASD is under recognised. Firstly the level of knowledge of professionals remains limited, often at best this is superficial. I have presented to this group before, that the lack of education hinders the development of service. Secondly FASD rarely

presents purely as that condition. Often it is the co-morbid difficulties that have the most obvious and which lead to referral. Until this changes and there is recognition of the underlying cause of the referral is highly likely to be FASD then this will continue to be an issue. This leaves families unsupported, always having to fight to be seen by someone with expert knowledge. These findings were identified as part of my own PhD and feedback from families where they have not been able to gain a referral to our service, or in many cases any service

Referral pathways and descriptions of how to improve the situation have existed for quite a while. Our original consensus meeting in 2013, later adopted in the 2016 BMA document highlights that hub and spoke model of service delivery will be one which the NHS could readily be set up to deliver. It does however require commitment. Our last application made to NHS England was unsuccessful in its attempts to gain central funding and remove these referral issues, however it was received at a time where new investments was being restricted and only if cost saving could be demonstrated, would central funding be allocated. We were not in a position at that time to demonstrate this. The hub and spoke model also was not conceived back then for use with FASD.

Some of the work highlighted by Cheryl, now helps to establish the possible level of need, alongside

growing interest and desire to set up services for this condition, means that this is now timely point to relook at this. It is encouraging that the Deputy Chief Medical Officer on behalf of NHS England has begun work on this area and alongside some of the research emerging will add to this. We are in a good position to respond quickly. With sufficient commitment it is my opinion that we could establish change, and support individuals with relatively small cost increase but then lead to significant cost saving to the wider health, social care and educational economy.

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Dr Cheryl McQuire

Research Associate in Epidemiology and Alcohol Research, University of Bristol PhD (epidemiology); MSc Forensic Psychology

Thank you for convening this roundtable discussion today and providing me with the opportunity to share the findings and implications of our recent study on the screening prevalence of FASD in the UK.

Also thanks to Dr Raja Mukherjee for providing a valuable overview of the current clinical and service provision context for FASD.

There are handouts with slides that provide an outline of what I am going to talk about if you'd like to follow them. I'll start with some information to demonstrate why more evidence on FASD is needed in the UK.

Existing FASD prevalence estimates

The UK has the 4th highest prevalence of drinking in pregnancy in the world, so there is reason to believe that FASD could be an issue in our population but previously there had been no general population based studies to estimate FASD prevalence in the UK.

Studies from other countries including the USA, Canada, Italy, Croatia and Poland place FASD as the leading cause of preventable developmental disability in the world.

In-school screening studies from these countries, which have lower rates of prenatal alcohol use than the UK, suggest around 2-5% of children in the general population have FASD. These are conservative estimates and a USA study, published this year, suggested that The UK has the 4th highest prevalence of drinking in pregnancy in the world, so there is reason to believe that FASD could be an issue in our population.

Dr Cheryl McQuire

this figure could be as high as 10%. Rates among looked after children and those in the criminal justice system are even higher – around 30%, and in rural parts of South Africa prevalence is up to 28%.

Hidden disability

Dr Raja Mukherjee has clearly described the issues around the lack of awareness of FASD in the UK and the need for improved services to effectively diagnose and support those affected.

Economic costs

We know the economic costs associated with FASD are considerable. For example, conservative estimates of the costs associated with FASD in Canada in 2013 totalled \$1.8 billion Canadian dollars - mainly due to costs around lost productivity, health care and involvement with the Criminal Justice System. FASD diagnosis made up a fraction of this cost at around \$5 million. Recent review-level

evidence places the average annual cost of FASD at approximately \$23,000 per child and \$24,000 per adult, mainly due to costs around lost productivity, health care and contact with the criminal justice system. These costs are 26% higher than those associated with autism.

These studies make a strong case for increased investment in FASD prevention, early diagnosis and intervention to reduce long term societal costs of FASD and to mitigate likelihood of adverse secondary outcomes. Studies make a strong case for increased investment in FASD prevention, early diagnosis and intervention to reduce long term societal costs of FASD and to mitigate likelihood of adverse secondary outcomes.

Dr Cheryl McQuire

A study from the USA estimated that the cost of raising a child with fetal alcohol syndrome would be roughly 30 times the cost of preventing fetal alcohol syndrome in the child. On this basis, the authors argued that the benefit to families, their children and society would be immeasurable.

Support for a UK FASD prevalence study

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.

Understanding how many people in the UK have FASD is essential for informing public health policy and for making sure that there is appropriate provision for FASD prevention, identification and support.

The preferred approach to estimating FASD prevalence is to carry out active-case-ascertainment studies, for example where researchers go into schools and screen children for FASD, as I previously described. These studies have been funded by government in other countries, protocols have been established and the results have been highly influential in determining the true scale of the problem and shaping policy, prevention initiatives and service

provision for FASD.

But to date, proposals to carry out an active case ascertainment study of FASD in the general population of the UK have not been successful.

Our study

To begin to address this important research gap, along with a team of researchers from Bristol and Cardiff University and clinicians, including Raja, we carried out a large FASD screening study using existing data from nearly 13,500 participants from the Children of the 90s cohort (also known as the ALSPAC study).

Our aims were to develop and validate new screening

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We developed our screening measure using the established Canadian criteria for FASD diagnosis and in consultation with clinical experts.

Consistent with these guidelines, in our study a positive FASD screen was defined as evidence of prenatal alcohol exposure with impairment in at least 3 different areas of learning and behaviour, with or without the physical signs (which included the distinctive facial profile and growth impairment).

The learning and behaviour assessments included comprehensive data on range of developmental outcomes relevant to FASD and measures of prenatal alcohol exposure that were collected at multiple time points during pregnancy. Tests of children's development were carried out by qualified personnel, including psychologists and speech and language therapists, and a range of informants, including parents and teachers.

Up to 79% of participants drank some amount of alcohol in pregnancy, with 25% at binge levels.

Dr Cheryl McQuire

Given the wealth of information available, we wanted to develop a screening measure that best reflected real life practice. We systematically varied which assessment measures we used, resulting a range of different screening measure specifications and we validated these using a multidisciplinary case conference panel.

Our panel included a FASD specialist, paediatrician and educational psychologist.

In this conference, the expert panel were given a random sample of participant profiles and asked to decide whether, on the balance of probability, each participant would receive a diagnosis of FASD or not if they were to come into their clinic.

For our screening prevalence analysis we selected the screening measure with the greatest levels of agreement with the expert case conference panel.

Addressing missing data

As is common in many longitudinal studies there was missing information on several of the measures that we were interested in, so we needed to come up with a strategy for dealing with this. To look at the impact of missing data on our screening prevalence estimates, we applied three different methods that are commonly used in research. These were complete case, single imputation and multiple

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Dr Cheryl McQuire

imputation. These strategies and their impact on the number of participants that were included in our study is shown in the figures on your handouts. But briefly, the most robust way of handling missing

data is through multiple imputation so the analysis based on this is what we took to be our primary screening prevalence estimate.

Results

So what did we find?

First, we found that drinking in pregnancy was common. Up to 79% of participants drank some amount of alcohol in pregnancy, with 25% at binge levels.

In our sample, between 6 and 17% of children screened positive for symptoms of FASD, with the range reflecting the different missing data methods that we used.

Most children who screened positive for FASD did not have the physical features (growth deficiency and facial anomalies), which is consistent with evidence suggesting that this is a largely 'hidden' condition. In terms of prenatal alcohol exposure, most participants who screened positive had mothers who reported low to moderate drinking in pregnancy (up to 6 glasses per week), although there was also evidence of increased binge and regular (weekly drinking) among participants with a positive screen, compared to those who did not screen positive.

Most participants who screened positive had mothers who reported low to moderate drinking in pregnancy. Dr Cheryl McQuire

Strengths and limitations

This is the first study to estimate the potential prevalence of the full spectrum of FASD in a UK population based sample. Between 6 and 17% of children screened positive for symptoms of FASD

We used established criteria for FASD, expert consultation and used appropriate methods to reduce the bias caused by missing data.

However, it's important to bear in mind that our screening measure is not equivalent to a formal diagnosis, which would require further specialist assessment. Nevertheless, the high levels of prenatal alcohol exposure that we observed coupled with the high prevalence of FASD-relevant symptoms suggests that FASD is likely to be a significant and previously under-recognised public health concern in our country.

Although information on prenatal alcohol use was collected several years ago and guidance on drinking during pregnancy has since changed, rates of prenatal alcohol exposure in the UK have remained high. Recent estimates suggest that three quarters of women drink some alcohol during pregnancy, with one third at binge levels. This suggests that many individuals in our population today could also have symptoms of FASD

This study suggests that much more needs to be done to both carry out more research in this area to get current general population estimates and to put resources into FASD prevention and support for those who suffer from this largely hidden condition.

Policy recommendations from the study

- Current UK prevalence study urgently needed. In-school screening (active case ascertainment) studies are the preferred approach internationally and should be carried out in the UK.
- Up to date data is needed for government and service commissioners to plan for and provide appropriate levels of service.
- This study reveals a mismatch between likely prevalence and clinical expectation that FASD is a rare condition. Early recognition and management of the disabilities associated with FASD can help reduce the risk of long-term adverse outcomes and the societal costs.
- Diagnostic capacity must be increased, as people with FASD can benefit from existing specialist services (e.g. speech and language therapy, educational psychology, mental health services).
- As part of the UK Alcohol Strategy, there needs to be coordinated, UK-wide, comprehensive action and training on FASD prevention, diagnosis and support that extends across the individual's lifespan.
- Inconsistency in national guidelines about prenatal alcohol use; NICE (and others) should update their antenatal guidance in line with the Chief Medical Officer's recommendations (abstinence during pregnancy).

I would like to end by pointing out that there are examples of existing government backed initiatives that we can draw upon here and templates exist for good practice.

For example:

- Scottish Government have a 'FASD awareness toolkit' and have committed to preventing FASD and increasing support in their 'Delivering for Today, Investing for Tomorrow' strategy document (2018).
- Awareness, prevention, assessment and intervention programmes already well established in other countries such as Canada and USA and have been rolled out in Australia and New Zealand.
- There is interest from UK government. The Department for Health and Social Care convened roundtables on FASD in September 2018 and there is the important work of the APPG on FASD.
- We are in discussion with Welsh Government about how FASD can feed into their new substance misuse and 'improving outcomes for children' strategies.

Thank you for your attention and I'd be happy to answer any questions.

Further information about the study is available here: http://bristol.ac.uk/news/2018/november/first-uk-prevalence-estimate-fasd.html

Georgia Roberts

Aged 16, affected since birth

A personal view on the importance of identifying FASD early and having knowledgeable support people in place.

I was finally diagnosed with FASD at the National Clinic in 2015, but I have had symptoms all of my life. My birth Mum drank and in September 2003 my sisters and I were taken into care when I was 15 months old. I have lived with the same family since then who are now my Special Guardians. Addenbrookes identified my FASD in 2009, but I received no support.

Before 2009 my life was very complicated. My first Primary School teacher described me as being lazy, defiant, obstructive and evil when I was in Year 1. My GP knew nothing about FASD, even though it was suggested at my adoption medical.

We moved in 2009 and we had a new GP who is an adopter with a son who has FASD. The new head at the primary school was also an adopter and her daughter behaved in much the same way as me. Both of these adults understood me and tried to put things in place to make my life easier, but not enough adults in my life understood enough and life is still a challenge for me.

Even with a diagnosis, Pupil Premium Plus and an Education, Health and Care Plan I was physically unable to get into school last year, my final year of GCSEs. Although the school SENCO tried hard to support me, my school deregistered me without any support from the County Council. I spent 6 months without any educational support. Tutors were My first Primary School teacher described me as being lazy, defiant, obstructive and evil when I was in Year 1. My GP knew nothing about FASD, even though it was suggested at my adoption medical... I saw CAMHS last week and they really told me that it's not really their job to support people with my conditions. They couldn't tell me whose job it was.

Georgia Roberts

appointed less than a month before I was due to take my first exam. It will be no surprise to you that I have no GCSEs.

Through all of that time my parents, SENCO and GP had been asking for CAMHS support. I had been discharged by CAMHS at the beginning of Year 11 because the Psychologist left her post. It took them 6 months to get some one to see me. Too little too late. I saw CAMHS last week and they really told me that it's not really their job to support people with my conditions. They couldn't tell me whose job it was.

So, I have care experience, but no social worker. I am on a college course that really is too easy for me and this frustrates me. The only real support that I get is from my family. At college it is just like going back to the start of every School that I have ever been in and I

have heard my Dad saying the same things to teachers again. The teachers then go and do 'some research' about how to teach people with FASD, but they never ask me or believe me.

I am blamed and punished for things that I can't actually help. There are things that I can't do but lecturers believe that I choose not to do them. I struggle to understand body language and gestures and take things literally. I say things exactly as I see them. But I do take great interest in things like History, which I research, but can't study as I don't have GCSEs. I can do things like this with the right support.

Sadly, I know that what I have experienced is not unusual. The results of this PhD research show this. My foster brother aged 10 has also been diagnosed by the National Clinic, but the advice about him is being ignored because people don't have the knowledge or understand about FASD. He cannot even get an EHCP at the moment. My older sister has just started the process of getting the challenges that she faces identified as FASD.

What I want is:

- People who know about FASD and can make a difference.
- People who listen to those who struggle. I know why I am different, and I know what works to help me to achieve.
- · People who are committed to working with parents / guardians and carers to support them
- People who understand the effects of FASD on minds and mental health and will support not make things worse. And mental health services who recognise and have services for those affected.
- People who will not give up on affected children and will support them growing up and especially at transitions and into adulthood.
- Real support for those of us with care experience as it adds to the challenges that we face. Despite the steps and progress made for children in care and adopted kids I have not been able to access the support
- And finally, not to be blamed for my conditions, especially when people have been told how these conditions affect me.

There are still too many ignorant people. You wouldn't tell someone off who is blind because they can't see, but I get told off most days for things I can't help. I want people who understand the effects of FASD on minds and mental health...Mental health services who recognise and have services for those affected...Not to be blamed for my conditions, especially when people have been told how these conditions affect me.

Georgia Roberts

Birth mother to a child with FASD

Hello, my name is Samantha and I am the birth mother to two amazing boys aged 10 and 11 years old. My 10-year old is what we call 'neuro typical'. My eldest is diagnosed with an FASD, specifically Partial Foetal Alcohol Syndrome.

My son was diagnosed in 2016 after many years of referrals to paediatricians, OTs, therapists, speech and language, CAMHS, school support workers, children's services and more. The list goes

on. It's only when you look back over the years that you realise just how many professionals it took, to finally get to the point of diagnosis and support. Yet, I have had to explain what FASD is to almost every single one of those professionals.

The study shows that despite so few birth mothers coming forward, for fear of stigma and judgement, FASD is out there. It needs to be identified much sooner. Early diagnosis and support will help to prevent children being passed from pillar to post in our health and education systems. I still find it astounding, the lack of knowledge amongst mental health workers, doctors and nurses.

I was watching a programme the other day about paramedics. They were talking to an elderly lady about drinking in 'her day'. "Women only drank stout or half a beer," she said, "not like today." This hit home as many people struggle to believe that FASD exists. They fall back on "My nan/mum drank in pregnancy and we're all fine." Well, yes, but I'm My son was diagnosed in 2016 after many years of referrals to paediatricians, OTs, therapists, speech and language, CAMHS, school support workers, children's services and more. The list goes on. It's only when you look back over the years that you realise just how many professionals it took, to finally get to the point of diagnosis and support. Yet, I have had to explain what FASD is to almost every single one of those professionals.

Samantha Hutt

pretty sure your Nan wasn't drinking 12% Pinot Grigio out of a 250ml glass every night – "Just the one". Or taking part in the odd binge drink – "I've not touched a drop all week!"

Society has changed since 'my Nan's day'. Therefore guidance needs to be stricter and clearer, more accessible. When I was pregnant I gave up all the standard stuff, as advised by my midwife: blue cheese, soft cheese, raw eggs, peanuts, etc. I'd like to think that had I been told about FASD and told not to drink, I would have done so, or at least asked for help.

What this study shows to birth mothers is that we are not unique. I am not a freak should have had more common sense. I am human and some humans need guidance, to be taught and sometimes, supported. You don't know the circumstance, background or needs of the mother.

To have a study show that three-quarters of women were drinking in pregnancy and that 1 in 3 were binge drinking proves that the message is still not out there. Every parent I speak to about my son's

diagnosis is shocked! "I've never heard of it," they say. "I didn't realise alcohol did that." You see a glimmer of realisation cross their face as they recollect their behaviours in pregnancy. A hint of fear. And yes, some of those parents have children with ADHD or some undiagnosed emotional/ behavioural disorder. As this study shows, ARND is the most common FASD subtype in the

screenings - no facial features of outward physical appearance. Easy to misdiagnose or simply *not* diagnose. Again, highlighting lack of knowledge.

The Government needs to work with the NHS on enhanced prenatal screening. To inform pregnant women as early in the pregnancy as possible. Every pregnant woman has the right to be given correct guidance on alcohol in pregnancy. They have the right to be informed, warned about FASD. To be given the chance to be able to choose a different path, to safeguard their child.

More needs to be done. If this study isn't enough to highlight the urgency, to make changes to prenatal care, I don't know what is.

Thanks for your time.

I'd like to think that had I been told about FASD and told not to drink, I would have done so, or at least asked for help....Every pregnant woman has the right to be given correct guidance on alcohol in pregnancy. They have the right to be informed, warned about FASD. To be given the chance to be able to choose a different path, to safeguard their child. More needs to be done.

Samantha Hutt

ROUNDTABLE PARTICIPANTS

Bill Esterson MP Jim Shannon MP Madeleine Moon MP Sophie Stowers Megan Meirion Jones	Chair, All-Party Parliamentary Group on FASD, MP for Sefton Central, Shadow Business and International Trade Minister MP for Strangford MP for Bridgend Office of Sharon Hodgson, MP for Washington and Sunderland West, Shadow Minister for Public Health Office of Tim Farron, MP for Westmorland and Lonsdale
Martin Butcher	East Hertfordshire and Area FASD Support Network
Sandra Butcher	National Organisation for Foetal Alcohol Syndrome-UK
Samantha Hutt	Parent
Paul Jackson	Parent
Rachel Jackson	Teen with FASD
Sharon Jackson	Parent, MUCH Laughter
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Jo Pennell	Treetangle Occupational Therapy
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Andrew Trathen	Public Health Registrar, Healthy Behaviours Team
	Department of Health and Social Care
Andrew Walker	Wycombe MRS

The ensuing roundtable discussion touched upon: unmet educational needs, the urgency of social workers/adoption agencies addressing FASD, challenges those with FASD face in the medical system, the lack of understanding among those in CAMHS and the impact on those who need mental health support, the unmet needs of adults with FASD, the hesitance of GPs and other medical professionals to address the risks of alcohol in pregnancy, the need to break past stigma and other topics.



REPORT PREPARED BY NOFAS-UK