



# 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

### KEY POINTS RAISED BY STAKEHOLDERS

- 1 - There is an urgent need for Increased awareness, training, information and tracking across all NHS platforms on the full range of the FASD spectrum diagnoses, drawing upon best practices that exist in the UK.
- 2 –Prevention is key. Women need appropriate support before and after birth. Education about the risks of alcohol in pregnancy should begin in school.
- 3 – Diagnosis, assessment and support across the lifespan are needed.
- 4 - FASD should be fully recognised as a neurodevelopmental disorder.
- 5 – Continuing engagement with stakeholders is essential. In particular, adults with FASD have a right to be heard.

Report prepared by NOFAS-UK  
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**FASD Stakeholders  
Meeting with Deputy Chief Medical Officer Prof. Gina Radford  
22 October 2018**

**SUMMARY REPORT<sup>1</sup>**

On 22 October 2018, 26 participants took part in what is many believe to be the first FASD stakeholders meeting convened by the UK Government.

**Background**

NOFAS-UK was approached by Professor Gina Radford the Deputy Chief Medical Officer at the Department of Health and Social Care England to host an event with her and service users and stakeholders to discuss the future policy development on issues relating to Foetal Alcohol Spectrum Disorders (FASD). This follows on from a meeting held 17 September with a panel of health and care experts to get their perspectives.

The Government recently announced its intention to publish a new Alcohol Strategy next year led jointly by the Home Office and Department for Health and Social Care. This presents a timely opportunity to engage with stakeholders and service users on FASD to touch base on the latest evidence base and provide an opportunity to learn about the best practices currently in place, identify any evidence gaps, and assist with possible recommendations to support the development of future policies regarding FASD prevention, diagnosis, and support.

**Summary**

The meeting was chaired by Professor Radford and was held according to Chatham House rules, which means the substance of the meeting can be reported out without attributing any of the comments to particular individuals. The agenda included presentations by:

- Martin Butcher, East Hertfordshire and Area FASD Support Network introducing a statement on behalf of the FASD UK Alliance;
- Pip Williams, on behalf of the UK-EU Birth Mothers Network-FASD;
- Brian Roberts, a former virtual school head who discussed Looked After Children, FASD and education;
- Andy Jackson and other adults with FASD;
- Sandra Butcher, NOFAS-UK offered brief closing comments.

The presentations are attached as appendices.

Many important points were raised by stakeholders throughout the meeting. A very powerful session involved six adults and young adults with FASD who shared their personal experiences trying to access diagnosis, support and services. This was the core of the session and a reminder that these issues deeply affect the wellbeing of individuals and families across the UK. Online feedback from 22 individuals with FASD also was distributed.

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<sup>1</sup> This summary was prepared by Sandra Butcher, Chief Executive, NOFAS-UK. There was no attempt in the meeting to achieve consensus.

Main points raised by stakeholders included:

- There is an urgent need for Increased awareness, training, information and tracking across all NHS platforms on the full range of the FASD spectrum diagnoses and not just the 10% of those with FASD who have the facial features of Foetal Alcohol Syndrome.
- Prevention is key. Support for pregnant women should be framed in ways that help not only decrease the incidence of FASD but also support women in the post-natal by providing access to early diagnosis and support for a child who might have been affected.
- To avoid tragic consequences, it is critical to ensure those affected (including adults) have access to FASD diagnosis and related assessments. Looked after children and those who are adopted should all be assessed for FASD and particular attention should be paid to training all professionals in these fields.
- Appropriate support is required across the lifespan of those with FASD – it is a lifelong hidden disability arising from organic brain damage due to alcohol exposure in utero. Failure to provide this support can have - and is having - devastating impact. This point was poignantly underscored by contributions from adults with FASD. A strengths-based approach is needed.
- FASD should be recognised as the neurodevelopmental disability it is, so all people with FASD no matter what their IQ-level can access services and benefits that are open to others with autism and other neurodevelopmental disabilities.
- Continuing engagement with stakeholders and service users must be a part of finding the way forward.

**FASD Stakeholders**  
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**AGENDA**

- 10.30 – 10.45 Welcome and introductions – Prof. Gina Radford, Deputy Chief Medical Officer
- 10.45 – 11.05 Statement on behalf of the FASD UK Alliance, a coalition of groups across the UK who collectively administer a 2000 person Facebook support group on why it matters to get early diagnosis/proper support, including overview of forthcoming results from the NOFAS-UK CCG/Trusts Freedom of Information requests - Martin Butcher, co-founder East Hertfordshire and Area FASD Support Network
- 11.05 – 11.20 Birth mothers experiences – Pip Williams, founder and executive director, UK-EU Birth Mothers Network-FASD
- 11.20 - 11.35 Looked after children, FASD and the importance of proper assessments and strategies at home and in school – Brian Roberts, foster carer, former Virtual School head
- 11.35 – 12.00 Discussion featuring adults with FASD. Andy Jackson, National FASD Advisory Committee, will lead off with a list of things adults with FASD want policy makers to know. We will share a print out of feedback from 22 adults with FASD
- 12.00 – 1.00 Roundtable discussion - Suggested topics for special attention:
- Examples of best interventions? What has worked well? What and where are the examples of best practices?
  - What is not working?
  - What can be done to better support local delivery of services?
  - What needs to be done regarding educating professionals or improving the evidence base?
  - Are things getting better? How so?
- Please note: it is recognised that we cannot solve the wide-ranging issues in one session. The goal was for those with FASD and those who help support them to provide some insight for policy makers based on real life examples.
- 1:00 – 2:15 *OPTIONAL - For those whose schedules allowed, NOFAS-UK extended the room booking as part of its Wellbeing Project and provided light sandwiches following the conclusion of the meeting. This provided an opportunity for further sharing of experiences and a chance for participants to get to know each other better.*

**FASD Stakeholders**  
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**PARTICIPANTS**

- Iain Armstrong-Alcohol Programme Manager, Public Health England
- Matthew Birkenshaw, Alcohol Policy Lead, Department of Health and Social Care
- Dr James Bowler, Parliamentary Scholar (working with Baroness Hollins)
- Emma Butcher, Actor, Facilitator at 2018 NOFAS-UK/E Herts & Area FASD Support Network “Brain Base: FASD Summer Fun Days”, Auntie to teen with FASD, working on play regarding lived experiences of those affected by FASD.
- Martin Butcher, Co-Founder East Hertfordshire and Area FASD Support Network, Co-author [FASDLearningWithHope.wordpress.com](https://fasdlearningwithhope.wordpress.com), Parent to teen with FASD
- Sandra Butcher, Chief Executive, National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK), Co-Founder East Hertfordshire and Area FASD Support Network, Co-author [FASDLearningWithHope.wordpress.com](https://fasdlearningwithhope.wordpress.com), Parent to teen with FASD
- Richard Clements, Adoptive father (invited)
- Nyrene Cox, Adult with undiagnosed but suspected FASD, member National FASD Advisory Committee, London
- Stuart Craig-Lau, Alcohol Policy Lead, Department of Health and Social Care
- Jan Griffin, Birth mum, London
- Rossi Griffin, Adult with FASD, London
- Baroness Sheila Hollins
- Andy Jackson, Adult with FASD, member National FASD Advisory Committee advising NOFAS-UK, Kent/Medway
- Sharon Jackson, Foster Carer, Mother to Five Adopted Children with FASD, Co-Founder FASD Awareness Southeast; Trainer and Co-Founder MUCH Laughter (raising awareness for FASD)
- Rachel Jackson, Teen with FASD, Kent/Medway
- Claire McFadden, Adult with FASD, member National FASD Advisory Committee, advising NOFAS-UK, London
- Anna Lucas, Maternity Lead, Public Health England
- Róisín Reynolds, Senior Advisor – Alcohol Exposed Pregnancies, Greater Manchester Health & Social Care Partnership
- Brian Roberts, Foster Carer at Bedford Borough Council (including for children with FASD); Independent Trainer and Consultant; Field of Enterprise Consultancy and Training; Former Virtual School Head Peterborough
- Debby Robinson, Adoptive Mum to an adult with FASD, Isle of Wight
- Florin Robinson, Adult with FASD, Isle of Wight
- Neha Shah, Alcohol Policy Lead, Department of Health and Social Care
- David Squires, Adoption UK Government and Policy Relations Officer, Adoption UK
- Anna Webster, Adoptive Mum, Blogger: <https://www.truerfilms.com/blog/>, Manchester
- Philippa (Pip) Williams, Birth mother of two adults with FASD, Specialist independent trainer, Founder and Executive Director of the UK & European Birth Mother Network, Co-Founder of the FASD UK Alliance



**Statement on behalf of the FASD UK Alliance  
Meeting with Deputy Chief Medical Officer Prof. Gina Radford  
22 October 2018**

**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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Pip Williams, UK & European Birth Mothers – FASD  
David Gerry and Annie Nugent, FASD Alliance Ireland  
Tracy Allen, FASD Awareness South East  
Martin Butcher, E. Hertfordshire and Area FASD Support Network  
Lee Harvey-Heath, FASD Devon and Cornwall Consultancy

Alison McCormick, FASD Dogs UK  
Pip Williams, FASD London  
Maria Catterick, FASD Network UK  
Susan McGrail, FASD Northwest  
Eileen and Ray Calder, FASD Scotland  
Sharon Jackson, MUCH Laughter  
Brian Roberts, Peterborough and Area Family FASD Support Group  
Carolyn Blackburn, SEND Consultancy  
Stacie-Leigh Doorbar and Ann Taylor, Stoke and Staffordshire FASD Support Group  
Sandra Butcher, National Organisation for Foetal Alcohol Syndrome-UK



**Meeting with Deputy Chief Medical Officer Prof. Gina Radford  
Pip Williams, Founder UK-EU Birth Mothers-FASD Network  
[eurobmsgroup@yahoo.com](mailto:eurobmsgroup@yahoo.com)  
Co-Founder, FASD UK Alliance  
22 October 2018**

Good Morning. My name is Pip Williams and I'm the founder of UK & European Birth Mother Network. Thank you for inviting us here today. I hope this is the beginning of our discussions on these issues.

The first point needs to be emphasised - no woman drinks because she wants to harm her baby. Women need to be given correct information so they can make an informed choice, for whatever the reason they are drinking in pregnancy. They need to be able to safely disclose their alcohol use without feeling judged, shamed, treated unfairly or fear of losing custody of their children.

There are 7 key reasons why women continue to drink in pregnancy:

1. They are unaware they are pregnant;
2. They are unaware of the harms alcohol can cause during pregnancy;
3. They are using alcohol to cope with difficult situations;
4. They might know someone who drank and their child is ok;
5. They face social or work pressure while out or haven't disclosed pregnancy;
6. They struggle with alcohol addiction;
7. Their partners pressure them - "just have one, it won't hurt baby". (Recent research shows 44% of partners initiated drinking in pregnancy.)

The women in our network all drank for one of those reasons though the majority were social drinkers or were going through a difficult situation. All were unplanned pregnancies. Only a small percent of women who drink in pregnancy are alcohol- or substance-dependent. For those who do drink there are barriers in coming forward and seeking support.

### **What is not working?**

It's not the abstinence during pregnancy message that needs to be changed, but the training of those delivering it so that it can be done in a supportive way so women can disclose safely what is happening in their lives

Women are still experiencing stigma from midwives, social workers, doctors and other professionals. When these professionals are not well-trained in how to have these discussions it can be very damaging.

A mother said - "No-one mentioned no drinking in pregnancy or FASD to me - I was afraid to disclose my drinking as the midwife was very judgemental saying 'you don't drink do you,' rather than asking, 'How much alcohol do you drink?'"

Midwives, social workers and other practitioners supporting pregnant women need to be more aware and have a better understanding not only of FASD but also of the intersections of trauma, substance use, and mental health issues that can arise especially in pregnancy and be familiar with referral pathways. (Millions are watching the fictional Hayley Slater's journey on East Enders.)

Recent studies show 33% of women experience domestic abuse for the first time whilst pregnant. Pregnant women and mothers who are experiencing any of these need linking in to other women with lived experience and local services e.g. mental health, alcohol & drug, domestic abuse services. It's a post-code lottery of which services are available.

International best practice demonstrates that well-coordinated and comprehensive support, with early access to antenatal care and specialist alcohol and drug treatment, can reduce harm and improve outcomes for women with problematic alcohol and drug use, and their babies.

## Perinatal

Many midwives still lack clarity, resources, referral pathways and research so prenatal alcohol exposure becomes a question they may seek to avoid. Women want to be asked.

It is challenging to fit all this into a 10-minute conversation. Many midwives just ask closed questions and from recent research say they are afraid to ask for 'fear of opening up a can of worms and not have enough time or know where to refer to'

A mother said - "No-one mentioned no drinking in pregnancy or FASD to me - I was afraid to disclose my drinking as the midwife was very judgemental saying you don't drink do you? Rather than asking how much alcohol do you drink?"

Midwives need a more compassionate, non-judgemental and informed approach when discussing any issues and have resources readily available to them to connect women into local specialised services, rather than immediately ringing social services. The whole team around the pregnant woman needs to be better trained in delivering a trauma informed service. There needs to be more specialist midwives as not enough currently have training in domestic violence and substance abuse.

Midwives often are focused only on the baby and are not seeing the full picture and how things connect. Practitioners need to understand how important the Mother-Child relationship is and the need to keep families together where possible.

## Postnatal

Practitioners need to be equipped in talking to women who have given birth to children with FAS, using correct language, making sure she has all the correct information, linking her to support groups and reassuring her she isn't hasn't done something wrong and is not a bad person!

Early response to problems and referrals improves outcomes. All professionals play a role. The message needs to be, "You are not alone. We are here to help "

One mother said, "The midwife was saying I was awful to do that to my child, I didn't know what she was talking about or what was wrong with my baby and didn't hear the word FAS until I was in court to fight for my child".

## What can be done to better support local delivery of services?

### CONNECTING SERVICES

An increased focus on supporting women at risk or who are drinking during pregnancy, and following through after the birth ties in with some the aims of the Better Birth – Maternity Transformation Programme and the continuity of care model which emphasises, personalised care, rapid referrals, multi-professional assessments, etc. Without this, the Better Birth aims are still not being implemented. Birth mums of those with FASD are not getting the same consistency of care other women are due to stigma and due to the lack of training of professionals on how to have these discussions.

Support needs to be joined up – statutory, community organisations, women's centres, peer support and online support should all be running together. Women need to be more included in decision making around their child.

## Examples of best interventions? What has worked well? What and where are the examples of best practices?

There are some positive examples, here are a few:

- Women are increasingly contacting the UK & European Birth Mothers group. They are finding it useful having an organisation that understands them and can help and support
- There are pockets of good practice – for example the Tameside Salford, parts of Yorkshire and in the North East who are developing FASD pathways
- Birth Companions have been successfully working with women in the community, supporting mothers perinatally to up to 3 years.
- Community hubs in local communities with midwife works well – there's more awareness about local services for women and easier referral.

- Research into women with multiple disadvantages birth companions/revolving doors agency will feed into the maternity transformation programme
- The Pause Project works closely with partners. Each Pause Practice is funded by and based within a charity or public sector organisation.

### Getting a diagnosis

It's the right for both the mother and child to have an FASD diagnosis. Diagnosis of Foetal Alcohol Spectrum Disorders is still too difficult to access, even when birth mothers come forward and express their concerns (obviously removing one of the biggest challenges for diagnosis, proof of exposure to alcohol in the womb).

Some have had bad experiences going to the doctors, who avoid the conversation, even if the woman might be a recovering alcoholic.

When women do come forward doctors sometimes give a 'sympathetic diagnosis' – downplaying the seriousness, "you didn't drink that much, your child looks fine" or blaming the issues on parenting, etc.

One mother said, "The doctor dismissed my concerns when I told him I had drunk heavily in pregnancy and I think my child has FASD. He refused to refer to me to the geneticist "

There needs to be ratified referral and support pathways for women and children with FASD e.g. counselling, medical referrals and connecting them with support organisations – Birth Mother Network–FASD, FASD UK Alliance, etc.

90% of birth mothers knew within first year that their child was different, yet for some it took till adulthood to get a diagnosis and the impact of a late diagnosis for many have been addiction, mental health, justice systems and sexual exploitation. FASD is sometimes multi-generational – we can break this cycle.

There needs to be a seamless FASD diagnostic pathway across the age span as many are not able to get diagnosed and are experiencing the secondary and tertiary impact from misunderstanding, lack of support, intervention

### What needs to be done regarding educating professionals or improving the evidence base?

The entire climate needs to change. FASD stakeholders and birth mothers should be invited to work with women's services, maternity service, perinatal services, children's services to help create a compassionate and non-judgemental approach. Kindness and a feeling of trust shapes a woman's experience profoundly. Women who are struggling want to be asked about their situations so that their specific needs are understood - e.g. how was their home life, domestic violence, substance misuse, mental health. Women want help and support but are afraid to ask for fear of losing their child and they distrust social services.

Women with lived experiences need to be included in research (and there needs to be more of it). It's a "WE" not an "US vs Them". Working together brings more robust and richer data. This is why it's important that research not limit its focus only on those in care or adopted children. Those issues are very important but it is not the full picture.

### Are things getting better? How so?

Things are getting better.

More mothers are coming forward through social media. For example, the FASD UK Facebook support group is a place where they can seek non-judgmental support along with others in the FASD community – and not just segregated into "birth mothers only" groups, though we have those too.

The UK and EU Birth Mothers Network-FASD has been part of a 2-year research project working with maternity commissioners in London via Birth Companions and Revolving Doors, First two stages were with North East London maternity commissioners and the 'Making Better Births a reality for women with multiple disadvantage' report is now available.

The report recommendations should be carried out for all maternity services. This would mean lots more early interventions and children staying more often with their parent. When that is not possible, the Pause Project could help avoid multiple similar situations.

The third stage of this research with North Central London maternity commissioners has just been launched for the better birth maternity transformation programme

Co-production of research and solutions must be the way forward.

### CONCLUSION

There is a phrase in the FASD community – "nothing about us without us." We know there is a lot of work ahead. The Birth Mothers Network is here to help. We want to contribute to the solutions. We know progress is possible and we also know the pain that can be avoided. We look forward to continuing engagement as Government becomes more proactive on this issue that affects so many lives.

Helping to prevent FASD is all our responsibility!

Thank you.





## Field of Enterprise Training and Consultancy

Supporting Vulnerable Young People  
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### Meeting with Deputy Chief Medical Officer Prof. Gina Radford Brian Roberts; Peterborough / Little Miracles FASD Family Support Group 22 October 2018

#### Looked After Children and the importance of proper FASD assessments: Strategies at home and in school

##### **Experience**

*Brian is a trained teacher who has fostered for over 25 years along with his wife, who was previously an officer in charge of a Bedfordshire Children's Home. In 2005, it is safe to say that we had never heard of Foetal Alcohol Spectrum Disorders (FASD). The placement of 3 girls with us in September 2003 changed that. When they were being assessed for their possible adoption in 2005, which never happened, the seed that they might have been affected was sown. 15 years later we now live with 2 of the girls aged 16 and 19, who we are special guardians for. We also have a 10-year-old boy in a permanent foster placement who was with us before his adoption and was placed back with us 6 years ago when his adoption broke down. He remains in care only because, from our experience with the girls, we feel that we also need the support of Social Workers to help to get the support he needs. All 3 have FASD, 2 were assessed at the national FASD clinic because the local CCG refused to do it locally, despite having the expertise within its own ranks. We live in a different area of the NHS Trust to where the specialist works and therefore cannot access her clinics. Our foster son's diagnosis was funded by Social Care and not the CCG.*

*Brian & his wife co-ordinates the Peterborough Family FASD Support Group in collaboration with the generous support of the Little Miracles Charity.*

*Brian has also been a Virtual School Head for Looked After Children in Dudley and Peterborough. He was one of the Virtual School Heads on the national pilot some years ago. In Peterborough his average working week consisted of 4 days talking about FASD to various people in teams around Peterborough children scattered around the UK and 1 day for everything else. He is now a part time self-employed trainer and consultant specialising in factors that affect vulnerable children achieving and full time FASD Parent.*

##### **Points for consideration**

As parents we have fought for assessments and support, but what has made the experiences manageable is that we have been able to speak to others who understand our experiences. That has included both our GP and the Head of our local Primary School who are both adopters with very similar children living with them.

I would just like to reflect on the fact that it is three years to the month since Adoption and Fostering the quarterly journal of the British Association of Adoption and Fostering / Coram published the first single journal dedicated to FASD in the UK (Oct 2015). I was a contributing author. Multiple copies of this journal are in children's services departments throughout the country and yet many working with children with care experience have little or no knowledge of the condition or its impacts on

individuals and families. Without clear assessments the pathways that are followed will remain the same as they are now. Nothing will change for the better if ignorance means that things stay the same.

I wouldn't suggest for a minute that having an assessment is a magic bullet, but it is essential to start a discussion about the support that is needed. In my personal experiences' assessments are often being blocked or delayed in a postcode lottery, that is also influenced by who you know and how loud your voice is.

Living with and caring about any child with FASD is a huge challenge, when affected children have care experience then the situation becomes even more complex. The organic brain damage associated with FASD in any child leads to significant challenges in learning and building the resilience and capacity to be thought of as being successful in our communities. It also presents very significant challenges to those that teach or parent them. Very often children with FASD suffer additional acquired brain damage which is caused by the stress of living with and coping with the condition. This leads to anxiety about their futures.

In 2010 **Bedford Borough Council Youth Service** (Locally published) worked with a small group of teenagers who had been identified as being affected by FASD. They showed that in addition to the normal worries that teenagers have, those affected by FASD also have concerns that were focused on their futures:

- ***The young people knew that they couldn't cope and felt that they weren't in control***
- ***Were confused and frustrated***
- ***Understood the challenges that they faced***
- ***Worried about the future and***
- ***Had a fear of growing up.*** (My own 16-year-old daughter often says that she would rather be 5 as life was simpler).

I would argue that any young person affected by FASD whether assessed or not would share similar concerns and experience similar stresses. There are many areas of research that show that living with these daily stressors can cause the characteristics associated with trauma, emotional difficulties, anxiety and other mental health conditions in addition to FASD.

With care experience we are looking at an even more complex set of circumstances. In most cases the anxiety and acquired brain damage is not only associated with their perception of their future but is also associated with the previous traumas that brought them into the care system and with living in care itself. Tackling the mental health situations is even more complex.

Additionally, there are significantly more adults involved in a young person in care's life. Without clear and expert assessments to inform care plans the best-meaning advice and guidance often becomes confusing and can be at cross purposes. In no way an environment for a young person to thrive.

At least in the care system there has been **statutory guidance for those undertaking medicals of children in care** since 2009 (**Department for Education**). The guidance says ( paragraph 44) ***"That Health Assessments should ... pay particular attention to health conditions that may be more prevalent in looked-after children (such as foetal alcohol syndrome or attachment difficulties) and which may otherwise have been misdiagnosed."***

As a Virtual Head on the National Pilot I was responsible for initiating the discussion that placed FAS in the list. However, it is rare to see that this actually happening. This missed opportunity for a formal assessment often means that strategies are not put in place early enough or are not put in place at all.

The often-quoted outcomes for children affected by FASD are that they are more likely to:~ Have low self-esteem, have poor or no educational qualifications, have mental health problems, use alcohol to extreme, be unemployed, engage in inappropriate sexual behaviour, have unwanted early pregnancies, have problems with the law, end up in prison, be homeless. These are strikingly similar outcomes for many Looked After Children despite the significant interventions that government has made over the last 15 years. I would suggest that there are strong overlaps between the two groups. I would further argue that this missed opportunity makes a significant impact that contributes to the educational and life gaps that children in the care system experience. Hard data on the numbers of children and young people in care affected are few and far between. In the BAAF / Coram journal quoted earlier Dr Ges Gregory (Peterborough's Looked After and Safeguarding Designated Doctor) and Myself both quoted the figures associated with Peterborough's in care population. 34% of the children undertaking their annual medicals in the year prior to publication had a birth mother who we knew drank during pregnancy and showed signs of FASD. That is well over 100 children and young people. We have no reason to believe that the figures for Peterborough would be significantly different to any English Local Authority.

More significantly the figure that we came around to for those children undertaking adoption medicals was considerably higher. 75% of those assessed had a birth mother who drank during pregnancy. In training that I co presented on in 2011 the LAC Doctor in Brighton was quoting a figure of 90% for children adopted under the age of 2. With this in mind I'd invite you to consider some other statistics from **Adoption UK** published in 2017

- ***Half of adopted children have special educational needs...***
- ***Of these 60% have needs so significant that they have Educational Health Care plans and***
- ***45% of them have EHCP that are in place for Social, Emotional and Mental Health needs.***

In the school situation

- ***4.7% of adopted children are permanently excluded***
- ***29% of them have changed schools because the adopters felt that the original school could not meet their needs***
- ***12% have had managed moves to avoid and exclusion and***
- ***12% are home educated, a figure far higher than the population in general.***

I wonder how many of these consequences are down to FASD, but I can only speculate as the assessments aren't in place that would put any meat on the bone of this thinking. I'd also add that over 2/3<sup>rd</sup>s of adoptions happen before a child is aged 4 with the average age of adoption being 3.4 (Office of National Statistics 2016). As a country we don't remove children lightly and therefore there are significant reasons, most are underpinned by drugs and alcohol, so its not a huge leap to expect that the same reasons were there during pregnancy. For all of the babies that we have fostered this is the case.

An assessment that results in a child being identified with FASD will not stop adoptions happening, but it will prepare adopters in some ways to support affected young people better.

Adoptions breakdown, over 1,200 in the last 5 years (Children and Young People Now Jan 2018), we don't know how many are because of the impact of FASD becomes too much for families to manage. However, every breakdown that I was involved in in Peterborough had FASD, often un assessed at the point of adoption, at its core and my 10-year-old permanent foster placements adoption broke down 6 years ago because of the impact that his then un assessed FASD had on his adoptive family. If the adopters were better prepared then he may not have suffered this additional and significant trauma in his life.

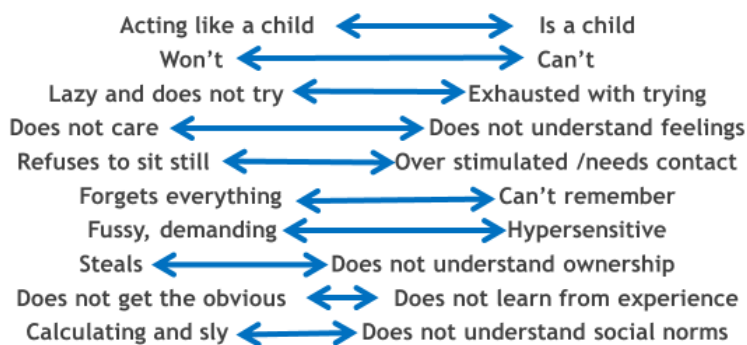
If a child has a diagnosis of FASD it will still be hard for everyone involved, but if we look at the situation in school if a child hasn't been assessed it is harder.

Teachers, have to teach and have to get groups of children to learn. The behaviours associated with FASD present a significant challenge to doing this successfully. Sometimes it can seem very personal. In my daughters case in Year 2 she sees the advice given to a teacher to 'get her hair cut like that again as it makes you look very pretty', the same as, 'don't wear that dress again Miss it makes you look really fat'. In her head both are helpful nuggets of advice, yet they did very different things in the teacher's head when these were said in front of the whole class. Or the Peterborough child who was on top of lockers and was taken down and appropriately and sensitively tutored by the Head so that he promised to never do it again and yet 20 minutes later he was back on top of the same lockers. Even with an insight these seem to be very personal slights, of course in both cases and many, many more they aren't, they are a feature of how a dysregulated brain functions.

However, if there hasn't been an assessment of the cause of the challenges that the teacher faces then the way that mis behaviour is managed reflects their lack of understanding. The way that you manage a child if you think that they won't do something you have asked or that they refuse to sit still will be totally different to the strategies you will try if you believe that they can't do something or that they are over stimulated and can't self-regulate. In making an accurate assessment of FASD the whole way behaviour is managed can be changed most of the time. The reframing of parental expectations is also a vital key to successfully providing for an affected child.



## Reframing



We won't get it right 100% of the time because the characteristics of FASD change over time and from day to day and we are human. In schools like most work places communication about a child's needs is not always as we would like it, but an accurate assessment allows adults to engage in learning how best to support an affected pupil or student, the best learning environment can be selected and effective learning plans are put in place with adequate support and our children can and do succeed.

Additionally, if a child has a recognised medical condition assessed and recorded there is significant legislation that in theory ensures that the young person gets their education. **The Statutory Guidance on supporting pupils with medical conditions** (DfE) is unambiguous.

- ***Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education.***
- ***Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions.***
- ***Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions are effectively supported***

Regrettably, if their FASD has not been assessed then this guidance cannot be implemented and too often the child or young person struggles or fails completely.

Parenting a child with FASD can be a lonely challenge. Increasingly in the care system, friends and relatives are undertaking this role with little support. The challenges of looking after a relative are exasperated by the characteristics of FASD. I am convinced that this has significant implications on the quality of Kinship placements.

It is the parent or carer who knows the child best and too often they are ignored, belittled, blamed and excluded from the planning process. Due to the lack of knowledge and expertise in the children's work force assessments aren't made and the parent has to become the expert. I for one would rather not be in that position.

Parents and carers have strategies that work more times than they fail. They deal with meltdowns after school which are far worse than those seen in school, because despite everything our kids understand that school and their education is important and work hard to hold it together. When they get home their defences come down and the impact of regulating the stress kicks in. As parents we also have aspirations for their children.

The infographic is titled "The delayed after effect" and features a green geometric background. It includes the logo for "Field of Enterprise" (a green leaf) in the top left. The main text is in green and blue. It shows a child sitting calmly at school and a child having a meltdown at home. The "FASD UK" logo is at the bottom right.

**The delayed after effect**

Child is nervous in formal situations - school, Reviews, SWs visits and accumulates stress hormones.  
The child can hold it together because they understand its important

Carer sees the meltdown when the child / young person is home in their secure base  
Others in the Team Around the Child don't see the same challenges and problems

**FASD UK**

Too often parents and carers are blamed for behaviours and tensions develop between home and school. Too often parenting classes are suggested to cure the disobedient, badly behaved, un disciplined child which will never work because the parents are dealing with un assessed FASD. By

working with parents and carers on an informed and consistent set of strategies affected children and young people can thrive, but accurate assessment is the key to making this happen. I also wonder that if assessments were in place and better support was provided then fewer children would be taken in to care. The behavioural characteristics of individuals affected by FASD can mirror those associated with disorganised and dysfunctional parenting. If FASD is not understood or the possibility assessed, then many of the strategies suggested to improve the situation might fail and the involvement of social care will naturally increase. One outcome will be that children may well be taken into care.

It is equally true that our children develop effective strategies to cope. They are really good at doing this. However, they need to be allowed to use the strategies that they have developed for their own mental health. A timely assessment enables this to happen.

I'll leave you with a tweet from Dr Raja Mukherjee last month '**It's not about fixing the person, but facilitating them to perform optimally**' at home, in school, in the work place and in our communities and without an accurate and informed assessment this will never happen.

**Andy Jackson**  
**Member, National FASD Advisory Committee**  
**Meeting with Deputy Chief Medical Officer Gina Radford**  
**22 October 2018**

**10 things about FASD**

1. People with FASD have challenges due to no fault of their own. They are innocent victims of prenatal alcohol exposure.
2. FASD is complicated and no two people are the alike. Prenatal alcohol exposure can cause damage to any system of the body. In recent medical literature there were found to be over 400 different diagnoses and problems with FASD.
3. Most of the time FASD is invisible. People with FASD can look normal, but struggle with normal day to day tasks. It most common for people with FASD not to have facial features.
4. Most people with FASD will have a normal intelligence. Some will have high intellect and still struggle. The majority will need a circle of external support for their lifetimes.
5. You cannot outgrow FASD. It is permanent and a life-long condition. There is no cure. It is a struggle to find diagnosis, support and help as there is no disability category where they fit into.
6. People with FASD can have memory and processing challenges, motor control, Visual and sensory processing issues. It is important to realize that our world is different to yours.
7. The brain is complex. just because you can say it, doesn't mean it's understood. We may need help with cognitive translation. Often times it not we won't do it, we may need a different way to be able to achieve it.
8. People with FASD just want to be understood, cared for and most of all loved like everyone else.
9. Its 100% preventable. It is the number one cause of prenatal brain injury and lifelong learning challenges.

Results from an online survey of 22 adults with FASD were shared. (This is not scientific. It is provided so as to share input from a wider number of adults with FASD than were able to be present at the meeting. Full feedback is available online: <http://www.nofas-uk.org/?cat=44>)

- 100% strongly agreed/agreed: "As an adult, I struggle because people don't understand my condition."
- 96% strongly agreed/agreed: "I needed more support in school. My teachers did not understand my needs."
- 82% strongly agree/agree: "I worry about the future"  
79% of those who have used these services (15/19): "Professionals in mental health and/or addiction services do not understand my FASD (or suspected FASD)"
- 78% strongly agreed/agreed: "I wish employers better understood my needs."
- 77% strongly agree/agree: "I struggle to access benefits, people making decisions don't seem to understand my needs."
- 72% strongly agreed/agreed: "My doctors don't understand FASD."
- 68% strongly agree/agree: "I worry about my housing situation"







**Facebook Support Groups:** FASD UK (more than 1,800 families) • FASD UK Professionals • FASD and Gender Identity • UK Teens & Adults with FASD

**YouTube Channel:** FASD UK Resources

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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.

**fasd-uk.net • fasd-uk@live.com • @FASD\_UK**

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