



OUR FORGOTTEN CHILDREN

The Urgency of Aligning Policy with Guidance on the Effects of Antenatal Exposure to Alcohol

A Roundtable Discussion with FASD Stakeholders
Co-chaired by Professor Sheila the Baroness Hollins and Mr Bill Esterson, MP
Houses of Parliament • 23 May 2018

KEY POINTS

- 1 - Government policy regarding Foetal Alcohol Spectrum Disorders (FASD) should be reviewed with urgency.
- 2 - Increased training on FASD is essential for achieving Government's goals.
- 3 - There is a continuing need for prevalence studies of the full FASD spectrum, but this does not justify inaction regarding improved delivery of diagnosis and support.
- 4 - FASD should be linked with Government efforts to improve mental health - stakeholders should be engaged.
- 5 - Policy leverage points exist and should be further explored.
- 6- This is the beginning of a heightened dialogue, engagement with constituents is key.

Report prepared by NOFAS-UK
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Key Points

On 23 May 2018, Baroness Sheila Hollins and Mr Bill Esterson, MP co-chaired a roundtable discussion in Parliament, “Our Forgotten Children: The Urgency of Aligning Policy with Guidance on the Effects of Antenatal Exposure to Alcohol” with approximately 25 stakeholders. Participants included representatives of national, regional and local Foetal Alcohol Spectrum Disorders (FASD) support networks and leading medical and educational experts. Brief messages of goodwill for the meeting were noted from Jeremy Hunt, Secretary of State for Health and Social Care, John Bercow, Speaker of the House of Commons, Jackie Doyle-Price, Under Secretary of State for Mental Health and Inequalities, and Dr Sarah Wollaston, Chair of the Health Select Committee, among others. This report highlights key action points, it does not seek to recreate the entire discussion.¹ Selected samples of the presentations and background documents are appended for those seeking more detail.

1) **Government policy regarding FASD should be reviewed with urgency.**

The UK has a network of experts and stakeholders ready to help Government develop a more comprehensive response to Foetal Alcohol Spectrum Disorders (FASD) and to explore a more efficient use of resources for FASD prevention, diagnosis and support. The British Medical Association first raised FASD in a landmark 2007 report, which it updated in 2016. Government has taken a positive step by issuing clear guidance in 2016 that the safest approach is to avoid alcohol when pregnant or seeking to become pregnant. In addition, the current Government has repeatedly emphasised the seriousness of FASD and the importance of early interventions. It has tasked local CCGs with commissioning services to support those with FASD.

- A review of the government policies regarding FASD prevention and support is needed to learn from best practices (such as in Scotland and the Northeast) and also to avoid the ‘post-code lottery’ that exists, leaving too many without access to diagnosis and support.

2) **Increased training on FASD is essential for achieving Government’s goals.** Too often front-line practitioners lack the skills and insights needed to support individuals and families when coping with the complexities of the organic brain damage of FASD and related conditions. The problem is systemic and needs a cross-disciplinary approach from leading bodies and colleges to address this.

- Participants highlighted the urgent need for a NICE pathway for diagnosis and coordinated support for those with FASD over their lifetimes.
- The CMO guidance on alcohol in pregnancy needs a higher profile and needs to be better resourced. It should be better promoted and publicised throughout the NHS and also incorporated into Personal, Social, Health and Economic (PSHE) education in schools. The NICE website needs urgent updating to put it in line with CMO guidance.



¹ This summary was prepared by Sandra Butcher, Chief Executive, NOFAS-UK, with thanks to Martin Butcher of the East Hertfordshire and Area FASD Support Network for taking notes. There was no attempt in the meeting to achieve consensus.

- A systemic and strategic approach to developing existing medical expertise is vital – from core medical school training through to updated training for consultants and CCGs. This could include working with the General Medical Council and Royal Colleges. Medical schools need to invest in a multi-specialty approach to teaching about FASD, including obstetrics, medicine, paediatrics, psychiatry, public health and addiction medicine.
- In addition, nursing, midwifery, social work, and education students should be taught about FASD as a core part of training, not as an add on. Law enforcement and legal representatives should also have training in FASD.
- Identifying lead CCG commissioners for FASD could be explored, but at a minimum all disability commissioners should be educated about the specific needs for those with FASD.

3) **There is a continuing need for prevalence studies of the full FASD spectrum, but this does not justify inaction regarding improved delivery of diagnosis and support.**

The UK has the 4th highest rate of alcohol consumption during pregnancy in the world. In the USA, Canada and some European countries 'active' screening has been carried out in schools that demonstrates FASD is a leading cause of preventable neuro-disability. Recent North American studies show 1-5% prevalence. Researchers from the University of Bristol and Cardiff University

will publish a UK-based study in the next few

months based on collected, detailed information from a longitudinal study. The forthcoming results show FASD is likely to be a significant public health concern in the UK.

- Studies are needed to inform policy, but policy does not need to wait for urgently needed next steps. Funding proper research should be an element of policy.



4) **FASD should be linked with Government efforts to improve mental health – stakeholders should be engaged.** A teen with FASD spoke movingly about the negative experiences she had due to a lack of understanding of her condition in schools, which led to self-harm. A birth mother noted how the lack of training and judgmental nature of many professionals compounded problems faced by those at risk for drinking during pregnancy (including a high proportion of social drinkers and professional women). Too often this becomes a transgenerational problem when proper supports are not in place, with impact on the birth mother and the developing child.

- It is critical to find ways to move beyond stigma and to understand FASD is an issue that affects a large portion of society.
- It is critical to work with those with "lived" expertise to explore best practices and develop national strategies that encourage healthier pregnancies and improved outcomes for those with FASD.

5) **Policy leverage points exist and should be further explored.** The UK has made great strides since earlier efforts to raise issues related to FASD prevention and support. It is incumbent upon policy makers to take steps to begin to raise the volume in policy circles about this 'hidden epidemic' that experts believe affects more people than autism. Some policy options include:

- A possible limited parliamentary inquiry could explore the success of government policy regarding CMO guidance on alcohol in pregnancy and CCG commissioning of services regarding FASD.
- Alcohol harm and alcohol labelling and marketing debates should include greater attention to the risks of alcohol and pregnancy.
- Industry should be encouraged to further address risks related to alcohol in pregnancy and to use its reach and resources to promote increased public education and prevention.

- Mental health initiatives and evaluations of CAMHS should include increased awareness of and training in issues specific to FASD.
- The APPG on FASD should be reinvigorated – perhaps starting with a panel of adults with FASD.
- MPs should raise issues related to FASD every time there is a debate on children’s mental health and/or alcohol in parliament. It was noted that there is only one condition-specific bill – the Autism Act. Whether or not such an act for FASD might be useful, all agreed that something needs to be done to recognise FASD and to put in place the appropriate supports that are needed.
- Government brings in large amounts of alcohol taxes and duties. Lack of funding is not credible as an excuse for governmental inaction.

6) This is the beginning of a heightened dialogue, engagement with constituents is key. Leaders of the FASD UK Alliance, a coalition of organisations representing thousands of families across the UK, released at this meeting a new publication “Hear Our Voices: FASD Stakeholders Share Their Experiences with Policy Makers.” The report provides insights into the widescale concerns and needs of the FASD community.

- MPs and ministers are encouraged to engage with constituents – both the stakeholders and practitioners seeking increased resources for this important work – to start a heightened and better-informed dialogue on this issue that affects the most vulnerable in our society, including a disproportionate number of those in care and who have been adopted.



**Attachment A:
Our Forgotten Children
23 May 2018**

Participant List

Co-Chairs

Professor Sheila the Baroness Hollins, Former Chair, British Medical Association, Former Chair, BMA Board of Science, Emeritus Professor of Psychiatry of Disability, St George's University of London

Mr Bill Esterson, MP, Chair, All-Party Parliamentary Group on FASD, Shadow Minister (International Trade), Shadow Minister (Business, Energy and Industrial Strategy)

Participants

Dr Neil Aiton, Consultant Neonatologist at Brighton and Sussex University NHS Trust

Michael Attwell, Chair, Board of Trustees, National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK)

Dr Carolyn Blackburn - Senior Research Fellow in Early Childhood and Inclusion at Birmingham City University, author of multiple books, including "Developing Inclusive Practice for Young Children with Fetal* Alcohol Spectrum Disorders: A Framework of Knowledge and Understanding for the Early Childhood Workforce"

Joanna Buckard, Specialist Trainer, Red Balloon Training, lecturer, programme advisor to NOFAS-UK on FASD training for midwives and GPs

Martin Butcher, Co-Founder East Hertfordshire and Area FASD Support Network, Parent of child with FASD, Co-author FASDLearningWithHope.wordpress.com (listed one of the Best FASD Blogs by Healthline in 2017), Parent to 13-year old 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, Parent to 13-year old with FASD.

Alan Campbell, MP, Opposition Deputy Chief Whip (Commons)

Maria Catterick, Founder/Director FASD Network UK, Co-author, "Understanding Fetal Alcohol Spectrum Disorder," Awarded Big Society Award by Prime Minister David Cameron, Co-Founder FASD UK Alliance, Foster Carer

Edie Fairservice, Office of Catherine McKinnell, MP

Jessica Faulkner, Office of Sharon Hodgson, MP

David Gerry, Co-Founder and CEO of FASD Community Circle Victoria, Father of 27 and 25-year old brother and sister, Co-founder Living with FASD Webinar series. Co-Founder FASD Alliance Ireland

Kelvin Hopkins, MP, Vice Chair, Alcohol Harm All-Party Parliamentary Group

Samantha, Birth mother to a child recently diagnosed with FASD; Former Child Protective Services Worker

Rachel Jackson, Young adult with FASD helping to raise awareness

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)

Paul Jackson, Foster Carer, Father to Five Adopted Children with FASD; Engaged in many local groups supporting adults and young adults with disabilities

Dr Cheryl McQuire - PhD in the epidemiology of prenatal alcohol use and foetal alcohol spectrum disorders (PhD Cardiff University; currently Research Associate at the University of Bristol)

Elizabeth Mitchell, Helpline Advisor, National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK)

Jobb Morris

Dr Raja Mukherjee, National Clinic for Fetal Alcohol Spectrum Disorder; Adult Learning Disability Consultant Psychiatrist for Surrey and Borders Partnership NHS Foundation Trust

Dr Kieran D O'Malley, Child and Adolescent Psychiatrist, Slievemore Clinic, Dublin and President, Intellectual Disability Forum, Royal Society of Medicine

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

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

**Please note: 'Fetal' is the international and medical spelling, 'foetal' is the UK usage.*

**Attachment B:
Statement of the FASD UK Alliance
Presented by Maria Catterick, Co-Founder, FASD UK Alliance and Founder, FASD Network UK**

We, the representatives of member organisations of the FASD UK Alliance are delighted to have the opportunity for some of our colleagues to meet with you today on behalf of thousands of individuals, families and practitioners across the UK who are deeply concerned that the UK government has failed to understand the impact alcohol in pregnancy has had on the lives of its children, and how continuing to ignore the needs of our vulnerable loved ones with Foetal Alcohol Spectrum Disorders damages society as a whole.

As stakeholders we are here to start a dialogue – a direct and honest dialogue on issues related to the health and wellbeing of those with FASD and those who support them. And on these matters, it is imperative that you hear our voices.

We ask that Parliament hold Government to account for its responsibility for FASD prevention, education, awareness and support. We ask our elected representatives to join with us as we loudly and clearly say that FASD is the leading cause of brain-based disability that we can do something about. FASD is a leading cause of co-morbidities that no one would wish on any young person – care experience, addictions, suicides, incarceration, unplanned pregnancies, homelessness, mental health problems.

But this can change. We can save lives and money if we are wise about how we approach FASD. If we diagnose early, do proper assessments, put in place relevant support and provide access to appropriate services for our young people affected by FASD, we can change their lives. With education about the effects of alcohol exposure in pregnancy in PSHE classes, in pubs and clubs, in professional education and training, we can do much to prevent young people being affected by FASD in the future.



Experts are here today who will tell you that FASD is believed to affect more than autism. It is likely that more than 15,000 babies will be born this year with an FASD and the damage done to their developing brain and systems will last their lifetimes. Let's let that sink in.

We have friends and colleagues here today who have FASD. They will tell you about their frustrations going through life with a hidden disability, being misunderstood and made to feel inadequate. We have with us birth parents, adoptive parents and foster carers who all want you to hear the challenges families face in seeking to meet the needs of some of society's most challenging children. They are sitting here next to some of the country's leading medical experts and educators who share the frustrations of knowing that colleagues in the medical, educational and related fields do not have the training to adequately address the full FASD spectrum, and those that do are terribly under resourced, marginalized or flat-out ignored by too many in positions of authority.

Together we bring notice to you of the heartbreak of not knowing how to answer the cries of an infant that can't be consoled, the despair of watching bright-eyed children who are misunderstood and fail in classrooms through no fault of their own and where many become so anxious they cannot attend they then grow into disillusioned young adults who end up excluded, adrift, self-medicating and defeated by a world that has refused to see the hidden brain damage that explains the challenges they have faced. We bring to you tales of people seeking diagnosis being misinformed by GPs and other frontline practitioners (who should, but often do not know better) in health, in schools and social care. Stories of young people being denied access to diagnoses in areas where Clinical Commissioning Groups do not have any pathways at all in place for diagnosis and

support, stories of adults with FASD having their benefits stripped from them with little notice, despite the fact they have a lifelong, irreversible brain-based condition that places great demands on their cognitive and adaptive functioning. Children with Care experience who should have the condition recognised in statutory medicals but aren't identified, adding to the barriers and stigmas that create significant gaps between them and their peers.

We also come here with hope. We have amongst us stories of great success. Stories of resilience and strength. There are areas in the country that have taken on board this challenge. Lacking government guidance, they have forged new pathways, they have innovated and responded to the need – Scotland has some model programmes from which England has promised to learn. The North East has conducted regional research into FASD and has been working strategically with health, education, social care and communities to innovate in prevention, diagnosis, education and support pathways for FASD. Other areas in the UK like Medway are starting this process.

We urge Parliament investigate these deficits, to gather best practices from here and abroad, to change the policies so we can begin to meet the needs of those living with FASD. The FASD UK Alliance is here to offer our help, our insights and our commitment to creating a brighter future for our loved ones. Today's roundtable dialogue is meant to be a 'get to know you' session. We are assembled here to show you a glimpse of our diverse network. To introduce you to more of us through the booklet we have provided – "Hear Our Voices."

We hope today you will ask questions about our lives. We are here to share anecdotes and insights – to introduce ourselves and our concerns. We hope this is the first of many future dialogues on increasingly focused topics.

There has been some progress. In 2016 we welcomed the Chief Medical Officers' guidance that the "safest approach is not to drink alcohol

at all" if you are pregnant or trying to conceive. We are pleased that Government repeatedly acknowledges that "early intervention services can help reduce some of the effects of Fetal Alcohol Spectrum Disorders (FASD) and prevent some of the secondary disabilities that result. Responsibility for commissioning these services lies with clinical commissioning groups."² These are positive steps forward, but now we need to explore how we as a nation are doing in

implementing these goals. In 2007 and again in 2016 the British Medical Association issued a comprehensive report on Alcohol and Pregnancy. In 2007, guidance on the medicals for children in care where professionals were charged with making special considerations for conditions more prevalent in Looked After Children, especially Foetal Alcohol Syndrome and yet we hear of children whose needs haven't been identified for years. The gap in response creates a post-code lottery that leaves some with support and others with little hope. Where is the NICE pathway for diagnosis and care for those with FASD? Where is government action to enforce the duty of CCGs and NHS Trusts to provide these services? We are stakeholders and we are prepared to assist your efforts to put in place a more comprehensive response to Foetal Alcohol Spectrum Disorders.

Thank you for listening.

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



² - Lord O'Shaughnessy, 10 February 2017
<http://bit.ly/2kdNiAV> (This policy has been repeated on other occasions)

Attachment C: Talking Points

Dr Raja Mukherjee, Consultant Psychiatrist and lead expert National FASD Clinic, Surrey

I have been involved now with FASD for 15 years. When I began, there were no specialist diagnostic services for FASD in the UK where I could go to learn. There were a few interested clinicians who were seeing patients. These tended to be local services and not widely available outside of their own area. Also 15 years ago there was no consistent education or research being undertaken in the UK. Clinicians were unfamiliar and not confident in the approach or requirements for a diagnosis, other than full Foetal Alcohol Syndrome (FAS) which was the main taught condition back then. How to recognise the spectrum remained unclear to most.

Diagnostically, there was a postcode lottery of services which people could access to obtain a diagnosis and get help.

Our own service only began on the back of an opportunity when our child Learning Disability service was moved. The model was based on a neurodevelopmental research clinic I was already involved with. I had learnt the diagnostic approach through reading, using online training resources but also most importantly through direct contact with US experts, such as Ed Riley, who had been attending regular conferences in the UK. It is from them that I learnt most about FASD. Being able to listen, learn and talk through questions at an early stage of my development was invaluable. There was nobody in the UK I could turn to at that time to learn from, with recognised expertise and who could answer the questions I had. 15 years ago this was part of the problem.

Whilst this situation continues partly now, we do have improved recognition and capacity, although still extremely limited. You will hear later, this is not a rare disorder and as such most

individuals must be seen close to their own home with only those who need to be seen regionally and nationally making the journey to the specialist centres. For a resource limited organisation such as the NHS, it is essential to manage funds appropriately directing and triaging people to appropriate levels of service. Having said that it is also important to ensure that there is equitable access where needed.

Diagnosis is important on so many different fronts. Even though it is a neurodevelopmental disorder, FASD presents differently to other conditions and changes how individuals are managed. It is a diagnosis that must be made in order to best utilise limited resources. For

example simply sending everybody to play therapy, when this will not work is a waste of a precious resource. It means a limited service availability is not being used efficiently by one group and therefore not available when required for those who do. Diagnosis and management is essential as the first stage in getting the individual and family the appropriate help they need.

In order to facilitate this and reduce the postcode lottery that continues, it is essential to have a systematic approach to the development of existing clinician's expertise, through support, as well as strategic development of training, including research, for those more junior clinicians who will be the future of the specialty. Whilst in the last 15 years there has been a growing amount of research and interested clinicians, it remains a few people's special interest rather than core work. This must change.

There remains a lack of confidence in how to diagnose FASD in many clinicians. This is not to say that people do not recognise the potential impact of the disorder and its importance, only



that they need support, especially where cases are less clear-cut to understand and make a diagnosis. Training is a core part of this. Currently in our National Centre we regularly have visitor and observers, but there is no consistent approach yet in place for training. Physicians need to be trained by other specialists from medical school level up to consultant. Conferences, such as that was held yesterday at the Royal Society of Medicine are an important step in facilitating this. The different medical bodies from the General Medical Council who defines curriculum for medical students through to the different Royal Colleges must include these as core components in their curriculum. Currently they are not.

The BMA board of science report in 2016 adopted the hub and spoke model of service delivery as an example of how diagnostic processes could be cost effectively implemented in the current NHS structure. Many CCG have failed to adopt this. This means people cannot get access to a diagnosis. The postcode lottery then remains.

Most cases will need to be seen locally by clinicians who have generic expertise rather than specialist. Generalists however need support from specialists when things become more complex. Relationships described in that document already to some extent exist. It needs

a systematic approach, as happened in Scotland recently, to facilitate the change in England. In Scotland it was recognised that there was a need. The Scottish government implemented a pilot program to develop a diagnostic team, very similar to the specialist team that I run, which is now proven its worth including cost effectiveness and is offering this liaison service across Scotland. England needs to do the same. The building blocks exist but a coordinated consistent approach is needed if this is to be done effectively.

I began by saying I've been doing this 15 years, and it has been challenging to condense 15 years of experience in thinking into five minutes. It is likely I will stop and hopefully retire in a further 15 years. I hope within that timeframe we have moved beyond discussions about structures and diagnoses to a position where we can begin to talk about how service have become established and how we continue to improve the quality of life of those affected. I would hope that the postcode lottery that still exists today is removed and individual access to diagnostic services is a core component of all children's services. One final point is that these children become adults and it does not go away. We need to ensure there is a lifespan approach and understanding. The NHS is well set up to deliver this if there is coordination and will.

**Attachment D:
Talking Points**

Dr Carolyn Blackburn, Senior Research Fellow, Birmingham City University

I've been involved in three research projects related to professional knowledge about FASD as well as supported a number of children/parents/teachers with educational strategies and local authority support. This includes the complex learning difficulties and disabilities (CLDD) project which included FASD thereby demonstrating the significance of FASD in the CLDD profile.

Findings from my research have shown that the majority of early years, primary and secondary school teachers are either not aware of FASD or have very little knowledge about the long-term psycho-socio-medical-educational impact, let alone how to support children in the classroom or work with families. This contrasts sharply with other countries such as the USA and Canada where billions of dollars are invested in early intervention and education programmes.

I have observed children in mainstream schools who have been disengaged from learning for up to 50% of their time in the classroom. This clearly impacts on their ability to learn and receive an effective educational experience.

As a teacher educator I've talked to hundreds of trainee and practicing teachers about the impact of FASD in the classroom. For trainee teachers trying to learn about special educational needs generally and FASD specifically at the same time is a significant challenge. For experienced teachers and teaching assistants, understanding the diverse and complex needs of children with FASD without sufficient training, Continuing Professional Development (CPD) and specialist resources limits their ability to provide quality first teaching based on neuroscientific understanding of FASD. We simply cannot allow this to continue and must acknowledge the impact of prenatal exposure to alcohol for children's learning and teacher education as a matter of urgent societal concern given the amount of time children spend at school. Without knowledge and training teachers can be disempowered and frustrated when tried and

tested pedagogical strategies do not achieve the same results with children with FASD as they might with other conditions. This has the potential to negatively impact on teacher-child/teacher-parent relationship. No-one wins in this situation, least of all children.

All of my own professional knowledge about FASD has been gained from listening to psychiatrists, psychologists and most importantly parents and children themselves. Whilst this has been beneficial, it would have been useful to have teacher/educator resources that had been developed in a UK context to draw on. Research and development funding for a comprehensive evidence-based teacher / educator programme and resources pack is called for urgently.

FASD should be a compulsory part of both Initial Teacher Training and CPD for all educators working across all phases of the education sector in my view. Reducing the number of children born with FASD should be a priority alongside finding the optimum educational strategies for children already in the school system.



**Attachment E:
Talking Points**

**Dr Cheryl McQuire, Researcher at the University of Bristol (alcohol-related harms)
Completed PhD on the epidemiology of prenatal alcohol use and FASD at Cardiff University**

I'm pleased to see that discussion on such an important topic is taking place at this level and I welcome the opportunity to contribute to it.

My particular interest is in the importance of research for raising awareness and improving outcomes among those affected by FASD.

We know that the UK has the fourth highest level of prenatal alcohol use in the world and so there's reason to believe that FASD is an issue here. But so far there have been no UK population-based studies to determine how many people are affected.

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. Existing UK studies have generally been limited to Foetal Alcohol Syndrome, which we know is only the tip of the iceberg when it comes to the full spectrum of FASD.

These studies have also relied on surveillance methods, such as birth defects registries and routine hospital data. We know that these methods are likely to significantly underestimate the true scale of the problem, because FASD is not normally detected at birth and it is not often the primary reason for hospitalisation. The fact that FASD is significantly underdiagnosed further complicates efforts to get a handle on the number of people affected.

Despite these research challenges, FASD prevalence studies have been conducted and offer a valuable insight. 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. Studies of this type have

been done in the USA and some European countries, including Croatia, Poland and Italy.

They show that FASD is one of the leading causes of developmental disability in the world. Conservative estimates suggest that around 2-5% of children in the general population have FASD. There was a study from the USA, however, published this year, which suggested that up to 10% of school children could have FASD and we know that FASD prevalence is even higher among Looked After Children.

Results from these studies have been used to make the case for improved FASD provision and 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.

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.

Some have argued that it has wrongly been assumed that FASD is a rare disorder and that the lack of UK-based research means that those affected are not getting the support that they need.

In this context, as part of a team of researchers at Cardiff University, and colleagues with expertise in FASD and child development, I carried out a study to address this important knowledge gap and the results will be published in the coming months.

To overcome the limitations of surveillance methods and in the absence of a UK in-school screening study, our study used existing information from the Avon Longitudinal Study of Parents and Children (known as the ALSPAC cohort). ALSPAC recruited over 14,000 women from the Bristol area during pregnancy and



collected detailed information on prenatal alcohol use. The children from this study are now around 25 years old and their development has been closely monitored. We were able to use this rich source of information to estimate the prevalence of FASD. To do this, we consulted with FASD experts including Dr Raja Mukherjee, Dr Andrea Higgins an educational psychologist and Professor Alison Kemp, a community paediatrician to develop a screening measure that estimated how many children in the general population could be affected by FASD in this country.

The results from our study will highlight that FASD is likely to be a significant public health concern in the UK. Given current patterns of alcohol consumption and recent changes in prenatal guidance, active case ascertainment studies of FASD in the UK are urgently needed. This type of evidence is essential for making the case for clear guidance around the risks of drinking in pregnancy and for highlighting the need for improved resources for FASD prevention, diagnosis, and intervention.

**Attachment F:
Transcription of Comments
Rachel Jackson, Teen with FASD**

School was challenging because I was the only one in my school group [with FASD]. And with the school, they always put me at a grade that I couldn't cope with. They always thought I had anger issues, even when I would have a meltdown because it was sensory overload. I felt like I was being bullied by everyone.

The majority of these people here are saying, you need to learn it at certain times [in training].

If you drink during pregnancy you will give your child brain damage.

The trouble I always had - I used to have meltdowns every time I came home if something bad had happened that day, but it wasn't my fault, I would blame myself. Did I cause a disturbance?

I don't blame the teachers because they had a lack of knowing about it, but I know if they had learned about it and were taught when they went into learn about being a teacher.

What you need to do is you need to teach about FASD, especially from a very young age. You need to drum it into kids.

But if the teachers did know [about FASD], I think I would not have had mental issues.

That is definitely one of the big problems. You have mental health issues. You self-harm like I did from a very young age. I started to reach a suicidal stage. It's hard to say that but in reality, the majority of young people do think of that

because they think it's their fault that they've got this problem. But it's not their fault, it's the parents' fault for not realizing that if you do drink during pregnancy - even with dads as well for talking their wives or girlfriends into that. If you don't get the support needed. I could still be with my birth family. I was glad I was brought out. I have a lovely mum and a lovely dad. If I wouldn't have, I would probably be doing really bad probably smoking or alcohol or really bad things.

I have had some help but there needs to be more, like for autism. There's autistic schools but I think there needs to be FASD schools as well. I am in an autistic school at the moment. And it's good.

They help me as much as they can, but I don't feel like they help me as much as I need.

I blamed myself for being born with FASD and self-harmed to relieve the stress of that. I didn't like it but it was an easy way to deal with problems. All doors seemed to be slammed in my face. Anxiety and stress about the coming day could be driven away with self-harm and that let me sleep.



**Attachment G:
Pip Williams, Founder of UK and European Birth Mother Network
Co-founder, FASD UK Alliance**

Good Morning. My name is Pip Williams and I'm the founder of UK & European Birth Mother Network.

Here are some key points that birth mothers have discussed and wish to convey to practitioners and decision makers.

If practitioners and service providers are to be effective in engaging with birth mothers, then they need to learn from the best advocates in the field – the birth mothers themselves.

I will break this information into three phases – Prenatal, Postnatal, and Diagnosis in later childhood.

PRENATAL

Firstly - No woman drinks because she wants to harm her baby. There are 7 key reasons why women continue to drink in pregnancy;

1. Unaware they are pregnant;
2. Unaware of the harms alcohol can cause during pregnancy;
3. Using alcohol to cope with difficult situations;
4. Knowing someone who drank and their child is ok;
5. Social or work pressure while out or haven't disclosed pregnancy;
6. Struggle with alcohol addiction;
7. Partner pressure - "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.



Many professionals haven't had enough training in discussing alcohol in pregnancy. Many say they lack confidence and don't know where to refer the women 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?"

Women need to be given correct information so they can make an informed choice and 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.

Mothers need linking in to other women with lived experience and local services e.g. mental health, alcohol & drug, domestic abuse services.

Midwives and social workers need to be more aware and have a better understanding of the intersections of trauma, substance use, and mental health issues that can arise especially in pregnancy and be familiar with referral pathways.

Recent studies show 33% of women experience domestic abuse for the first time whilst pregnant.

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.

POSTNATAL

Another 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".

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

Practitioners needs to understand how important the Mother-Child relationship is and the need to keep families together where possible.

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

DIAGNOSIS IN LATER CHILDHOOD

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 “

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.

There needs to be a seamless 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.

TO CONCLUDE

All professionals can have a critical role in the prevention, identification of FASD and supporting families and individuals.

There needs to be a compassionate non-judgmental empathic pathway that creates trust, where social care and health care professionals work together with the women to help them have healthier pregnancies and give their child the best start in life.

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

Nothing about us without us.

Helping to prevent FASD is all our responsibility!

Thank you.

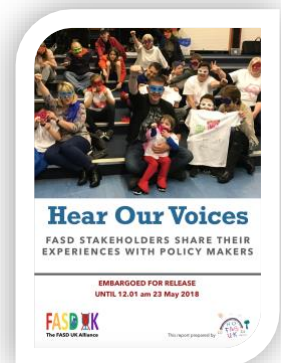


Attachment H: Background Materials

“This meeting was an opportunity for MPs and peers to hear of the significant and under-addressed daily challenges those with FASD and their families face”, said Sandra Butcher, Chief Executive of the National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK), the lead organisation on this initiative. “As stakeholders we are asking Government to hear our voices, to review their policies and to understand that their delay in appropriately tackling issues related to FASD is seriously affecting the quality of life for thousands of our most vulnerable citizens and those who seek to support them.”

The meeting was an informal roundtable discussion where the FASD UK Alliance launched a new publication, prepared by NOFAS-UK, “[Hear Our Voices](#)”. This highlights the wide range of experiences of adults and children with FASD, as well as parents and carers – including their struggles with diagnosis, access to post-diagnostic care, achieving to the best of their ability in education, the impact of the lack of understanding by the public, the risks of alcohol and drug addiction, as well as problems with the police and the justice system.

Foetal Alcohol Spectrum Disorders are a range of disorders associated with alcohol consumption in pregnancy. A large number of children are born every year in the UK with an FASD, bringing lifelong physical, behavioural or cognitive disabilities. Thought to affect more people than autism, yet little known by the public at large, FASDs have a substantial impact on the lives of individuals affected and those around them. The condition is poorly recognised and understood even by most medical professionals. Individuals are often undiagnosed. Even with diagnosis, without proper support they struggle to achieve at school, to successfully hold a job and can easily become addicted to alcohol or drugs, or fall foul of the criminal justice system, placing a great strain on society’s resources.



For more information contact Sandra Butcher, Chief Executive of NOFAS-UK, on 07920 747560 or at Sandra.Butcher@nofas-uk.org.

Additional Quotes and Insights³

Dr Raja Mukherjee, Consultant Psychiatrist and lead expert National FASD Clinic, Surrey:

“The lack of coordinated diagnostic approaches in the UK in identifying and supporting people with FASD continues to perpetuate the inefficient use of resource as well as failing to improve the quality of life for those affected by this disorder.”

Dr Carolyn Blackburn (Birmingham City University), teacher educator and researcher, advocate for children and families:

“As a teacher educator I've talked to hundreds of trainee and practising teachers about the impact of FASD in the classroom. For trainee teachers trying to learn about SEN generally and

FASD specifically at the same time is a significant challenge. For experienced teachers and teaching assistants, understanding the diverse and complex needs of children with FASD without sufficient training, Continuing Professional Development (CPD) and specialist resources limits their ability to provide quality first teaching based on neuroscientific understanding of FASD. FASD should be a compulsory part of both Initial Teacher Training and CPD for all educators working across all phases of the education sector in my view.”

Joanna Buckard, Specialist FASD Trainer and Health & Social Care Lecturer Red Balloon Training:

³ Please note these are not excerpts from the 23 May meeting but were mostly provided ahead of time in a pre-meeting media release. There was not attempt at the meeting to provide a transcript of the discussion.

"I have been delivering FASD training throughout the UK and the Channel Islands for over a decade. I have delivered training to social workers, foster carers, parents, midwives, psychologists, paediatricians, GPs, teachers, behaviour support teams, alcohol support teams and many more. What I have found has been a combination of widespread lack of knowledge around FASD and also carers, parents and guardians who have had poor experiences from health, social care and education in their quest for diagnosis and support. There continues, to date, to be shock during the training sessions and exclamations of, 'Why don't people know about this'!! It is also evident that regardless of background, education level, job or location the misunderstanding around units and safe levels of alcohol during pregnancy (none) is ubiquitous. One of my biggest concerns is for children who are looked after, who have moved from home to home and remain without diagnosis and appropriate support as they move to independence. The risks to these young people are especially profound. There is a great need for significant education about FASD prevention, recognition and diagnosis and continuing support from health, social care and education for those individuals with FASD and their families."

Martin Butcher, Adoptive Father of a 13-Year Old with FASD, Co-Founder of E. Herts and Area FASD Support Network and Blogger at FASDLearningWithHope.wordpress.com:

"Although FASD is thought to affect more people than autism, services and post-diagnostic support are non-existent. Our support network was founded at the urging of our paediatrician, because she had literally nothing to offer families given the news their child has life-long organic brain damage! In East Herts we are forced to fight even to get a diagnosis, and then to scabble for help from services meant primarily for others. This despite the fact that over 100 children are likely born with the condition each year in East and North Herts, and early diagnosis and intervention are essential in improving life outcomes. The East Herts and Area FASD Support Network has members from across Hertfordshire and much of Essex. We call on our MPs to help ensure that the NHS, education and social care systems provide the support our families need."

Maria Catterick, Foster Carer and Founder/Director FASD Network UK, supporting 800 families in the North East:

"FASD Network UK raises awareness of FASD from its base in the North East and Yorkshire. The North East region has worked together with Public Health England on an FASD Healthcare Needs Assessment and there is evidence of diagnosis using NHS systems, FASD training for practitioners, training and support for schools and local support groups for families. Some areas have FASD on the PSHE curriculum, prevention pathways for health visitors and midwives, poster and leaflet campaigns and health scrutiny committee investigations on the progress of the work. Whilst multi-agency professionals have had freedom to innovate without imposed constraints, there is a struggle to commission funded services due to the lack of NICE guidance which often dictates commissioners' actions. More needs to be done to consistently deliver quality services which meet the health, education and social care needs of children and families affected by FASD."

Samantha, a birth mother who had to fight for years for diagnosis for her son, despite telling doctors she drank in pregnancy (not understanding the impact it could have):

"As a birth mother, the efforts it takes to find out about FASD, piece together whether it's a possibility, navigate the referral system and at the same time face the stigma attached to drinking alcohol in pregnancy, is overwhelming. It is long, drawn out, emotional, frustrating and at times, unbearable. There is no consistency among health professionals, no support for the family or the child themselves, and plenty of brick walls to keep banging your head against. No wonder women find it hard to a) find out about FASD and b) pursue it as a diagnosis. In the medical world there is absolutely no provision for a child with FASD and the associated anxiety. Long stays in hospital are pitted with psychological trauma as our children are misunderstood, threatened with security if they become scared and physical. They are offered no medical intervention such as anti-anxiety medication or sedation. They are treated like naughty children who just need to do as they're told. This is completely unacceptable. In every hospital, in every children's ward, there needs to be

understanding and training on FASD. It should not be that hard for a child to access urgent medical treatment."

David Gerry, FASD Ireland Alliance (an all-Ireland sister alliance to the FASD UK Alliance)

"The average life expectancy of those with FASD is just 34 years. Locally, nationally and globally we are facing a silent tsunami for which proven interventions and effective supports exist; what is needed now is the societal and political will to implement the necessary changes across the life span for those with FASD."

Lee Harvey-Heath, an adult with FASD and founder of FASD Devon and Cornwall:

"Children with FASD go through enough of a battle on a daily basis, why then should they be ignored by society? Without the support they desperately need the future of these amazing individuals is bleak. They need a diagnosis - not to be labelled, but to be acknowledged and supported as they grow."

Dr Cassie Jackson, Clinical Psychologist:

"One roadblock to children and young people getting an appropriate diagnosis is that FASD is a great mimicker of so many other neurodevelopmental conditions, and children frequently pick up several of these before reaching the right diagnosis, if they even get to this point. This is partly because clinicians are afraid of asking the difficult questions around alcohol use in pregnancy. We are scared of offending and of alienating families. Therefore, calling it atypical autism or ADHD or other feels more comfortable as it doesn't have the same emotional loading. However, until we feel comfortable talking about this subject with families we continue to perpetuate its taboo status, which does nothing to break down institutionalised ignorance about FASD and its effects on children. We need to hold the child at the centre of everything we do as clinicians. FASD needs talking about. It needs recognition across all systems and agencies.

"It is completely nonsensical to say that a 'small' amount of alcohol is 'probably ok' in pregnancy. A zero alcohol: zero risk message is

the only logical approach to this issue, which cuts out all confusion and therefore potential exposure through miseducation."

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):

"Until FASD is recognised and the diagnosis given the respect it deserves, we will have to keep on fighting for the RIGHT support and services that our children need, which is a national shame as given the right support our children and young adults can achieve great things!!!!"

Dr Kieran O'Malley, Child and Adolescent Psychiatrist, President, Intellectual Disability Forum, Royal Society of

Medicine:

"The scourge of FASD/NDPAE (Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure) is plagued by many critical systemic issues. The alcohol industry needs to acknowledge that alcohol can cause an acquired brain injury (FASD/NDPAE) in the developing foetus. The alcohol industry needs to acknowledge the transgenerational impact of alcohol which includes the diagnosis of FASD/NDPAE in a child becoming a potential marker for premature death in the birth mother due to alcohol-related medical causes. The medical and social impact of lifelong transgenerational alcohol needs to be a core subject in medical school, nursing school and social work school and placed on par with cancer or heart disease, otherwise the professional denial and minimisation will continue."

Dr Cheryl McQuire, Research Associate in Alcohol and Epidemiology, University of Bristol; PhD from Cardiff University:

"The UK has one of the highest levels of prenatal alcohol use in the world, but little is known about FASD in this country. More research is needed to understand the true impact of FASD



and plan action for prevention and service provision."

Elizabeth Mitchell - Helpline Advisor, NOFAS-UK

"The calls to our Helpline have become much harder to solve. The problems we are receiving today are much more complex compared to how they used to be as the affected children become adults. In Canada where they have carried out research into FASD, they believe that between 23-50% of the prison population have the disorder. It is likely that the UK may well have a similar percentage or even possibly higher, given our binge drinking culture."

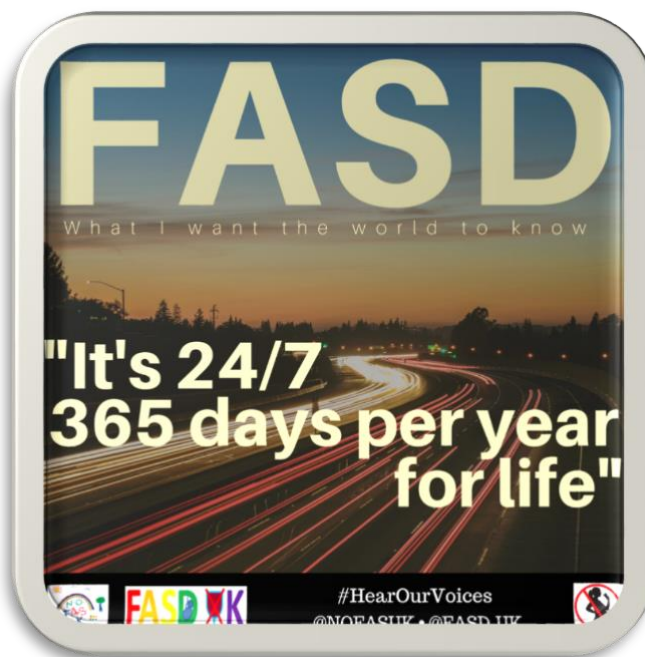
Brian Roberts, Special Guardian, Foster Carer, Former teacher and Virtual School Head, Peterborough and Area FASD Support Network:

"All children have a huge potential and those affected by FASD are no exception. As a special Guardian and Foster Carer I live with 3 affected children and at least another 5 have passed through our home and every day presents us all with challenges. None more that with education. I have also been a Virtual Head for Children in Care where our numbers of affected children were approaching at least a 1/3 of all the children in care. Education is such a vital foundation for life long wellbeing and security that failing to support children who perceive the world differently creates issues and challenges for our whole community that last lifetimes not to mention the amount that it costs us all. Currently the problem with trying to provide an appropriate learning environment for effected pupils is hampered by a) the lack of knowledge about FASD, b) the lack of understanding of effective teaching strategies for affected students and c) often the complete lack of joined up thinking within the teams around our children. Only yesterday at a training I was providing in Norfolk a parent told me that they had been told that there was no point in getting a diagnosis because nothing could be done. A false premise in so many ways, but something that I hear too regularly. We can't make the blind see, but we don't do nothing. Alongside an effective prevention programme, we need to have an effected education programme for everyone in society that offers effective and

accurate information, advice and guidance about FASD. If we were able to stop FASD today there would still be a legacy of effected adults stretching forward for 80 plus years. Therefore, everyone who educates children, supports them in anyway and the teams that take over when the child becomes and adult need to be properly educated to provide effective and timely interventions that allow affected individuals to achieve the best they can. Affected children can do as well as any other child if they receive the correct support. As a parent of affected children, if the supports existed with in our education system then I for one would have more time to parent children that are very different from the typical child. This would be a huge benefit all round. I really believe that not only are our children different, they are some of the most vulnerable children and young people in society. If we don't get education right, we lay a foundation that will create vulnerable and dependent adults and it doesn't have to be this way."

Pip Williams, FASD Trainer & Consultant. Founder UK & European Birth Mother Network - FASD. Co-Founder FASD UK Alliance; Founder of FASD UK FB group supporting over 1800 families

"No women 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 continuing to drink in pregnancy, they need to be able to safely disclose their alcohol use without feeling judged, shamed, treated unfairly due to substance misuse or fear of losing custody of their children. The women we support in the network all had different levels of drinking though the majority were social drinkers or were going through a difficult situation in pregnancy. All were unplanned pregnancies. All professionals can have a critical role in the prevention, identification of FASD and supporting families and individuals. There needs to be a compassionate non-judgemental empathic pathway that creates trust, where social care and health care professionals work together with the women to help them have healthier pregnancies and give their child the best start in life. Helping to prevent FASD is the responsibility of us all!"



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

CONTACTS

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FASD UK London

Pip Williams, fasd-uk@live.com

FASD Network UK

Support groups throughout the North East
www.fasdnetwork.org • Maria Catterick, fasnnetwork@mail.com

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

FASD Northwest

www.facebook.com/NorthWestFASD/

FASD Scotland

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