FASD UK
Together We Are Stronger

Statement of the FASD UK Alliance

"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[1]

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.

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[1] Full report available here: http://www.nofas-uk.org/WP/wp-content/uploads/2018/06/20180523_Report_FIN.pdf

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

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