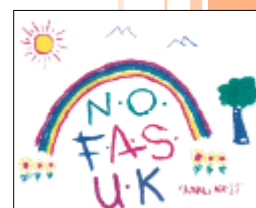


## **FASD Policy Focus Paper - No. 1**

### **Overview of FASD Policy Debate in the Context of the Westminster Hall Debate on Alcohol Harm, 2 February 2017**

Summary: Foetal Alcohol Spectrum Disorders (FASD) encompass a range of physical, mental, behavioural and/or learning disabilities that are life-long and often lead to further secondary disabilities. The Westminster Hall debate on Alcohol Harm was a welcome step forward with regards to raising attention to FASD and highlighted the need for policies and practices to address this often-overlooked disability. As Kelvin Hopkins, MP said in the debate, “Tackling FASD must be the priority for the Government’s alcohol policy.” And, as Marie Rimmer, MP said, “The Government must do more than they are doing now.” This document highlights 10 Action Points arising from the debate and extensively quotes those parts of the debate that relate to FASD as part of NOFAS-UK’s efforts to make policy discussions more accessible to a wider audience.

Sandra Ionno Butcher, Chief Executive  
National Organisation for Foetal Alcohol Syndrome-UK  
02/06/2017



# FASD Policy Focus Paper - No. 1

## *Overview of FASD Policy Debate in the Context of the Westminster Hall Debate on Alcohol Harm, 2 February 2017*

Summary: Foetal Alcohol Spectrum Disorders (FASD) encompass a range of physical, mental, behavioural and/or learning disabilities that are life-long and often lead to further secondary disabilities. The Westminster Hall debate on Alcohol Harm was a welcome step forward with regards to raising attention to FASD and highlighted the need for policies and practices to address this often-overlooked disability. However, the lack of detailed proposals and repetition of time-worn refrains about the lack of prevalence studies on which to base policy highlighted the need for further more targeted and in-depth exploration of pressure points for progress on FASD-related issues, the urgency of accessing funding streams to help address this issue, and the need for increased dialogue with stakeholders on key issues.

As Kelvin Hopkins, MP said in the debate, “Tackling FASD must be the priority for the Government’s alcohol policy.” And, as Marie Rimmer, MP said, “The Government must do more than they are doing now.”

## **Action Points Arising from the Westminster Hall Debate**

1. Parliamentary offices and the House of Commons Library need access to update-to-date information about FASD
2. Government should review its alcohol policy and include FASD as an integral component
3. A Policy Paper or Green Paper specific to FASD is needed
4. Key stakeholders must be included in formulation of policy
5. Efforts to raise public awareness should be expanded
6. Prevalence studies are urgently needed but the lack of such studies no longer qualifies as an excuse for failure to meet the needs of those affected by FASD and their families
7. Better training for health care professionals is essential, and those with experience should be consulted regarding diagnostic and post-diagnostic protocols and pathways
8. Similarly, educational professionals urgently need better training and information about FASD, and those with expertise in this area should be consulted regarding best practices
9. Particular attention should be paid to FASD issues faced by adopters, foster carers and kinship carers. Better training, transparency and increased support is urgently needed throughout the system
10. Long-term political will, non-partisan partnership and bravery are needed. The voices of those most affected must be heard

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<sup>1</sup> This FASD Policy Focus Paper was prepared by Sandra Ionno Butcher, Chief Executive, National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK), [sandra.butcher@nofas-uk.org](mailto:sandra.butcher@nofas-uk.org). The source document for most of the quotes in this brief is Hansard, House of Commons, 2 February 2017, Volume 620, available online at <https://hansard.parliament.uk/Commons/2017-02-02/debates/5583eba9-c39d-4e1c-a42c-fd5b2168a920/WestminsterHall>.

## Introduction

On 2 February 2017, the Alcohol Harm All Party Parliamentary Group sponsored a [Westminster Hall Debate<sup>2</sup>](#) in the UK Parliament. Issues related to Foetal Alcohol Spectrum Disorders were addressed throughout. This issue brief provides an overview of the discussion specifically with regards to FASD. The emphasis of this document is to provide access to quotes from the debate as they relate to FASD. **Kelvin Hopkins, MP** said “By far the most tragic of all the problems caused by alcohol, in my view—this view is probably shared more widely—are foetal alcohol spectrum disorders.” [Column 415WH]

## Insufficient Background Documentation on FASD

An information pack, “[Tackling Alcohol Harm<sup>3</sup>](#)” was prepared for the debate by the House of Commons Library and posted on 1 February 2017. This background information lacked detailed information about FASD. While it did include a useful summary of recent parliamentary material addressing FASD, it also included without context a news article entitled, “[Health chiefs attacked over 'nanny state' alcohol guide<sup>4</sup>](#).” It failed to provide detailed information about the new [2016 CMO guidelines<sup>5</sup>](#) on drinking during pregnancy (though it did mention other aspects of these guidelines). This new guidance clearly states “If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.” The background material also failed to highlight a [new study<sup>6</sup>](#) published in *The Lancet* which indicated that the UK foetal alcohol rates among the worst in the world, with more than 40% of women drinking alcohol in pregnancy. This study has profound implications. The UK must update its policies and practices regarding FASD, as addressed in a 19 January 2017 [joint press release<sup>7</sup>](#) by the National Organisation for Foetal Alcohol Syndrome-UK and the FASD UK Alliance.

The inadequacy of the background material was highlighted by **Bill Esterson, MP**, who chairs the All-Party Parliamentary Group on FASD, “I was really disappointed that the briefing note for this debate did not make reference to foetal alcohol spectrum disorder. It made some really good points about other issues that we have discussed today, but it did not mention FASD. Given that FASD was one of the topics clearly indicated in the bid for the debate, that was really unfortunate—I shall not say anything stronger.” [Column 419WH]

**Action Point 1:** All relevant Parliamentary offices and the House of Commons Library need up-to-date and more complete information regarding issues related to FASD. This can be ensured via wider consultation with a diverse number of

2 <http://www.parliament.uk/about/how/business/debates/westminster-hall-debates/>

3 <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CDP-2017-0041#fullreport>

4 <http://www.telegraph.co.uk/news/health/12088101/Health-chiefs-attacked-over-nanny-state-alcohol-guide.html>

5 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/545937/UK\\_CMOs\\_report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/545937/UK_CMOs_report.pdf)

6 [http://www.thelancet.com/journals/langlo/article/PIIS2214-109X\(17\)30021-9/fulltext](http://www.thelancet.com/journals/langlo/article/PIIS2214-109X(17)30021-9/fulltext)

7 <https://www.facebook.com/notes/nofas-uk/uk-foetal-alcohol-rates-among-highest-in-world-advocates-across-uk-call-for-prev/1407003649332851>

professionals and groups working on these issues so that current information can be conveyed, analysed for related policy implications and debated.

## Need to Review Government's Alcohol Strategy and Specifically its Approach to FASD

Many MPs spoke out about the need for a review of the [Government's alcohol strategy, last updated in 2012s](#). **Fiona Bruce, MP** set the context for debate. "It is a measure of the concern across the House that there are not one but three all-party parliamentary groups concerned with alcohol harm. It was the three chairs of those APPGs who applied for the debate: myself, as chair of the APPG on alcohol harm; the right hon. Member for Birmingham, Hodge Hill (Liam Byrne), who chairs the APPG on children of alcoholics; and the hon. Member for Sefton Central (Bill Esterson), who chairs the APPG on foetal alcohol spectrum disorder. I will leave it to those Members to speak of the harm caused to children and unborn children through alcohol consumption, but as vice-chair of those two APPGs, may I commend and say how much I fully support their work?... As we will hear, one thing is clear: the Government's alcohol strategy, which is now five years old, must be reviewed." **Kelvin Hopkins, MP** said, "Tackling FASD must be the priority for the Government's alcohol policy." [Column 416WH]

**Bill Esterson, MP** said: "[T]he 2012 alcohol strategy...makes the risks very clear and which refers to lifelong conditions that can have a severe impact on individuals and their families. Those conditions are caused entirely by drinking during pregnancy, so they are completely preventable. It is all already there in the strategy, which leads to the question of why the Government have not done more to promote awareness and reduce the incidence of this terrible problem" [Column 420WH] **Marie Rimmer, MP** pointed out that while great steps can be taken locally, "without a national response from the Government, FASD as an issue will continue to be overlooked by the population .... The Government must do more than they are doing now." [Column 432-433WH] **Jonathan Ashworth, MP** joined "the call that others have made for the Government to come forward with a renewed alcohol strategy." [Column 437WH]

**Action Point 2:** NOFAS-UK supports calls for a review of the Government's alcohol strategy, encourages issues related to FASD to be an integral part of this review, and stands ready to assist.

**Action Point 3:** While covering FASD should be an integral part of any alcohol strategy, a Policy Paper or a Green Paper on FASD would further highlight the specific courses of action that might facilitate a deeper understanding for Government of how to address this widespread, under-addressed, and complex problem that affects UK society on multiple levels and at great cost.

## Extending Best Practices for Interventions for At-Risk Populations

MPs discussed the need to address at-risk populations. **Fiona Bruce, MP** laid out the overall context: "There are 1.5 million dependent drinkers, only 6% of whom access

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8 <https://www.gov.uk/government/publications/alcohol-strategy>

treatment.” [Column 412WH] **Fiona Bruce, MP** continued, “It is interesting to note that the Public Health England report confirms that health interventions aimed at drinkers already at risk and specialist treatment for people with harmful drinking patterns are effective approaches to reducing consumption and harm and ‘show favourable returns on investment.’ However, it points out that their success depends on large-scale implementation and funding. Will the Minister look at how her Department can give a national lead to share and implement best practice in this field, such as that which I have described?” **Patricia Gibson, MP** highlighted the comprehensive approach taken in Scotland, “A whole-population approach is required to reduce the harm caused by alcohol.” [Column 422WH] **Bill Esterson, MP** emphasized the need: “to understand why women are drinking during pregnancy to the extent that they are.” [Column 421WH]

As this was a debate about Alcohol Harm generally, there was a focus paid to children of alcoholics. **Liam Byrne, MP** said: “We need a national strategy for children of alcoholics. We talk about children’s mental health and we talk about alcoholism, but, again, children of alcoholics are in the middle. They need a national strategy of support... We have to properly fund support for children of alcoholics... We need to increase the availability of support for families... we need to develop a plan to change public attitudes.” [Column 428WH] **Jonathan Ashworth, MP, Shadow Health Secretary** said, “I attended this debate because I wanted to speak out, as my right hon. Friend has, and ask the Government to consider putting in place a strategy for children of alcoholics as well as an alcohol strategy... including in that strategy a statutory duty on local authorities to put in place local strategies, both to deal with alcoholism and to support children of alcoholics.” [Column 438-439WH]

**Parliamentary Under-Secretary of State Nicola Blackwood** reinforced the Government’s view that, “All health professionals have a public health role, and we need to ensure that our frontline workforce are properly trained to tackle such challenges, especially alcohol misuse and drinking in pregnancy.” [Column 442WH] She emphasized that Government is “trying to disseminate... information through health professionals in a more targeted way. Health professionals are supposed to discuss it with pregnant women as part of their routine work, but women who are heavy drinkers are much less likely to engage with antenatal care, so identifying them can be challenging. Over the past year, PHE has therefore been undertaking a piece of work to identify those at risk and provide advice. It has piloted in three regions of England a training programme developed in Wales called ‘Have a Word’, which sounds much like what the hon. Member for Sefton Central proposed. PHE is considering the findings from the pilots with a view to rolling the programme out across England if it is effective. We are particularly looking at the findings on how pregnant women can be targeted. I am happy to share those findings with the hon. Gentleman, as I suspect they will address his concerns on raising awareness and targeting pregnant women.” [Column 443WH] She further stated “we are trying to take steps, through the troubled families programme, to improve the situation for children of alcoholics. The troubled families programme has a responsibility to tackle problem drinking and to commission appropriate prevention and treatment services — including to support the children of those families.” [Column 445WH] **Blackwood** stated, “The key message today is that children of alcoholics in the United Kingdom should not feel as though they are alone—they should feel as though support is there, and they should know that they will find help when they seek it.” [Column 445WH]

**Action Point 4 – Focus on at-risk populations:** NOFAS-UK encourages any programmes that address interventions for ‘at risk’ populations to pay special attention to the needs and urgency of key stakeholders, including: a) pregnant women who are drinking alcohol. In particular, we urge consultation with [The UK & European Birth Mum Network – FASD](http://www.eurobmsn.org)<sup>9</sup>, and b) adults and young adults with FASD, who often wrestle with addiction and other secondary disabilities making them a particularly vulnerable and at-risk population. We urge consultation with [FASD Devon and Cornwall](https://www.facebook.com/FASDDAC/)<sup>10</sup>, which is run an adult with FASD who was diagnosed in his mid-20s after struggling with alcohol addiction and incarceration. If a separate strategy for children of alcoholics is undertaken, this should include attention to the special circumstances of the too often over-looked subset of children, young adults and adults with FASD, and their unique and urgent needs.

## Warning Labels and Public Education

Concern was repeatedly expressed by MPs that public education and awareness campaigns about the risk of drinking alcohol during pregnancy remain insufficient. **Fiona Bruce, MP** stated, “the chief medical officer’s guidelines on this issue have not been sufficiently promoted by the Department of Health.” [Column 419WH] **Kelvin Hopkins, MP** pointed out that, “In the US and elsewhere, alcoholic drinks containers are required to have warning labels—not just a small symbol of a pregnant woman, and not on a voluntary basis. [Column 415 WH] “Such a warning should be compulsory on all UK alcoholic drinks containers and should also be displayed in all NHS medical facilities—GP surgeries, clinics and hospitals—as well as all establishments selling alcohol.” [Column 415 WH] **Bill Esterson, MP** said, “The guidelines now say that women who are pregnant or are trying to conceive should not drink alcohol at all. That is right, but by no means does it go far enough, because people do not know the guidelines—I am afraid that the increase in alcohol consumption suggests that, sadly, that is all too true. As part of our strategy, we have to increase awareness, not only among professionals but among the wider population, of the support needed for women before pregnancy. In North America, which my hon. Friend the Member for Luton North mentioned, information is displayed in all the health facilities, education facilities and even airports—I have seen big signs in Canadian airports that say “Don’t drink if you’re pregnant or trying to conceive”. [Column 419WH] **Esterson** continued, “Labels are just not adequate. They are so small and insignificant that they are ignored or are not noticed, and they are not enough anyway. Again, in North America, such information is displayed in big letters on the walls of pubs, bars and so many other places. That is another suggestion for the Minister: more awareness in places where people are drinking and more information on the bottles themselves.” [Column 410WH]

MPs suggested that education on FASD should also be targeted at younger people, including students. **Kelvin Hopkins, MP** said, “The Government must wake up to the tragedy of FASD and take urgent action to ensure that all women know about it... in Canada the Government take the matter so seriously that girls are made aware of the problem in primary school. They are asked in class what they must not drink when they have a baby in their tummy, and they all say, “Alcohol.” They know about the problem. [Column 415WH] **Bill Esterson, MP** said, “We must raise awareness among girls—and

<sup>9</sup> <http://www.eurobmsn.org>

<sup>10</sup> <https://www.facebook.com/FASDDAC/>



among boys too, because it is really important that boys and men play their part in influencing their partners in abstaining from drinking.” [Column 419WH]

**The Parliamentary Under-Secretary of State for Health Nicola Blackwood** said, “Officials are now working with partners in industry to update the advice provided on packaging and labelling to reflect the latest evidence... we remain committed to high-impact public education campaigns.” [Column 441-442WH] **Blackwood** continued, “I will certainly consider the comments made about putting that information on labels, in GP surgeries and in other appropriate locations. One of the other ways in which we are trying to get that information out is through the ‘One You’ campaign and the drinks tracker, which I have just mentioned.” [Column 443WH]

**Action Point 5 – Increase public awareness:** NOFAS-UK strongly supports efforts to increase public awareness of the risks of drinking alcohol while pregnant. This should be a partnership across governmental departments, and working on cooperation with local authorities, industry, the medical profession and the schools. The International FASD Awareness Day on 9 September - the 9th day of the 9th month drawing attention to the 9 months of pregnancy – is an ideal time to raise these issues specifically. NOFAS-UK and others stand ready to help develop materials and events that would help amplify the Government’s guidelines.

## The Need for Prevalence Studies

During debate the vastly different figures that were provided demonstrated the need for statistically rigorous domestic studies on prevalence. While the background information provided an answer from Government on ‘official figures’ for 2014-15 for FAS (286) or FASD (27)<sup>11</sup>, the numbers are useful only to prove that diagnosis criteria and adequate coding is lacking. Too few children are being properly identified in the NHS system. Kelvin Hopkins MP provided a low-end estimate of 6,000 [Column 415WH], which would represent less than 1% of births. **Marie Rimmer, MP** gave the figure of 7,000 [Column 431WH] which equals 1%. **Bill Esterson, MP** provided the high-end estimate of 35,000 [Column 416WH] – which would represent some 5% of births.<sup>12</sup>

**Parliamentary Under-Secretary of State for Health Nicola Blackwood** said, “One problem I have been made aware of is the lack of research in this particular field and the

11 Mr Philip Dunne | Department: Department of Health, HC Deb 20 October 2016 | PQ 48847, quoting Hospital Episode Statistics (HES), NHS Digital. In providing these figures, the government states, “Therefore, it is not possible to identify all Foetal Alcohol Spectrum Disorders using data derived from ICD-10 codes.” Tackling Alcohol Harm, House of Commons Library, p. 27

12 Penny Cook and Raja Mukherjee, two UK experts stated, “We don’t know how many people have FASD in the UK, but based on a large review of data from other countries, it’s estimated that it may affect as much as 2% of the population. This would put FASD on a par with well-recognised developmental disorders such as autism spectrum disorder.” In “How foetal alcohol spectrum disorders could be a hidden epidemic,” The Conversation, 13 January 2016. More recently, a new study by the Canadian Centre for Addiction and Mental Health (CAMH) published in the Lancet Global Health (12 January 2017) estimates that in the UK the prevalence of FAS is 61.3 per 10,000 persons - significantly higher than the global average of 15 out of 10,000. This ranks the UK 7th behind South Africa (585.3), Croatia (115.2), Ireland (89.7), Italy (82.1), Belarus (69.1), and Denmark (68). Russia is behind the UK with an estimated 54.2 per 10,000. These figures are predicted using advanced statistical analysis – methodologically sound studies are needed in the UK to pinpoint the prevalence further. Please also note that these figures are, according to the study, only “the tip of the iceberg” since they deal only with Fetal Alcohol Syndrome and not the full range of Foetal Alcohol Spectrum disorders. According to experts, the rate of FASD may be as much as 9 or 10 times higher.

need to increase it. Although the World Health Organisation has started a global prevalence study, which he called for, it recognises that information is lacking in many countries, including the United Kingdom. That creates a number of challenges, because the feasibility of estimating prevalence is difficult given the ethical challenges associated with research in that area.... Public Health England recently published the most comprehensive and up-to-date review of current harms of alcohols and the evidence on the effectiveness of alcohol control policies. We are currently engaged in further work to understand the impact of parental drinking on children; we discovered during the initial work that we did not have sufficient evidence on that, so we are going forward with that work. Public Health England is also developing prevalence figures at local authority level, as well a toolkit to support local authorities to respond to the issue of parental drinking.... One challenge we face is insufficient evidence, which is why we are trying to build the evidence base up so that we can assist medical professionals and local authorities as they try to make decisions; if they do not have the evidence, it is very difficult to make proper policy decisions in this area.” [Column 444WH]

**Action Point 6 – Concurrently fund prevalence studies and support:**

NOFAS-UK recognizes that methodologically sound studies are needed in the UK to pinpoint the prevalence of Foetal Alcohol Spectrum Disorders and we strongly encourage funding these studies as a priority. However, this need for domestic research cannot excuse the lack of Government attention and action focused on addressing the needs of those in this country who have FASD. Immediate steps can and should be taken to make progress on meeting the needs of this under-served at-risk population.

## Need for Increased Diagnostic Capacity and Capacity of GPs

**Bill Esterson, MP** laid out the dire need for commissioning more FASD clinics and increasing the capacity for the UK medical system to diagnose and address the needs of those with FASD: “There is only one specialist clinic in this country to diagnose FASD—it is in Surrey, and is led brilliantly by Dr Raja Mukherjee, who gave evidence to our inquiry—but that simply is not good enough.” [Column 418WH] **Esterson** continued: “The symptoms are misunderstood and significantly misdiagnosed, and too many professionals dismiss them.... We must improve understanding among health professionals” [Column 418WH] **Marie Rimmer, MP** discussed the need for a “diagnosis and a care package.” [Column 431WH] **Martyn Day, MP** emphasized the overwhelming agreement on “the need to improve health professionals’ knowledge. I fully agree on that; there is great consensus in the Chamber today.” [Column 433 WH]

**Bill Esterson, MP** highlighted the need for other professionals who come into contact with those with FASD to have increased training, “We must improve awareness, information and education among professionals, not just in health but in education.... we need greater support, awareness, understanding and training for education professionals as well as those in health and elsewhere.

**Parliamentary Under-Secretary for Health Nicola Blackwood** highlighted some areas of Government progress, though it is not clear the extent to which these steps specifically target the issue of drinking during pregnancy: “Since April 2015, the



standard GP contract has included the delivery of an alcohol risk assessment to all patients registering with a new GP, which offers the opportunity to raise awareness of alcohol as a risk factor. In addition, the inclusion of an alcohol assessment in the NHS health check is a good opportunity for healthcare professionals to offer advice. That check is offered to all adults between 40 and 74 in England. That large-scale intervention has the potential to make a real difference.... evidence shows that that is one of the most effective interventions available to us. Since we mandated the alcohol assessment and advice component in 2013, more than 10 million people have been offered a check, and nearly 5 million people have taken up the opportunity, which is a take-up rate of about 48%. That is progress, but we want to go further.” [Column 443WH]

**Action Point 7 – Increase capacity of the health profession:** NOFAS-UK strongly agrees with the need for teaming with health care professionals to increase FASD prevention, diagnosis, and support. This starts with wider public education efforts but critically includes ensuring that all areas of the medical profession which might come into contact with pregnant women or children, young adults and adults with FASD should have in hand and distribute current, clear information about FASD. A post-diagnostic protocol and “joined-up” follow up care and support from multiple services is a complicated question that deserves attention with urgency. NOFAS-UK’s flagship project in recent years has been a [midwives training programme](#)<sup>13</sup> that has reached more than 15,000 midwives. We stand ready to assist in these efforts. We also encourage attention to pockets of excellence in this country, such as the North East, where progress is running far ahead of national practice and a useful partnership has developed between [FASD Network UK](#) and local services to increase regional capacity<sup>14</sup>.

**Action Point 8 – Increase capacity of education profession:** NOFAS-UK supports a similar effort in the schools to increase training for teachers, SEN professionals and other relevant services. NOFAS-UK launched a detailed [FASD education project](#)<sup>15</sup> and we seek to expand and update this effort in cooperation with the relevant agencies.

## Need for Attention in the Fostering, Adoption, Kinship Carer Services

**Bill Esterson, MP** said, as “many as three quarters of children in care could be affected by alcohol damage during pregnancy. It is one of the major factors contributing to them ending up in care in the first place.... we heard adoption described by one adoptive parent as a family-finding service for foetal alcohol spectrum disorders. It is a family-finding

<sup>13</sup> <http://www.nofas-uk.org/?cat=16>

<sup>14</sup> For example, in the North East, FASD Network UK (<http://www.fasdnetwork.org>) led by Maria Catterick working with local partners has launched a series of local initiatives, including: schools lessons for children; poster schemes in surgeries and pubs; multi-agency training; protocols for midwives, health visitors and paediatricians; they have already used 'Have a Word' (the Welsh scheme mentioned in debate); recommended Audit C use in various settings; put in place joined up regional working strategies (in 2014 the entire NE of 12 LA's changed the advice to pregnant women to no alcohol in pregnancy, 2 years ahead of the CMO guidance); and conducted a prevalence study based on bloods. They also have been pushing from this regional platform for NICE guidance regarding FASD so that practice guidelines can be changed. See for example, <http://expressnorth.co.uk/i-dont-just-want-to-raise-awareness-of-foetal-alcohol-spectrum-disorder-i-want-social-change/>.

<sup>15</sup> <http://www.nofas-uk.org/?cat=27>

service with inadequate support.” [Column 417 WH] **Marie Rimmer, MP** gave the example of one family in her constituency who were trying to adopt a child with FASD and who were advised that if the adoption was not completed in a certain timescale, the child would be removed from them.” [Column 431WH] **Rimmer** also said, “In Peterborough, 75% of children referred for adoption have a medical history of pre-natal alcohol exposure. Most of the looked-after children in St Helens come from alcohol-related problem families.” She emphasized local efforts to combat this but reinforced the need for a “national response.” [Column 432WH]

**Bill Esterson, MP** emphasized “the need for support for adoptive parents. All too often there is no post-adoption support, particularly with this condition of FASD. It is even more important than perhaps we knew in the past.” [Column 431WH]

**Action Point 9 – Increase support for parents, adopters, guardians, and other carers:** NOFAS-US strongly supports the call for additional support for adoptive parents, foster parents, kinship carers and all those in care system and other services who might come in contact with those affected by FASD and their families. Training is needed for staff. Prospective parents/carers have a right to full information about the risks and also should be able to access services, therapies and medical teams that can help increase the chances of success.<sup>16</sup>

## Costs of Inaction and the Power of Speaking Out

**Bill Esterson, MP** said, “My hon. Friend the Member for Luton North spelled out how those in North America have managed to calculate the economic costs; the same will be true here. The societal costs are fairly obvious, from what I have described, but there is also an impact on families. If they must care for a child with the kind of disability that we are describing...it can often have a dramatic financial impact, because people have to give up work to care full time, with little or no support.” [417WH] **Esterson** further highlighted “the need for support for adoptive parents. All too often there is no post-adoption support, particularly with this condition of FASD. It is even more important than perhaps we knew in the past, so perhaps I can make that point via my hon. Friend to the Minister to pass on to colleagues in the Department for Education.” [Column 431] **Esterson** also drew attention to the “High numbers of care leavers and people with mental illness end up in prison. ...[O]nce we start to explore the root cause—I hope that such work can be carried out—to find that alcohol during pregnancy is a primary contributory factor.” [Column 417WH]

**Parliamentary Under-Secretary for Health Nicola Blackwood**, responding to the sharing of personal experiences by some of the MPs in the debate (while not particularly referencing FASD), said “I hope that ...more people—not only in this building but across the country—will feel that they can be open about their personal experiences of addiction and of being in families with those with addiction, and will be able to seek help... [W]e cannot be satisfied.... There is much more we can and must do, and I hope I have reassured colleagues today of my personal commitment to ensure we strengthen the information, support and, if necessary, treatment we give people to reduce the harms of

<sup>16</sup> One recent study showed how important appropriate interventions can be. “How thinking about behavior differently can lead to happier FASD families,” University of Rochester, 18 November 2016. Available online at <http://www.rochester.edu/newscenter/how-thinking-about-behavior-differently-can-lead-to-happier-fasd-families-189582/>.

alcohol misuse. With a health challenge as culturally entrenched as this, it can sometimes feel as though it is a mountain we will never successfully climb, but I take courage from today's debate. Great social change requires three things: long-term political will, non-partisan partnership and bravery. I have heard all three of those today. I hope that each Member who has spoken here today will continue to work with me as we fight on to tackle this social injustice." [Column 448WH]

**Fiona Bruce, MP** concluded by saying generally, "[W]e need the Government to take a lead on tackling alcohol harm, which is one of the most serious health challenges of our time, and to do so urgently. We need action—enough reviews have taken place. Public Health England's report clearly says that there are policies that have significant potential to curb alcohol-related harm, but we need action to be taken urgently. Successive Governments have completely underestimated the challenge. I appreciate what the Government are doing now, but we need more to be done.... this is not some moral crusade, it is a matter of social justice. Taking effective action will help literally all of our society, but disproportionately the poorest, the most vulnerable and the youngest. We have heard today about the financial costs of excessive alcohol consumption, but the cost in the loss of life chances and potential, for children in particular, and the sheer heartache that people have suffered and continue to suffer are incalculable. I am pleased that the Minister is determined to look particularly at how we can help the children of alcoholics who are suffering now—how we can help to protect them and prevent that from happening in the future—and, I hope, unborn children, too. Those are real priorities, and I am delighted that she has committed to emphasising that work in particular. [[Column 449-450WH]

**Action Point 10 – Engage with stakeholders:** NOFAS-UK takes heart from the rich and wide-ranging Westminster Hall Debate on Alcohol Harm. We support the Under-Secretary of State for Health's call for long-term political will, non-partisan partnership and bravery. We fully agree with the need to raise up the voices of those most deeply affected by alcohol harm, and strongly suggest that individuals affected by FASD, their families and caregivers, and those who support them in the schools, in the health professions and in other services are given opportunities to share their experiences and wisdom. The issues are more complex than can be addressed fully in one afternoon's debate or in this brief overview of that discussion. NOFAS-UK takes this opportunity to convey the urgency of this issue on behalf of those stakeholders who are largely silently struggling with too little support

## ATTACHMENT 1: BACKGROUND SHEET



### Foetal Alcohol Spectrum Disorders – Background

Foetal Alcohol Syndrome is noted in a 2016 BMA Report as [“the leading known cause of non-genetic intellectual disability in the Western world.”](#) Foetal Alcohol Syndrome is one of a range of conditions caused by exposure to alcohol in utero that fall under the umbrella of Foetal Alcohol Spectrum Disorders (FASD), which some experts call a [‘hidden epidemic’](#).

Exposure to alcohol in the womb causes injury to the brain and other parts of the body. More than [400 conditions can co-occur with FASD](#). A [2016 BMA report](#) highlighted that “Inadequate diagnosis and support of FASD can lead to a far greater chance of secondary comorbidities for the individual, including mental health issues”.

Despite the serious lifelong impact of this condition, families often struggle to get a diagnosis for their child. As the child gets older, the cognitive challenges become more obvious since they relate to more abstract thinking, “executive functions,” and the way different parts of the brain communicate. Very often secondary issues related to behavioural and mental health issues become the focus rather than the underlying brain injury. The statistics show that many end up in prison. This is a population often excluded from schools that don’t understand them, teens who self-medicate and become addicted themselves. These vulnerable young adults are often bullied and led astray.

The stresses FASD can place on families were the focus of [Carol Sarler’s 27 December article](#) in the Daily Mail and a [piece by Libby Purves](#) on 2 January in the Times. Most of the debate that followed focused on adoption and presented an unbalanced perspective on the issues related to Foetal Alcohol Spectrum Disorders (FASD). While a national debate about FASD is desperately needed, as NOFAS-UK said in a [statement](#), not by demonizing kids with FASD, not by shaming birth mothers, and not by providing inaccurate and misleading impressions that all families who raise a child with FASD are doomed.

With early diagnosis, intervention and support, this picture can change. There are pockets of excellence across the country where best practices exist, where things are working differently, where kids are growing up into adults that can

and do contribute their many talents to the community. Groundbreaking work has been done by the [FASD Network](#) UK in the North East promoting an integrated approach, working in cooperation with local and regional expertise and agencies. Lee Harvey-Heath who founded [FASD Devon and Cornwall \(FASDDAC\)](#) helps and works with teens and adults with FASD. [ELEN - UK & European Birth Mum Network](#) offers support and offers peer mentoring to pregnant women and support women and their children who may or have FASD. [NOFAS-UK](#) has conducted an exciting program that has reached more than 15,000 midwives across the UK. The FASD UK Alliance runs a vibrant [online support group](#) that engages more than 1,100 affected individuals, parents, guardians and carers.

There are known strategies, resources, therapies, sometimes medication, and other programs that can help. But for that change to happen, resources and funding need to be allocated to address the problem. The UK is home to some leading experts who prove that there are ways to diagnose and support people with FASD – people like Dr. Raja Mukherjee at the [National Clinic for Fetal Alcohol Spectrum Disorders](#), Professor Moira Plant, an expert on gender and alcohol at University of the West of England, Dr Maggie Watts, Director of Public Health in the Western Isles who formerly served as Fetal Alcohol Spectrum Disorder Co-ordinator for Scotland, and Professor Barry Carpenter, OBE and Dr. Carolyn Blackburn who have done ground breaking work on [education and FASD](#). These experts and many, many more, work in cooperation with families, birth parents, and those with FASD to help chart pathways to brighter futures.

The [FASD UK Alliance](#) (<https://fasd-uk.net/>), a coalition of organisations across the UK working on FASD prevention and support, stands ready to help meet these needs. Support and assistance is available. But national attention and governmental muscle is critical to change the course of this hidden epidemic.

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**For further information:**

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## ABOUT NOFAS-UK

The National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK) has a twin mission – prevention and support. Through our programmes we seek to raise awareness of the risks of drinking in pregnancy, to promote support for women who are pregnant, and to work toward minimizing the number of young people born in the UK with this preventable brain injury. We seek to help the wider society – and especially young people – more fully understand the CMO's guidance. We also seek to provide support for those with FASD, those who love them and raise them, and the various professionals who engage with them medically, educationally, and via the various social care networks. The brain injury caused by in utero exposure to alcohol will never go away, but early diagnosis, educational support, therapies, alternative parenting strategies, caregiver support and helping those with FASD attain a level of understanding of their condition can all potentially change the fate of those with FASD. This support can save lives.

NOFAS-UK has been leading policy debates related to FASD since 2003. NOFAS-UK works closely with experts, allied professionals, and industry to increase training and awareness about FASD. A recent flagship programme has reached more than 15,000 midwives to date. We are affiliated with the FASD UK Alliance, the international NOFAS network, and work in cooperation with many alcohol and FASD related networks, including the Alcohol Health Alliance, the EU FASD Alliance, the Royal College of Midwives, among others. NOFAS-UK is a registered charity (number 1101935).

## Selected Recent Media

*We must increase awareness of the risks of drinking during pregnancy and urgently put in place programmes people can access across the country to support at-risk women and to diagnose and support those individuals and families affected by this hidden disability.*

Chief Executive Sandra Butcher, quoted in *The Times*, 20 January 2017,

<http://bit.ly/2k9sgmw>

*The latest advice from the UK's chief medical officer is clear, but it has not yet filtered through to all levels of our society. 'If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all....These figures show that the UK needs greater national and local attention to issues related to Foetal Alcohol Syndrome. Chief Executive Sandra Butcher, quoted in *The Daily Telegraph*, 20 January 2017, <http://bit.ly/2kj4S1K>.*

**PRIME MINISTER MAY, 9 JAN 2017: "No parent should feel helpless when watching their child suffer. No teacher should feel ill-equipped to deal with a troubled pupil. No teenager should have to leave their local area to seek treatment. No child should ever be left to feel like their life is not worth living."**

**We agree - so let's talk about**



# FASD

*Inadequate diagnosis and support can lead to a far greater chance of mental health issues. BMA 2016*