A CRISIS OF COMMISSIONING

CCGs Are Failing Government Policy on FASD

FASD Policy Focus Paper No. 2 • NOFAS-UK

The National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK) is dedicated to supporting people affected by Foetal Alcohol Spectrum Disorders (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy. NOFAS-UK is a source for information on FASD to the general public, press and to medical and educational professionals.

This report was written by Martin Butcher on behalf of NOFAS-UK, with assistance from Sandra Butcher, Chief Executive. We would like to thank all those who contributed advice and support throughout this project and report drafting, especially Dr Raja Mukherjee, Dr Inyang Takon, Nyrene Cox, Richard Clements, Brian Roberts and the other individuals with FASD and families who have provided insight through various online polls via the FASD UK Alliance and NOFAS-UK social media. They are of course not responsible for the final content.

NOFAS-UK is acutely aware that this report is limited and does not replace a desperately needed audit of FASD services across the UK. We appreciate the limitations of the questions we submitted. We nevertheless offer this snapshot as undeniable proof that there is a gaping mismatch between stated government expectation and on-the-ground realities with regard to FASD services. It is now up to decision-makers in government at all levels and public health services to take this to the next step. We also are aware that the answers supplied by CCGs and NHS Trusts in some cases do not capture the full picture of their services, but we have attempted in good faith to summarise the information as provided to us.

We would like to thank mysociety.org whose website, www.whatdotheyknow.com was used to conduct the Freedom of Information Act requests upon which this report is based. We appreciated the expert assistance from their staff in how to phrase and process the questions.

We also thank those CCGs and NHS Trusts that took time to thoughtfully reply to the FOI requests. We have some sympathy with CCGs who, due to lack of training of healthcare professionals on all levels and in the absence of central guidance, find it hard to assess the need or how to best meet their responsibilities with regard to FASD. We even know some CCGs have tried to start this process but have become overwhelmed and their efforts stalled. Exciting progress has been and is being made by some very forward-looking teams – regionally, in certain CCGs and increasingly at high levels in various quarters. We appreciate there is an increasing focus on FASD in the Department of Health and other bodies. We hope this report is welcomed by all those seeking improvement in services. NOFAS-UK stands ready to help.

As a sister organisation in the FASD UK Alliance, NOFAS-UK is committed to working side-by-side with other organisations to build Third Sector capacity to meet the challenges posed by FASD. This is a task many have been undertaking for decades. Their earlier and sustained work was essential to building the momentum that seems to be gathering today.

But as highlighted by this report, promoting healthy pregnancies and improving the outcomes for those with FASD are not the responsibility of charities and support groups alone. Our public health entities are responsible for the health and wellbeing of the nation. And that includes people with FASD and those who love and care for them.

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Executive Summary

New research by NOFAS-UK based on Freedom of Information research reveals:

1) The vast majority of Clinical Commissioning Groups (CCGs) are not commissioning specific services for Foetal[1] Alcohol Spectrum Disorder (FASD) prevention, diagnosis or post-diagnostic care of people with FASD.

2) This contradicts government policy as repeatedly reinforced by ministers, which unequivocally and clearly states that responsibility for commissioning FASD services lies with Clinical Commissioning Groups.

3) Without commissioning, most NHS Trusts do not provide FASD services.

4) This includes specialist mental health, learning disability and community service Trusts which generally provide no specialist services for people with FASD and do not see this as part of their remit.

5) Most Trusts and CCGs regard FASD as a paediatric issue only. Few even consider diagnosis and post-diagnostic services for adults with the condition.

6) There is a general assumption in CCGs and Trusts that access to wider healthcare services for those with an FASD, where provided, is sufficient. However, those providing such services are unlikely to have specific training in managing a patient with an FASD and this is likely to render non-specific services less effective than they should be.

7) Many CCGs appear to regard prevention education as the responsibility of public health authorities alone.

8) At best, CCGs expect providers to give prevention information after a woman is already pregnant.

9) Many Trusts do not report giving information on alcohol risks and FASD at pregnancy booking. Of those that do, alarmingly some report they are still using old guidance.

The results reported here demand a considered response.

NOFAS-UK recommends a Parliamentary inquiry to explore the situation outlined in this report in depth. Parliamentary oversight on government policy is clearly needed. In addition, NOFAS-UK calls on Government to issue a Green Paper, using the consultative process to initiate a debate both inside and outside Parliament about the change needed to improve FASD prevention and services across government.

NOFAS-UK calls upon the Department of Health, NICE, Royal Colleges and other relevant bodies to use their considerable expertise to help struggling CCGs and healthcare professionals train up on these issues. Given the lack of experience and training regarding FASD, it is essential to provide clear pathways for diagnosis, assessment and support. Ideas for good practice exist and should be implemented[2]. This then will signal across government that people with this neurodevelopmental disability and their families are indeed entitled to appropriate support in all areas of their lives, including education, housing, benefits and other support services. It also will ensure more efficient use of limited resources in this strained healthcare system.

Anything short of that will continue to fail a vulnerable but multi-talented population - people with hopes, dreams and considerable strengths that if appropriately supported and developed can contribute in many ways to our communities. Stakeholders consistently state that the biggest challenge of living with FASD or caring for someone with FASD is getting appropriate services.

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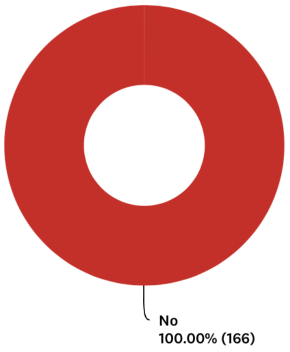
[1] This report uses the UK spelling of “Foetal”. The international spelling is “fetal” and this is reflected in various quotes in this paper.

[2] See for example: British Medical Association, “Alcohol and pregnancy: Preventing and managing fetal alcohol spectrum disorders,” 2007, rev 2016. https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy. Also, Mukherjee, R (edit), “Consensus Statement Regarding the Recognition and Diagnosis of Foetal Alcohol Spectrum Disorders Across the Lifespan in the UK: Development of Proposed UK Clinical Pathways,” Report on the Findings from the first National Medical and Healthcare Professionals Conference held on the 12th and 13th October 2011, published by the FASD Trust, 2013.

Key Findings

Steve Brine, Health Minister repeated on 19 February 2019 what has been government policy for years: “Responsibility for commissioning Fetal Alcohol Spectrum Disorders (FASD) services lies with clinical commissioning groups working together across all sectors.” To test whether CCGs are implementing this policy, NOFAS-UK sent Freedom of Information requests to over 450 NHS Trusts, CCGs, Health Boards and other bodies in England, Scotland and Wales and Northern Ireland. Replies were received from 166 CCGs and 167 Trusts. The only possible conclusion from responses received is that CCGs are failing to meet government policy. Decision-makers need to find out why the UK is systemically failing so many vulnerable people with neurodevelopment disabilities.

- None of the CCGs who have provided responses have a policy for commissioning services specifically for Foetal Alcohol Spectrum Disorders.
- Most Trusts said they hold no information on FASD services or do not code post-diagnostic services to record information.
- Only 21.69% of CCGs say they currently provide for the diagnosis of FASD in children.
- Only 8.43% of CCGs say they provide diagnosis for adults and only 4.9% of Trusts say they actually do.
- Just 22 CCGs told NOFAS-UK that they expect the Trusts they commission to provide education and training on FASD. Only 24.55% of NHS Trusts told NOFAS-UK that they provide FASD training in some form.



DOES THE CCG HAVE A POLICY FOR COMMISSIONING SERVICES FOR FASD?

- The vast majority of CCGs are not holding any form of public consultation on these issues.
- Only 23 CCGs (13.86% of responses processed) have an FASD lead.
- Only 31 Trusts (18.5%) told NOFAS-UK that they provide post-diagnostic care for those with FASD.
- Referral to necessary services like Occupational Therapy, Speech and Language Therapy, Physiotherapy, learning disability and children’s mental health services is *ad hoc*, uncoordinated and not managed for the complex needs of a person with an FASD.
- Most Trusts and CCGs regard FASD as a paediatric issue only, few even consider diagnosis and post-diagnostic services for adults with the condition.
- Many CCGs appear to regard prevention education as the responsibility of public health authorities alone. Only 37.8% of CCGs said they expected maternity services to give prevention messaging consistent with the 2016 CMOs guidance that “If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all.” Only 42.51% of NHS Trusts said they provide such prevention education.
- There are a number of issues of particular concern around the provision of specialist services, such as ambulance Trusts or CAMHS, where NHS Trusts seem to believe FASD is not an issue that concerns their service.

Foetal Alcohol Spectrum Disorders (FASD) is a term used to describe the range of disabilities that occur in an individual exposed to alcohol in utero. FASD is a neurodevelopmental disability, a brain-based condition with behavioural symptoms, notably including executive functioning difficulties. There are 400 associated conditions. Recent research led by Dr Cheryl McQuire at the University of Bristol found that a minimum of 6% and as many of 17% have symptoms which indicate they may have an FASD. Early diagnosis and appropriate support changes lives. The BMA has been showcasing best practices for more than a decade.

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Introduction

It has become obvious to stakeholders throughout the UK that FASD services ranging from prevention education, to diagnosis for children and adults, to post-diagnostic care are at best woefully inadequate and for the most part non-existent. Anecdotal evidence in the 2,200 member online FASD UK[3] Facebook support group, for example, suggests a gaping hole in the commissioning of services for people with Foetal Alcohol Spectrum Disorders.

Daily, members of that online support group report their struggles to access the help they so desperately need and recount the innumerable times they are rebuffed. People seeking help for themselves or loved ones are being told that the services they want do not exist, or that a diagnosis would be a useless label on a person struggling to understand why he or she cannot find their place in the world. This is tragic since diagnosis and proper support change lives.

NOFAS-UK set out to use the tools of democracy to discover just what services are available and what the gaps are. Freedom of Information requests were sent between July and September 2018 to over 450 NHS Trusts, CCGs, Health Boards and other bodies in England, Scotland and Wales and Northern Ireland. Replies were received from 166 CCGs and 167 Trusts. We are following up those that have not replied and will continue to develop this work. But enough CCGs, Trusts and Health Boards have responded to give a clear picture of the crisis in lack of provision for prevention, diagnosis and post-diagnostic care for FASD which we present in this report. Our report is not a completely comprehensive picture. Follow-up research is needed by official bodies.

The picture NOFAS-UK has uncovered is every bit as bad as individual testimonies day after day suggest. It reveals a need for a concerted effort from the Department of Health, with strong scrutiny from Parliament, to ensure that government policy on the commissioning and provision of services for FASD is followed. As we demonstrate in this report, there is a systemic failure to commission services necessary for prevention, diagnosis and post-diagnostic care for FASD, or to train medical and other health professionals to recognise the condition and provide those services.

The All-Party Parliamentary Group on FASD led by Bill Esterson, MP has been at the forefront of efforts to gain attention to this issue. It is essential that their work to bring oxygen to this issue in corridors of power are supported by officials at the highest level and by a wider range of MPs and Peers. FASD affects every constituency across this UK and the failure to address it further strains already overburdened services. As Mr Esterson said in his January 2019 adjournment debate on the floor of the House of Commons, FASD “is a hidden epidemic, and it is time that it was out in the open…This is too big just for good intentions.”[4]

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[3] The FASD UK Alliance (www.fasd-uk.net) is a coalition of groups and individuals from across the UK who are 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. The organisations jointly support the FASD UK online support group. NOFAS-UK is a sister organisation in the Alliance and its chief executive is one of the administrators of the FASD UK Facebook group. This report is however a NOFAS-UK publication and the FASD UK Alliance is not in any way responsible for any errors or conclusions of this report.

[4] Bill Esterson, MP, 17 January 2019, Hansard, Volume 652, http://bit.ly/2L9UkEp.

“This is too big just for good intentions.”
Bill Esterson, MP, Chair All-Party Parliamentary Group on FASD

What is FASD?

Foetal Alcohol Spectrum Disorders (FASD) is a term used to describe the range of disabilities that occur in an individual exposed to alcohol *in utero*. FASD is a neurodevelopmental disability, a brain-based condition with behavioural symptoms, notably including executive functioning difficulties. It affects lifelong cognitive, emotional and physical capabilities (it also can impact physical systems). FASD is the leading known cause of developmental disability.

FASD is an umbrella term that currently covers Foetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Alcohol-Related Birth Defects (ARBD), Foetal Alcohol Effects (FAE) and partial Foetal Alcohol Syndrome (pFAS). (These terms may soon be changing, please see the section on developments related to the new Scottish SIGN guidance at the end of this report).

Alcohol is a teratogen, meaning that it is toxic to, and can negatively influence, prenatal development. The developing foetal brain is particularly sensitive to the effects of prenatal alcohol. When a woman is pregnant and drinks alcohol, the alcohol not only enters her system, but also passes freely through the placenta. It enters the system of the developing foetus, where it can remain for up to three days. The alcohol exposure injures the body systems and organs that are developing at that stage of the pregnancy. Even though different parts of the body develop at different times during pregnancy it is important to note that the brain is developing the entire time and at every stage of pregnancy. The more a pregnant woman drinks, the higher the risk of FASD. And yet, that said, there is no proven safe amount of alcohol in pregnancy and no safe type of alcohol to drink, which is why the UK Chief Medical Officers issued strong guidance in 2016 that “the safest approach is to avoid alcohol” if you are pregnant or planning a pregnancy. NICE updated its information in 2018. This change reflects the fact that individual risk from the exposure cannot be identified, thus the need for a consistent global message. This report in part explores how CCGs and Trusts are doing in cascading that information to service users and how the public health messaging is doing in giving prominence to the importance of this guidance.

The effects of FASD range from reduced intellectual ability and Attention Deficit Disorder to heart problems. FASD may be undetected at birth but can become apparent later in life and carries lifelong implications as there is no cure for the underlying organic brain damage. It is a spectrum. No two presentations are the same. There are more than 400 associated conditions[5] that are known to co-occur, making individuals with FASD extremely complex medically. One of the main symptoms is dysmaturity. Social and emotional development can lag considerably behind chronological age, with massive implications for transitions to adulthood. The BMA released a seminal report on FASD in 2007, updated in 2016,[6] that should be the starting point for anyone exploring these issues. In the introduction, Baroness Hollins pointed toward the “scandalous lack of support” for those with FASD.

Why Does it Matter? What is the Prevalence of FASD in the UK?

Research around the world indicates that FASD is a leading cause of preventable developmental disability. The UK is no exception to this rule. If anything, the high rates of alcohol use in pregnancy in the UK are likely to indicate it’s more of a problem here than in most other places. The UK was shown to have the 4th highest levels of consumption in pregnancy in a 2017 review[7].

Recent research led by Dr Cheryl McQuire at the University of Bristol used data from a cohort of 13,495 children born in the 1990s and found that a minimum of 6%, and as many of 17%, of these

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[5] “Over 400 conditions co-occur with Fetal Alcohol Spectrum Disorders, study finds,” Science Daily, 6 January 2016, https://www.sciencedaily.com/releases/2016/01/160106091842.htm.

[6] British Medical Association, “Alcohol and pregnancy: Preventing and managing fetal alcohol spectrum disorders,” 2007, rev 2016. https://www.bma.org.uk/collective-voice/policy-and-research/public-and-population-health/alcohol/alcohol-and-pregnancy.

[7] Popova, S. et al, “Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis,” *Lancet Glob Health* 2017; 5: e290–99 , Published Online January 12, 2017 http://dx.doi.org/10.1016/ S2214-109X(17)30021-9.

individuals have symptoms which indicate they may have a Foetal Alcohol Spectrum Disorder.[8] This would suggest that a minimum of 3.96 million people in the UK could be affected by FASD[9] - most of whom are undiagnosed adults. This study suggests an urgent need for government to fund wide-scale active-case ascertainment studies to determine the full extent of the problem, as have been conducted in other countries. For example a recent study involving 13,146 children in four cities in the USA conservatively indicated 1-5% of the population have FASD – a prevalence rate higher than autism.[10]

A higher estimate of prevalence in the UK is hardly surprising given that 79% of mothers in the Children of the 90s cohort reported consuming alcohol during pregnancy. By some estimates, more than 40% of women continue to self-report as doing the same[11]. There are other studies that indicate these numbers may be higher. International studies indicate it is older, more educated women who are more likely to drink in pregnancy.[12]

This prevalence data is widely unknown by decision-makers and its implications are unappreciated. To use just one example, the CCG in the London Borough of Bexley replied to NOFAS-UK that they do not commission services for people with FASD, nor do they see a need to conduct research into the condition, because it is simply not a local problem. In 2017 the population of the Borough was 246,124.[13] Dr McQuire's results would indicate that between 14,767 and 41,841 of their local population might have an FASD – indicating that could indeed be quite a significant local problem.

UK Conservative, Labour and coalition governments since the 1970s have noted the importance of determining just how many are affected by FASD in the UK. Yet a full study has never been conducted.

What is evident from Dr McQuire's and her colleagues' work is that the problems associated with FASD are likely to be of such a proportion here in the UK that we cannot wait for gold-standard prevalence studies before we act. The time for intransigence has past. The UK has been dragging its feet since Mr Moyle, Secretary of State for Social Services, advised on 23 January 1979 that "the matter is kept under review."[14] The long saga of inaction continued for decades, leaving generations of people with FASD in the shadows of government statistics.

NOFAS-UK and FASD advocates throughout the country enthusiastically welcomed then-Health Minister Steve Brine's indication that he was hopefully drawing the line under this 40-year old indifference when he stated on the floor of the House of Commons that "The Government take alcohol concerns, across the board, very seriously and even more so when they relate to pregnancy. We are making progress—I hope—to prevent future FASD cases, and trying to change the landscape on prevention and treatment for those affected. But there is not an ounce of complacency in us—there certainly is not in me. We will continue to work towards improvements in the area."[15]

This report is put forward in hopes of helping government fulfil this promise, by highlighting an area where its policy is falling short of intentions.

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[8] Preventive Medicine, *Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: A population-based birth-cohort study*, Cheryl McQuire, Raja Mukherjee, Lisa Hurt, Andrea Higgins, Giles Greene, Daniel Farewell, Alison Kemp, Shantini Paranjothy. Available at https://doi.org/10.1016/j.ypmed.2018.10.013.

[9] The Office of National Statistics estimated the population of the UK to be 66.04m in 2017. https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/november2018.

[10] May, P et al, "Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities," *JAMA.* 2018;319(5):474-482. doi:10.1001/jama.2017.21896.

[11] Popova, S. et al, "Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis," *Lancet Glob Health* 2017; 5: e290–99 , Published Online January 12, 2017 http://dx.doi.org/10.1016/ S2214-109X(17)30021-9

[12] Older U.S. women more likely to drink while pregnant, study shows," Reuters, 20 July 2012, quoting a study by the US Centers for Disease Control. https://www.reuters.com/article/us-usa-health-pregnancy/older-u-s-women-more-likely-to-drink-while-pregnant-study-shows-idUSBRE86J03B20120720

[13] See the data from the UK Office of National Statistics available at https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates.

[14] Mr Moyle, Hansard, 23 January 1979, Vol 961, http://bit.ly/2xhEHkb.

[15] Steve Brine, Health Minister, 17 January 2019, Hansard, Volume 652, http://bit.ly/2L9UkEp.

> *"There is not an ounce of complacency in us—there certainly is not in me. We will continue to work towards improvements in the area. I can promise…that." Steve Brine, then-Health Minister, 2019*

Specifically, this report highlights an immediate need for CCGs to commission services for people with FASD, to ensure that health service providers understand the magnitude of the problem and to put in place oversight to track how they are making provision for the many and varied needs of those with FASD. Current *ad hoc* arrangements are simply not working.

Responsibility for the Provision of Services for FASD

Over the years, some committed MPs and Peers have repeatedly asked government in Parliament for information related to FASD prevention, diagnosis and post-diagnostic support. Policy has been clearly elaborated, most recently in February 2019, when then-Parliamentary Under Secretary of State for Public Health and Primary Care Steve Brine MP said that, "Responsibility for commissioning Fetal Alcohol Spectrum Disorders (FASD) services lies with clinical commissioning groups working together across all sectors. We know diagnosing FASD is a complex process and we have learnt from recent engagement events with FASD sufferers [sic][16] that diagnostic pathway should be improved. The Department is considering how we can improve access to such services and the diagnostic pathway learning from best practice." (While the answer below highlights adoption, the issue is wider.)

This reiterated stated government policy going back several years, although the inclusion of the intention to learn from people with FASD, their families and carers, in order to improve services is new. Despite this, it is clear that CCGs are not fulfilling their duty with regards to FASD. In circumstances where NHS budgets have fallen substantially in real terms since 2010 and continue to fail to keep pace with inflation and increased needs, it is easy to imagine why CCGs to continue to ignore a poorly understood condition. But their failure to address FASD strains the system in untold ways they have yet to explore. This cost-inefficiency should be studied by the National Audit Office.

PARLIAMENTARY QUESTION (*Written question – 219508)*

Asked by Andrea Jenkyns (Morley and Outwood), 11 February 2019:
To ask the Secretary of State for Health and Social Care, what support his Department provides to people adopting children with Fetal Alcohol Spectrum Disorders.

Answered by Steve Brine, Health Minister, 19 February 2019:
Responsibility for commissioning Fetal Alcohol Spectrum Disorders (FASD) services lies with clinical commissioning groups working together across all sectors. We know diagnosing FASD is a complex process and we have learnt from recent engagement events with FASD sufferers that diagnostic pathway should be improved. The Department is considering how we can improve access to such services and the diagnostic pathway learning from best practice. We will also ask the National Institute for Health and Care Excellence to consider the recent SIGN 156 guidelines 'Children and Young People Exposed Prenatally to Alcohol 'in Scotland to review if this guideline could be applied in England.

The Department for Education is the lead Department for adoption. As part of the adoption process potential adopters will be given information known in relation to the child's health condition and a meeting with a health professional responsible for that child's care. A care plan will be provided for the child. Both the child and the adoptive parent(s) should have access to local support and services post-adoption to support their child, along with access to the health and care services as part of the local commissioning process.

The Government, through the Adoption Support Fund, also provides families who have adopted or are providing special guardianship to children previously in care with access to funding for specialist assessments and therapeutic support. These may include FASD as part of the wider assessment of a child's needs.

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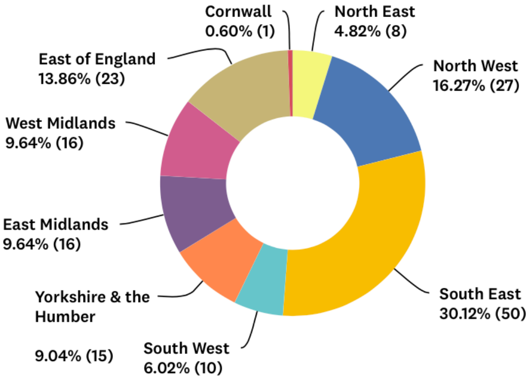
[16] NOFAS-UK rejects the use of the word 'sufferer' to refer to a person with FASD. We encourage all involved in these issues to see the "FASD Language Guide," produced by the Manitoba FASD Coalition. http://www.fasdcoalition.ca/looking-after-each-other-project/fasd-language-guide/.

In order to provide for promised improvements in FASD services, it is important to understand what is currently being commissioned by Clinical Commissioning Groups (CCGs) and provided by the NHS Trusts that they commission. NOFAS-UK has undertaken this survey using the Freedom of Information Act to questions CCGs and NHS Trusts, as well as Health Boards in Wales, Scotland and Northern Ireland to provide as much information as possible to government on the topic.

Geographical Spread of Responses

Clinical Commissioning Groups only exist in NHS England, so this report is skewed toward England. We received a broad spread of responses from 166 CCGs across the country. While not every CCG responded to our FOI request, the number and distribution of responses is enough for a representative sample and for the data uncovered to be taken seriously by the Department of Health.

We received responses from 167 NHS Trusts (data includes Trusts in England and other NHS bodies in Scotland and Wales. No responses have yet been received from Northern Ireland).



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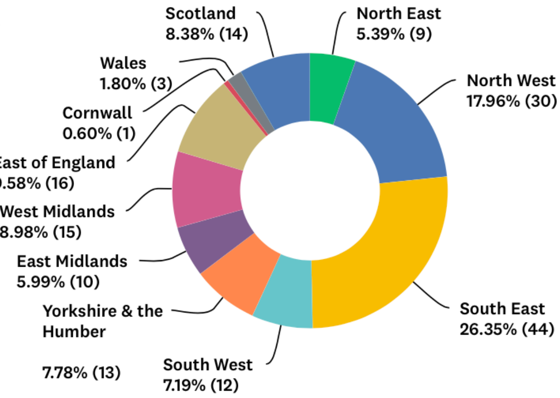


NHS TRUSTS & HEALTH BOARDS

FASD Service Commissioning and CCGs

Despite the clearly stated policy of the government, CCGs are not fulfilling this duty.

None of the CCGs who have provided responses have a policy for commissioning services specifically for Foetal Alcohol Spectrum Disorders for adults or for children.

This demonstrates an absence of awareness and understanding of the scope of need for FASD provision and of the benefits of provision of consistent and comprehensive services in improving the quality of life for people with an FASD. CCGs are required rightly to make effective use of resources. Services they commission must be of the maximum benefit to the greatest number of people. Autism, estimated to have a prevalence of 1.1% and to affect about 695,000 people,[17] receives significant attention and funding by the NHS and policy makers – properly so – because it is better understood and because the extent to which it affects the population is well known. FASD is estimated to affect more people and yet remains largely ignored and unseen.

The absence of commissioning policies for the wide variety of inter-related services necessary to provide a decent quality of life for a person with FASD means that there is no coordination nor consistency in their provision. Services can only be accessed on an *ad hoc* basis. Services where staff have little or no training in FASD are unlikely to be effective and may be damaging (see below). This is an inefficient use of limited health resources.

RECOMMENDATION: In order to make the most effective use of resources, NOFAS-UK recommends that CCGs develop policies for the provision of services for FASD and that pathways for diagnosis and support across the lifespan should be clearly delineated by central bodies.

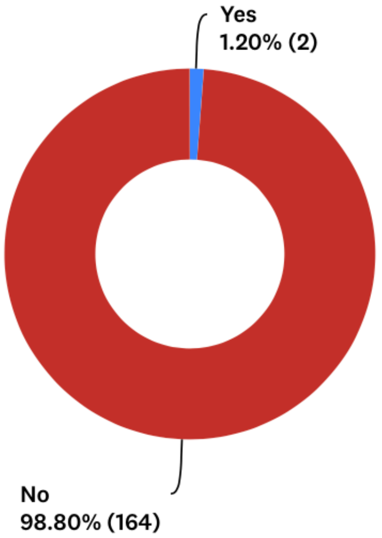
One other point on statistics: only 9% of CCGs indicated they received any inquiries on FASD over a 5-year period. This demonstrates the complete systemic lack of awareness that CCGs are supposed to be providing these services. It also shows the need for better tracking of FASD in NHS and related record-keeping.

This study did not attempt to collect data on the numbers that have been diagnosed. We understand that record-keeping is patchy at best and the numbers that do exist strongly point toward a post-code lottery. Replies received showed a snapshot of this inequality. For example, as part of their responses to our FOI requests, the Ayrshire and Arran Health Board (where services exist and are being further developed) reported 198 children with diagnoses, while Birmingham Women and Children's NHS Trust said they have had no diagnoses in the past five years. These replies both wildly under-indicate the true extent of this problem.

RECOMMENDATION: Improved record-keeping about FASD must be an integral part of any Department of Health action moving forward. We understand that there are steps moving forward in this regard.

Budgeting for FASD Services

Only two CCGs responded that they had a budget, but in fact none were able to detail a specific figure to be spent only on FASD. Even North West Surrey, which is home to the National FASD Clinic run by Surrey and Borders Partnership NHS Foundation Trust as an NHS-based service, told NOFAS-UK that they had no specific FASD budget but funded activities from a wider budget for relevant services. Few CCGs said they were willing to meet an Individual Funding Request (IFR) for diagnosis. The East and North Herts CCG, for example, has in recent years clamped down on IFRs for referrals to the National FASD Clinic, with one family being forced to engage their MP, councillors and local support group in their effort (eventually successful) to obtain the vital funds after being told in a letter that "I am still not clear what the clinical benefits will be as a result of this referral nor why CAMHS is unable to manage this." The trap that those with FASD fall into at a time of continuing NHS cuts is that there is no budget for local services and the budget for IFRs to specialist clinics is so tightly controlled as to be almost inaccessible. FASD is put to the bottom of the pile because the vast majority of CCGs have little understanding of the condition or the benefits of a diagnosis. While expertise may be lacking, neither are they buying in supervision to increase their expertise or sending people out of area. As a result, they are neglecting this group totally.



DOES THE CCG HAVE PLANS FOR SERVICE EXPANSION IN FUTURE YEARS?

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[17] Information from the Autism Society at https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx.

> *The trap that those with FASD fall into at a time of continuing NHS cuts is that there is no budget for local services and the budget for IFRs to specialist clinics is so tightly controlled as to be almost inaccessible. FASD is put to the bottom of the pile because the vast majority of CCGs have little understanding of the condition or the benefits of a diagnosis.*

Only two CCGs, both in the Manchester area, indicated any plans to expand services or put a budget in place. Most expect services to be provided by local Trusts from standard services covered by block grants such as community paediatricians, CAMHS, and therapists such as Speech and Language teams. Others simply do not regard it as an issue for CCGs to consider, with one CCG telling NOFAS-UK that FASD is a public health issue with which they were not concerned. This shows the importance of training. The details of FASD are not in most people's training, so they simply overlook it through ignorance.

Several CCGs responded that there has been no system-wide consideration of the need for FASD services by CCGs and therefore they cannot be expected to provide specific services.

RECOMMENDATION: Specific services should be commissioned for FASD and budgeted separately to ensure they are delivered. If it is considered more appropriate to provide for FASD needs through block commissioning of services, then expectations for services for adults and children with FASD must be specified clearly in the terms of that contract.

Let us be clear. Lack of funding is simply a non-starter as an excuse when it comes to providing FASD services. In 2018-2019, the government expects £11.6 billion in revenue from alcohol duties[18]. Surely those affected by alcohol before they drew their first breath should be first in line when policy makers decide how to allocate those resources.

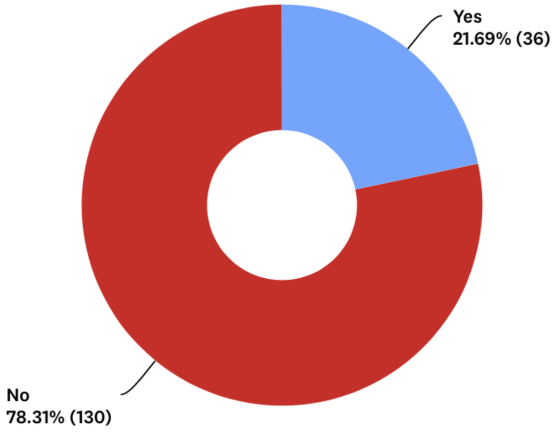
Diagnosis

Only 21.69% of CCGs say they currently provide for the diagnosis of FASD in children.

Where diagnoses are provided, most do so only through general services where staff have little or no training in FASD, or through Individual Funding Requests to finance a visit to clinics such as the National FASD Clinic – which was set up to only diagnose only approximately 50 complex children per year.

The answers from NHS Trusts were very similar. **Only 28.74% of Trusts reported that they diagnose children with an FASD.**

Almost all of these however are non-specialist services where the level of training and expertise vary greatly. (Most of them could train up with support, but they don't.) This leads to a postcode lottery resulting in wildly varying numbers of diagnoses, patchy level of services, and draws into question the capacity of many CCGs to fulfil their mandate from government. Also, in some counter-intuitive cases, East and North Herts Trust is an example, expert paediatricians who have the training and ability to diagnose FASD have been instructed not to accept referrals for FASD because the Trust is not commissioned to provide such services or elsewhere practitioners who have tried to address this need have become so frustrated within the NHS that they have begun offering private services. In no case that NOFAS-UK is aware of is any CCG providing diagnostic services for the full number of people likely to have an FASD in their area. Even where best practices exist, the structures are not yet adequate to meet the need.



DOES THE CCG PROVIDE SERVICES FOR DIAGNOSING FASD IN CHILDREN?

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[18] Office for Budget Responsibility, accessed 29 April 2019, https://obr.uk/forecasts-in-depth/tax-by-tax-spend-by-spend/alcohol-duties/.

In no case that NOFAS-UK is aware of is any CCG providing diagnostic services for the full number of people likely to have an FASD in their area. Even where best practices exist, the structures are not yet adequate to meet the need.

An example by which the situation could be improved, but has not been supported, is the current lack of central commissioning for the National FASD Clinic. The clinic states its aspiration to assess the most complex cases whilst helping to support the development of local services through supervision and sharing expertise. This is in keeping with a hub and spoke model of service delivery common in the NHS. The lack of funding has prevented this from occurring. Several NHS Trusts replied that they were unaware the Clinic exists, and so would not even be able to seek to have patients referred there. Only 23 specifically said they would accept an IFR for referral there. While the National Clinic was established as a NHS service to meet the needs of the most challenging cases, at present it is one of very few centres were diagnosis can be made (especially for adults). The lack of understanding of need by CCGs, combined with the central perception that the condition is common enough to not require central support means that is it is often underfunded and forced to try to meet a need it cannot possibly cope with and without a guaranteed budget year by year.

National FASD Clinic Forced to Turn Away Nearly Half of Appropriate Referrals Due to Refusal of Funding

From January 2017 - January 2019:

- 195 enquiries
- 118 appropriate referrals received
- 60 have agreed funding (17 private, 35 CCG and 8 Adoption Support Fund/Adoption services via council)

Reasons for refusal of funding:

- “I am afraid we cannot fund the £3500 that is requested for your assessment. This is not currently funded by our Trust and our Department.”

- “Unfortunately the CCG are unwilling to fund the cost therefore please cancel this referral.”

- “At the moment we are not going to pursue any further assessment, partly because there doesn’t appear to be any major advantage in confirming the suspected diagnosis.”

- “I had referred to our local PIN panel, who referred to the Community Mental Health Panel, who referred to another organisation and unfortunately they feel that they are non it a position to fund the assessment at your FASD service.”

- “I am very sorry to inform you that the [deleted] CCG have turned down the funding request…as it did not qualify for the IFR panel consideration. Funding for this treatment or service is currently not available and the request is being considered as potential service development.”

(Data provided by Fetal Alcohol Spectrum Disorders Behavioural Specialist Clinic, Surrey and Borders Partnership, NHS FoundationTrust, 29 April 2019, as part of submission to UK Parliament’s APPG on FASD.)

This is one example where a central commission by NHS England to a few centres of developing and established excellence, such as the National Clinic in Surrey and Borders, would prevent fighting for its small budget of under £200,000 per annum and allow it to use resources more effectively to meet its service aspiration. Instead Surrey and Borders Trust currently is forced to charge £3,500 for referrals from outside the area. Agreed funding is the single biggest block to an individual being seen. In a time of ever reducing NHS budgets (even the government’s most recent £20 billion supplementary funding announcement does not allow the budget to even keep pace with NHS inflation, let along catch up the past 8 years of severe underfunding) the lack of dedicated funding for services related to FASD means that adults struggle to access any appropriate services at all and parents must fight for children’s access to paediatricians, mental health services and therapists at every step. Too many are refused, with tragic impact.

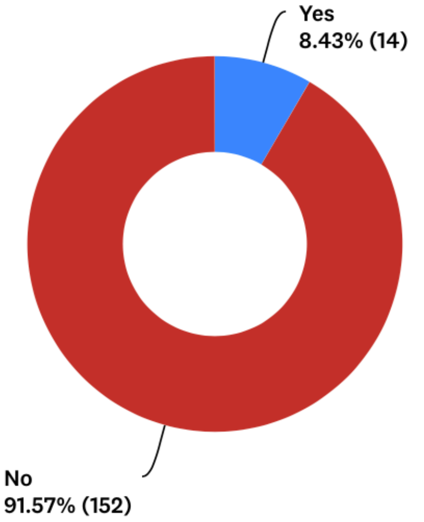
The situation for adult diagnosis is even worse.

Only 14 CCGs (8.43% of those who responded) say they provide funds for the diagnosis of FASD in adults.

And in Trust reporting the actual situation appears to be worse than that.

Only 7 Trusts and other organisations across England, Scotland and Wales (4.19%) say they can diagnose adults.

This is explained by the general perception within most Trusts and CCGs that FASD as a paediatric issue only. Many Trusts responded that they do not provide maternity services, so FASD is not an issue for them or, like the Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust, that they do not provide paediatric services, so could not respond.



DOES THE CCG PROVIDE SERVICES FOR DIAGNOSING FASD IN ADULTS?

The dire situation in adult diagnosis and care is illustrated by one London woman in her 40s who has been battling with the system to get assessment for a possible FASD diagnosis for five years. Despite strong evidence of maternal alcohol consumption throughout pregnancy and clear indicators of symptoms, she has only recently secured an initial appointment, though as of this writing she has yet to receive the needed neurodevelopmental assessment. Rather than being granted funding for the National Clinic she was sent to the Maudsley Hospital, which responded to our FOI request saying simply that it provides no services for FASD and cannot answer our questions. This is an inefficient waste of resources and more importantly valuable time in the life an adult with FASD, who in particular seeks a diagnosis to be able to secure appropriately supported employment so she can continue to support her family. The lack of national direction and acknowledged pathways continues to hinder efficient referral pathways.

The lack of dedicated funding for services related to FASD means that adults struggle to access any appropriate services at all, and parents must fight for children's access to paediatricians, mental health services and therapists at every step. Too many are refused, with tragic impact.

Diagnosis and appropriate support give individuals and those supporting them insight. Adults with FASD are left vulnerable in society. This population has been proven to be at high risk for poor life outcomes, including mental health issues, an inability to hold down a job, negative interaction with the criminal justice system, addictions, sexual exploitation, homelessness, early pregnancies and more.

Inconsistent diagnosis is also a problem. Even when people are technically able to access a diagnosis, the lack of consistent professional training is a serious issue (especially given the lack of current guidelines on diagnosis). This problem is illustrated by the response of the Royal Devon and Exeter NHS Foundation Trust. Its diagnostic guidelines are extremely heavily focused on the sentinel facial and other features of Foetal Alcohol Syndrome (FAS), to the exclusion of other diagnoses on the FASD spectrum. This would lead to a potential conclusion that doctors in the Trust are only recognising about 10% of potential FASD cases, the figure for FAS. Unless a case is absolutely obvious, under-trained staff could miss 90% of cases or interpret symptoms in ways that they do understand. This often leads to diagnoses of autism, anxiety disorder, sensory issues and other conditions which may form part of the picture, but do not form a comprehensive diagnosis and which might need adapted methods of support that take into account the individual's full cognitive profile. This lack of understanding of FASD and what support can do to improve outcomes is also likely to lead to a refusal to diagnose at all. "Why do you want a label?" is something individuals with suspected FASD, parents and carers hear all too often.

One example of best practice comes from NHS Shetland. They serve a population of 23,000 and yet are able employ a GP with special interest in Child Health. Based on the neurobehavioural model for FASD, the Shetland Health Board says her role for those with FASD is "to support families and school staff/carers in adapting their approach and the child's environment rather than trying to change the child." This is an example that could be followed elsewhere. NHS England might be able to encourage this model in its commissioning of GP services, for example.

What has been the impact of being unable to access diagnosis, assessment, support or benefits for FASD on you/your family?

- It has made our lives a living hell. Living with FASD is hard enough but with no understanding and diagnosis, all our energy is on fighting the system.

- As a single parent, it is a very lonely journey and I am exhausted constantly having to fight to get help or to get others to understand my daughter's complex conditions.

- I have recently been to the GP to ask for help, but he was unable to offer any as he didn't know what help he was able to give!

- We paid for diagnosis and assessment privately. It’s expensive and time consuming and we realise that that is not an option for everyone.

- Have felt forced into home-schooling.

- Very difficult to get any respite.

- Our foster son is in a school that is no good for him but as we cannot get a diagnosis of FASD, his EHCP says he only has ADHD.

- Preventing a child who could thrive and make a positive contribution if only basic (and cheap) support was available.

- It has destroyed family life and our marriage. As a mother my physical and mental health had deteriorated from the constant stress, anxiety and depression caused by the lack support.

- Our son is not getting the correct help, support or education and we worry constantly about his future.

- Extended time out of education.

- Her ability to process language and her lack of executive language function causes problems daily but they refuse to see her and I'm told 'she'll get by'. Perhaps she will but only with another there to guide her and explain in a way that's appropriate. It causes huge issues for her ability to function appropriately with her peer group and form relationships/ friendships. Lack of a sensory service from OT has left our daughter without appropriate therapy that could help her integrate with others and get enjoyment from activities most children access. This leads to social exclusion and poor self-esteem.

- My daughter had a breakdown aged 14, stating she'd "gone mad". As a result of the lack of understanding and targeted services, her mental health deteriorated dramatically. She had herself put into LA care, took two serious overdoses and began a year of self-harm. She has been in 4 placements in 12 months, has absconded several times and has been arrested. No specific services have been identified.

- The delay has meant behaviour such as child on parent violence may have been avoided or minimised with using strategies for FASD. In our initial six months of mounting violence it could have led to adoption disruption.

- I personally have lost my career in the civil service and my 20-year marriage. Directly as a result of the battle to know what we were dealing with and the lack of support.

- My children fight every day in mainstream school just to survive. It’s barbaric.

- Years of inappropriate support from social services for violent behaviour. There should be a proper pathway of support for FASD compared to attachment disorder.

- I fear for my foster child's future. I know he will need ongoing support as an adult, most likely assisted living. Being unable to get an executive and adaptive functioning assessment I won't have a report that highlights his needs. Without a report from a professional his needs won't exist.

- It's been a black hole of despair.

Source: *Responses to “Problems Facing Individuals, Families & Practitioners Affected by FASD - What Parliamentarians Need to Know,” collected via SurveyMonkey by the FASD UK Alliance and NOFAS-UK, 5-24 April 2018.*

Education and Training

The lack of funding for properly commissioned services has further serious effects. Trusts are not commissioned to provide FASD-specific services, so make little effort to ensure that staff have training in the condition. CCGs do not see training or education in FASD as their job, so do not commission it. **Just 22 CCGs, some 13.25% of respondents, told us they expect the Trusts they commission to provide education and training on FASD**. A number of CCGs said they expected Trusts to provide training for staff, without specifying any detail or explaining how this would be done with no funds available in the absence of commissioned services. Those who did provide details discussed only training of midwives and maternity professionals. While this is important, and NOFAS-UK has been involved in educating more than 16,000 midwives over recent years, it is only part of the picture. There is an urgent need to train GPs to recognise FASD and refer potential cases to paediatricians and adult neurodevelopmental specialists. NOFAS-UK has a current project focused on GP awareness, but much more needs to be done, beginning in medical schools and continuing through ongoing professional training.

Only 24.55% of NHS Trusts told NOFAS-UK that they provide training in some form on FASD for their staff. The vast majority of those were of midwives, with some training for paediatricians. There was very little systematic in-house training or recognition of the need for it. There is also a need to train specialist staff including nurses, psychologists, speech and language, physical and occupational therapists, learning disability teams and others. Social workers and midwives must be trained on how to interview women in a supportive way regarding alcohol use and taught to routinely mention maternal alcohol consumption in case notes. Much of this needs to be done at medical school, degree and post-graduate training level. But it is clear that CCGs do not see continuing professional education on FASD as their role at present.

An exploratory, small poll of GPs by NOFAS-UK showed:

- 41% of GPs said they have not received clear guidance from their local Clinical Commissioning Group regarding a pathway for diagnosis and support of FASD.
- When asked if they felt confident that all those with a Foetal Alcohol Spectrum Disorder are being diagnosed properly, the numbers show a deep uneasiness – only 23% strongly agreed, 28% somewhat agreed. An alarming 30% of GPs either somewhat or strongly disagreed that those with FASD are being properly diagnosed, with 19% neither agreeing nor disagreeing.
- Only 31% of the GPs said they had in-depth education regarding FASD in their medical school training – most said their education on FASD was brief (57%) or they had none at all/couldn't remember (12%).
- The respondents to this survey identified the most effective ways for GPs to learn more about FASD would be through Clinical Commissioning Group-organised sessions for their protected learning time and through online courses.[19]

Further research needs to be done to assess the level of understanding among relevant medical professionals. The NOFAS-UK poll was limited in its reach, but the RCGP or BMA could perhaps get a fuller picture through polling their members.

Anecdotally, we know that many families are denied referral for diagnosis because a child is "too tall" or "too pretty" or for a variety of reasons that show the lack of training.

"So my GP refers my daughter to paeds.
Receive an appointment letter. Then a week later, a cancellation letter as won't help with anything to do with FASD it appears."
Parent, in support group (reprinted with permission)

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[19] Source: The study was conducted by OnePoll between 22 August 2017 and 1 September 2017 and polled 150 GPs that work in England. Participants were recruited online and were paid to participate.

This lack of understanding and training of GPs regarding FASD means that many people are never referred to specialist services, or even to community paediatricians for FASD. People go undiagnosed or misdiagnosed as physicians and others are unable to recognise the condition.

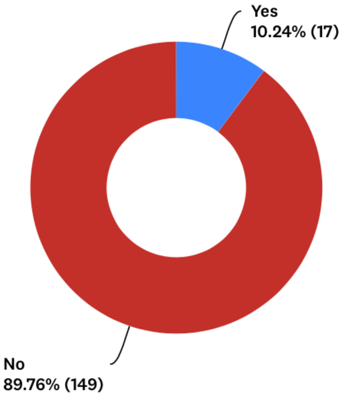
When therapies are made available by agencies such as CAMHS, they are often inappropriate and indeed damaging, as even senior staff have little or no training and experience in dealing with people with FASD. Therapies that may work for those with Autism Spectrum Disorders can be completely counterproductive for someone with FASD, even if they present with traits of ASD. Professional training is vital to rectifying the damage that is currently being done.

An audit needs to be done of the level of CAMHS personnel training regarding FASD. Anecdotally, we hear repeated and consistent stories of devastating interactions for those with FASD and their families in CAMHS. This all has profound negative affect on already struggling families.

Identifying Local Need

It is absolutely essential that people with an FASD, birth mothers, as well as parents and carers are involved in planning commissioning arrangements, in developing and considering proposals for change and in decisions affecting the operation of commissioning arrangements.

Without research into the condition, CCGs are unaware of the scope of the problem. They cannot understand the prevalence of drinking during pregnancy, the prevalence of people born with an FASD, the range of conditions affecting those with an FASD in their area, the need for paediatric and adult support services for those individuals, their families and carers, or the way in which those fortunate enough to gain access to existing services may use resources inappropriately or receive treatment or therapies that are inappropriate for them and cause harm requiring further support.



IS THE CCG INVOLVING INDIVIDUALS WITH FASD OR THEIR CAREGIVERS IN PLANNING OR DEVELOPING PROPOSALS

RECOMMENDATION: The National Institute for Health Research should invest in research on FASD, as it has on autism, with a view to fulfilling their mandate to improve the health and the wealth of the nation. This research is needed to help inform CCGs and other policy makers.

The need to include stakeholders in all phases of researching and planning projects is a point the UK and EU Birth Mothers Network-FASD has been particularly advocating for many years, since too many assumptions are made about why women drink in pregnancy and the type of support they might need. There has been some encouraging progress in Manchester, the North East, London and Blackpool, to name a few examples of places that have engaged with stakeholders while exploring prevention messaging and programmes for improving pregnancy outcomes.

Who is Responsible for FASD in CCGs?

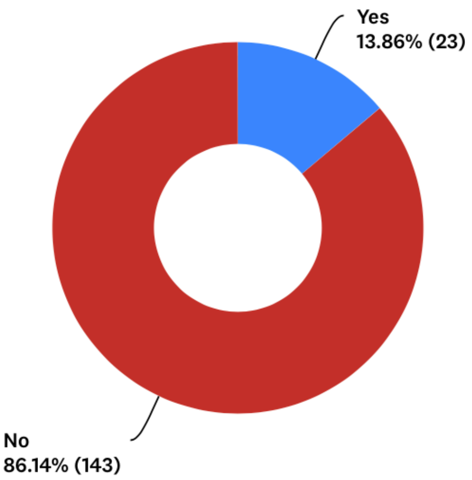
This situation is exacerbated as **only 23 CCGs (13.86% of responses processed) have an FASD lead**, and almost all of those are maternity or children's services leads, with FASD as part of their responsibility. There are therefore very few people who even have a responsibility to try to understand the existing needs and to provide services for those affected. And the need for adult services, or even the fact that there is a need for adult services, goes completely unrecognised and unmet.

RECOMMENDATION: All CCGs and NHS Trusts should appoint an FASD lead who can work with the Department of Health lead to ensure the full range of service needs are met.

Post-Diagnosis

Only 19% of CCGs indicated in responses to NOFAS-UK that they expect the service providers they commission to provide **post-diagnostic services** appropriate for those with an FASD.

With CCGs not specifically commissioning the services needed by people with FASD, it follows that **only 31 Trusts (18.5%) told NOFAS-UK that they provided post-diagnostic care for those with the condition**. Some Trusts, for example the Camden and Islington NHS Foundation Trust, simply said they are not commissioned to provide services for FASD, while others like the Doncaster and Bassetlaw Teaching Hospitals said there is no clear post-diagnostic care pathway for FASD. Cambridge University Hospitals said that they have neither budget nor care pathway.



IS THERE A LEAD PERSON IN THE CCG ON FASD?

Only 31 Trusts (18.5%) told NOFAS-UK that they provide post-diagnostic care for those with FASD.

The majority across the country from the Royal Cornwall Hospitals to the Chesterfield Royal Hospital simply said they hold no information on FASD services, or do not code post-diagnostic services to record information. This does not mean that people with FASD are not accessing some services. It simply means that the care they do access is disjointed and in some cases completely inappropriate. Children are generally seen first through community paediatricians who, for the most part, lack the training to recognise most cases of FASD.

Referrals to necessary services like Occupational Therapy, Speech and Language Therapy, Physiotherapy, learning disability and children's mental health service is *ad hoc*, uncoordinated and not managed for the complex needs of a person with an FASD. The lack of training for staff referred to elsewhere means that even if a service is accessed, there is no guarantee it will be of benefit to a person with an FASD as therapies that work for some conditions can be positively harmful in an FASD context. Anecdotal but consistent feedback is that CAMHS is particularly weak on FASD with often devastating impact as the children and families are often at peak crisis when they reach this stage.

There are some bright spots. The Lothian NHS Board in Scotland told NOFAS-UK that a business case for an FASD service will be drawn up following conclusion of Edinburgh pilot scheme and publication of the SIGN guidelines. This will provide resources for a Lothian wide service. Airedale NHS Foundation Trust in Yorkshire reported that while they have no formal diagnostic pathway, the local community paediatric team have an awareness of and expertise in FASD. They are working with colleagues across Yorkshire to see what an assessment model should look like, taking into account expertise from Australia, Canada and the recent Scottish SIGN guidance. Their aim is to establish a multi-disciplinary team with child therapists, OT, SALT, clinical/educational psychologist/paediatricians.

If Airedale is successful in establishing this model within the NHS in England then it might serve as a model across the whole country. The National FASD Clinic could play a vital role in education and training, initial supervision and expert input, supporting the establishment of multi-disciplinary clinics and supporting high standards of diagnosis and care. This will not represent a new cost, rather a more effective use of resources that are already being inefficiently used in a piecemeal fashion with a resulting postcode lottery, or worse a situation where those parents or carers who push the hardest get the best access to services and would support recommendations put forward by the BMA.

Where private diagnosis and assessment centres exist, such as with the new Centre for FASD in Suffolk, CCGs could commission their services to make these services freely accessible via the NHS.

Prevention Education

Many CCGs appear to regard **prevention education** as the responsibility of public health authorities alone. At best, CCGs expect providers to give warnings about the risks of alcohol consumption for her baby when a woman is seen by maternity services at booking, several weeks into a pregnancy. **Only 37.8% of CCGs said they expected maternity services to give prevention messaging consistent with the most up to date CMOs guidance** that "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" and "Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk."

Superdad Paul from Grange Park knows no amount of alcohol is safe during pregnancy.

He's going alcohol-free with his partner to help protect their baby from:

- Miscarriage
- Birth defects
- Learning difficulties
- Behavioural issues
- Emotional and physical problems

For more advice talk to your midwife, GP or visit **blackpoolbetterstart.org.uk**

BLACKPOOL BETTER START'S "BE A HERO" CAMPAIGN IS AN EXAMPLE OF BEST PRACTICES

Blackpool Better Start has recently rolled out an encouraging new public health campaign, "Be Your Baby's Hero, Keep Alcohol to Zero."[20] It was based on extensive consultation, including with stakeholders, and it is funded in cooperation with Blackpool Council. It shows that it is possible to develop exciting partnerships across local areas, working in cooperation with appropriate medical professionals.

Only 42.51% of NHS Trusts that responded to the survey said they provide prevention education advice in line with the 2016 CMOs guidance.

Without PSHE classes covering alcohol risks including FASD and with little public health education being done on the topic, perhaps the most concerning aspect of the advice from NHS Trusts is that, for the most part, it comes only from midwives at pregnancy booking. This means that a significant number of babies have already been exposed to alcohol before a woman is told about the risks this carries. This issue needs consistent visibility from public health officials. It was especially concerning when in 2018 Professor Dame Sally Davies's tenth report[21] as Chief Medical Officer for England considered what the state of the public's health in England in 2040 could look like and the report highlighted the importance of tackling smoking in pregnancy but completely omitted addressing alcohol in pregnancy. While we understand this doesn't necessarily represent a lack of commitment from Dame Sally or the department to addressing FASD, it is yet another glaring missed opportunity to signal the salience of this issue.

That said in some areas progress has been made and best practices do exist. For example, Tameside and Glossop Integrated Care NHS Foundation Trust works with other authorities in Greater Manchester and uses the ground breaking Maternity Alcohol Management Algorithm to assess and warn about risk. This issues very clear warning about the FASD risk and explains it in simple terms, making it a very effective education tool.

In contrast, Mid Cheshire NHS Foundation Trust reports it is still using the old CMO guidelines which merely advise restricting alcohol consumption in pregnancy as far as possible. This is also the advice reported by the City Hospitals Sunderland NHS Foundation Trust. Mid Cheshire further reports that maternity services warn women that consuming "too much alcohol" can cause Foetal Alcohol Syndrome, but there are no warnings about lower levels of consumption and all conditions in the FASD spectrum.

Some Trusts provide confusing and contradictory advice. For example, the East Kent Hospitals University NHS Foundation Trust replied that it advises women not to drink in pregnancy and provides

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[20] https://blackpoolbetterstart.org.uk/be-hero/

[21] Professor Dame Sally Davies, "Annual report of the Chief Medical Officer 2018: health 2040 – better health within reach," 21 December 2018, https://www.gov.uk/government/publications/chief-medical-officer-annual-report-2018-better-health-within-reach?

leaflets from NOFAS-UK reflecting the CMO guidance but also stated that it is apparently using old material from the Royal College of Obstetricians and Gynaecologists recommending that low levels of alcohol consumption are safe (which has since been changed). It is no wonder that some women do not understand the information they are given.

The importance of prevention education is shown by a nationally representative poll[22] of 2,000 adults NOFAS-UK recently commissioned to see if people could correctly identify the CMO guidance.

While 70.15% of the public thought that the safest course is to drink no alcohol at all, in the 18-34 age group where pregnancy is most likely, as many as 34.3% did not know that this is what the Chief Medical Officers advise, with well over 20% believing that some alcohol consumption is safe during pregnancy.

In the North East, where the FASD Network UK has over years maintained close and sustained cooperative work with local authorities on FASD education,[23] over 85% of respondents in that region identified the CMOs 2016 guidance. This suggests what a good public health education effort working in cooperation with the Third Sector can achieve.

RECOMMENDATION: NOFAS-UK recommends that the Department of Health, Public Health England and the Department of Education need to do far more to educate the public about the risks of FASD from alcohol consumption in pregnancy, This should be a mandatory part of the PSHE curriculum in schools, with GPs and midwives raising the topic with patients from their teens onwards. All Trusts need to consistently reference the CMO guidance to all patients. Posters with the guidance should be displayed.

Specialist Providers and FASD

There are a number of issues of particular concern around the provision of specialist services where NHS Trusts seem to believe FASD is not an issue that concerns their service. This thinking is potentially dangerous for those with FASD and overlooks the rights people with this neurodevelopmental disability have to access specialist services. Often this is based on the false assumption that there are no interventions or adjustments that are suitable for people with FASD.

For example, all the Ambulance Trusts that responded did so saying their services were not relevant to FASD. However, ambulance personnel, as with other emergency responders, may well be dealing with a person with an FASD without even knowing it. Under stress, a person with FASD generally reacts from the fight or flight part of the brain and may well become abusive or violent, or attempt to flee the scene, if handled improperly by an emergency responder. If, as seems to be the case, training and expertise on the management of a person with an FASD under stress is missing in most or all cases, then this will prove a substantial issue. There is a need for training for ambulance staff, as much as any other medical personnel, to be able to recognise a potential case of FASD and how to manage a person with the condition in a stressful situation. There is also possibly a need for a nationally agreed card, bracelet or other identifier, that can show to a first responder that the person they are dealing with has an FASD.

Most, if not all, community healthcare Trusts responded that they provided no services for FASD. This is extremely concerning since these Trusts are responsible for providing services including CAMHS, learning disability services, occupational therapy, physiotherapy, and speech and language therapy amongst others which are vital to the care of people with FASD.

NHS England should ensure that these specialised services include capacity to meet the needs of those with FASD.

In a recent poll, approximately one-third of adults of child-bearing years could not identify current CMO guidance on alcohol in pregnancy.

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[22] Source: OnePoll, nationally representative survey of 2,000 UK adults, 11/04/2019 - 15/04/2019 (single-question research commissioned by NOFAS-UK)

[23] See for example, Greaves, Z., “Healthcare Needs Assessment: Fetal Alcohol Spectrum Disorders in the North East of England,” Public Health England, undated.

Most, if not all, community healthcare Trusts responded that they provided no services for FASD. This is extremely concerning since these Trusts are responsible for providing services including CAMHS, learning disability services, occupational therapy, physiotherapy, and speech and language therapy amongst others which are vital to the care of people with FASD.

Moorfields Eye Hospital responded that as a specialist service it provided no services for FASD. In one sense this is true, but at a minimum the learning disability staff of the Trust need to understand the care and management of patients with an FASD or results could be tragic. In one case that NOFAS-UK is aware of, at a hospital other than Moorfields, a child with FASD needed treatment for an abscess behind his eye. Staff at that hospital – including the learning disability team - had no understanding of the profile of a person with an FASD or how best to manage them in stressful circumstances. As a result, the child became non-compliant with treatment as he experienced meltdown after meltdown due to stress and anxiety. He was unable to stay in hospital, was sent home with IV antibiotics (a potentially dangerous situation, especially for a person with a disability) and could not have a needed second operation. His eye was in danger. There is a need for Moorfields, and other specialist providers, to have staff that understand FASD and are able to advise general hospitals in the care of people with the condition.

Specialist children's hospitals are another case in point. Great Ormond Street Hospital did not respond to the survey, despite several requests. From anecdotal experience we know that the hospital's record in FASD diagnosis is mixed. Some have had a good experience, while others have been categorically told their child did not have an FASD, only for a diagnosis of FAS with full facial features to be given later elsewhere. Alder Hey Children's Hospital in Liverpool replied that they could not answer our survey as they are not commissioned to provide any services for FASD. Parent/carers have told us of extremely poor experiences with services from the hospital. While FASD is not just a paediatric question, world leading children's hospitals should be providing a better service for those with the condition.

How this impacts one 19-year old

One former looked after young person, since subject to a Special Guardianship Order, eventually managed to be successfully referred to the Cambridge Universities Hospitals Trust, Medical Genetics Service, supported by her parents and GP, who all are very experienced in supporting people affected by FASD. In December of 2018 the consultant produced his final report. In the assessment he used photocopies of the Canadian diagnostic pathway to investigate the possibility of her being affected by FASD and concluded that her presentation was consistent with having an Alcohol Related Neurodevelopmental Disorder, a sub division of FASD. He correctly noted that she had been exposed to alcohol in utero, identified associated behavioural and cognitive difficulties and even was able to note some physical indications of the clinical signs of FASD.

However, his final recommendation was to refer her to the National FASD & Behavioural Clinic in Surrey so that, 'a formal assessment could be made by a health professional experienced in diagnosing … FASD' because he felt he did not have the expertise to do it. Therefore, despite a leading UK international teaching hospital recognising numerous features associated with an FASD, this young person may have to wait 12 months or more for a formal diagnosis, if this ever happens. In discussion with the Cambridgeshire & Peterborough Clinical Commissioning Group relating to funding this recommendation, they were insistent that they did not have a referral pathway for adults with the condition and had regarded FASD as a paediatric condition. This fact borne out by their response to the Freedom of Information request which stated that diagnosis 'will take place via normal diagnostic routes for developmental issue'. In the same response the CCG also states that it does not commission services from the National Clinic, which is not in fact the case, as several residents in both Peterborough and Cambridgeshire have been assessed in the National Clinic funded by the NHS in recent years - indicating that the referral pathways are unclear and that records of accessing the clinic are incomplete

For this particular young person it means that she continues to struggle with what has all but been diagnosed as an FASD, without having the official diagnosis to inform those working with her and she remains in limbo as she has done for 15 years since she was taken into care. This leaves her in a very precarious situation as she transitions into adulthood.

SIGNs of Change

Scotland has recently introduced SIGN Guidance 156, “Children and young people exposed prenatally to alcohol.” FASD Scotland and other stakeholders were engaged in developing these guidelines which provide “evidence-based recommendations on measurement of alcohol consumption in pregnancy and consensus-based recommendations on:

- identification of children at risk of FASD
- criteria for diagnosis and use of FASD as a descriptor
- the medical assessment
- physical examination
- sentinel facial features
- neurodevelopmental assessment
- the multidisciplinary assessment team
- special considerations in the neurodevelopmental assessment
- management and follow up of children and young people affected by PAE.

Detailed treatment options for individuals affected by prenatal alcohol exposure are not included.”

SIGN guidance draws upon international best practices as well. One major change is that it does away with the confusing alphabet soup of old-school diagnoses. As in Canada and elsewhere, “FASD” will now be the diagnosis, with or without “sentinel facial features.”

The UK Department of Health has asked NICE to consider these SIGN guidelines to see if they can be applied in England. There may be some adjustments needed, but building upon UK-based best practices like this can significantly address in a timely way some of the most egregious gaps by putting in place pathways for diagnosis and support.

A related development is the Fetal Alcohol Advisory and Support Team in NHS Ayrshire & Arran and funded by the Scottish Government, whose aim is “to work with multidisciplinary teams in Health Boards across NHS Scotland to improve access to diagnostic services and improve clinician confidence.” They have published some exciting new materials, available at https://tinyurl.com/AyrFASD.

There is a lot that can be learned from exploring best practices across the UK, and the Department of Health has been actively meeting with leading practitioners, stakeholders and others, examining possible ways forward. Change is coming. But it requires parliamentary scrutiny and policy oversight to ensure it is on a scale that meets the need for this vulnerable population.

Hear Our Voices – Stakeholders Share Experiences

These issues matter greatly to the lives of individuals and families affected by FASD. We hear time and time again that people grow weary of fighting for services, for recognition of this neurodevelopmental disorder. A 2018 publication by the FASD UK Alliance and NOFAS-UK, “Hear Our Voices: Stakeholders Share Their Experiences With Policymakers,” outlined some of the concerns of the community.[24]

Parent/carers/guardians

A recent parent/carer survey[25] by the FASD UK Alliance asked what would improve wellbeing. Over 70% of respondents said that the most important thing would be for professionals to understand FASD and know how to support those with the condition. This is consistent with published research. Clearly, those with FASD and their families feel massively underserved by health professionals at present (please see the box on page 12 for additional insights.) CCGs also must take into consideration the impact of the lack of coherent policy and access to services on parents and carers who are quite often unfairly judged and put under great stresses as a result of the systemic failure to diagnose and properly support those with FASD. Services should be in place to help all parents and carers, including birth parents, access respite and other services.

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[24] FASD UK Alliance and NOFAS-UK, ““Hear Our Voices: Stakeholders Share Their Experiences With Policymakers,” http://www.nofas-uk.org/WP/wp-content/uploads/2018/05/HearOurVoicesPublication_FINAL2_ForWebsite.pdf

[25] “FASD Caregivers Survey,” FASD UK Alliance, February 2019 (unpublished). Survey designed by Ali McCormick and conducted amongst FASD UK members in February 2019. FASD UK is a closed group on Facebook with over 2200 members including people with FASD, parents, foster carers, those with an SGO and family members. The page provides an online support group role where advice and support can be crowd sourced from the community of those living with FASD.

Over 70% of parents/carers said that the most important thing to make their lives easier would be for professionals to understand FASD and know how to support those with the condition.

The second most important issue they identified would be for schools and educational professionals to understand FASD, something which will be impossible until the condition is routinely understood, recognised and diagnosed, with core services being widely available.

ANSWER CHOICES	RESPONSES	
Respite care so I can have a break	39.37%	176
Professionals who know about FASD & know how to help my loved one	70.02%	313
Funding to make home safer/more sensory-friendly	17.67%	79
Appropriate support in school/workplace for my loved one	53.24%	238
Greater understanding of FASD among family/friends	29.53%	132
More information on strategies to help my loved one	30.20%	135
Knowing my loved one will have access to support/benefits as an adult	54.14%	242
Help with my own mental health/depression/relationship strains	18.79%	84
Being able to keep outside employment while caring for someone with FASD	17.00%	76
Total Respondents: 447		

PARENT/CARERS - WHAT THREE THINGS WOULD MOST IMPROVE YOUR WELLBEING?

Looked after and previously looked after children/young people and adopted children

FASD disproportionately affects looked after children and those who have been adopted. While again, recent engagement with high-level officials on this issue (for example, a delegation organised by Adoption UK, and involving NOFAS-UK, met with Children’s Minister Nadhim Zahawi and addressed FASD in November 2018), there is a need for explicit action to ensure those involved with the care and adoptions systems better understand FASD.

For example, despite clear statements from government that the Adoption Support Fund can be used for FASD-related expenses, on the front-line this message has not permeated down to those local decision-maker who repeatedly deny ASF funding. The existence of ASF does not excuse CCGs from properly funding services. Diagnoses and initial assessments ideally should be done sooner. LAC paediatricians need explicit training in how to recognise and support those with FASD and all children in care should be routinely screened for FASD, with EHCPs put in place for those who need them.

For over 10 years the Department for Education (Department for Children, Schools & Families) statutory guidance for the annual looked after children’s medicals has been that the health practitioner making the assessment should consider whether FASD is a contributor to the characteristics that the child shows. This annual review (6 monthly in under 1's) informs the adoption medicals. Sadly without expertise, information and the commissioning of services for FASD the reality is that this statutory guidance is often over looked.

In October 2015 Coram BAAF published[26] a UK informed journal on FASD in fostering and adoption. This recorded that in a screening study in Peterborough 34% of the then looked after population were possibly affected by FASD and 75% of those who were freed for adoption. This means that in this vulnerable population accurate and informed medical advice about childhood affects and long term impacts into adulthood is vital. This report records that fact that once again this is in short supply.

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[26] Identifying children at risk of FASD in Peterborough: Working in a community clinic without access to gold standard diagnosis Gregory, Reddy & Young Adoption & Fostering Quarterly Journal Special Edition: Foetal Alcohol Spectrum Disorders (FASD), Vol 39, October 2015.

Birth mothers

As previously mentioned, birth mothers have been leading the way on research and consultation regarding FASD prevention, encouraging ways to move services beyond the stigma toward addressing the needs of women in a holistic manner. At recent policy roundtables, the founder of the UK EU Birth Mothers Network-FASD, the late-Pip Williams identified areas of best practices and laid out clearly defined next steps for prevention work.[27] She noted too many women who drank during pregnancy avoid coming forward with concerns about their children due to lack of training of social workers and fear of having their children removed.

Adults with FASD

Adults with FASD consistently report the need for better services and understanding of FASD. It is important to remember that the vast majority of those 6-17% of the Children of the 90s cohort estimated by Dr Cheryl McQuire to have an FASD remain undiagnosed. There are people in every community, every constituency, being underserved by the medical and public health bodies who are supposed to promote their health and wellbeing.

Adults with FASD Highlight Need for Better Services

- 100% strongly agreed/agreed: "As an adult, I struggle because people don't understand my condition."
- 72% strongly agreed/agreed: "My doctors don't understand FASD."
- 79% of those who have used these services strongly agree/agreed: "Professionals in mental health and/or addiction services do not understand my FASD (or suspected FASD)"
- 77% strongly agreed/agreed: "I struggle to access benefits, people making decisions don't seem to understand my needs."

- “Totally struggle with services assessing my needs around FASD. They don’t use correct assessment“

- “Misdiagnosis just makes it worse”

- “Try to help the condition to be recognised as a disability and have access to more benefits”

- “I was supported through foster care but as I became independent, I really started to struggle. After a particularly difficult time sofa-surfing I was prescribed antidepressants and got support from mental health team to secure a bedsit. Earlier diagnosis could have helped to sign post me to support and help.”

- “I don’t want to be labelled but [a diagnosis] would help me and others to help better understand why i am like I am and why I do the things I do, to get more support in areas where I need it.”

- “Children, teenagers and adults with FASD need more support within education and more help and support transitioning into adulthood.”

- “FASD is a time bomb waiting to explode. There must be so many people out there now with wrong diagnosis and without any understanding of what is wrong with them.”

- “I need help.”

Source: “Insights from UK Adults with FASD(or Suspected FASD),” 22 adults with FASD shared their views with the National FASD Advisory Committee (comprised of adults with FASD), collected Sept – Oct 2018. Insights were presented in a meeting 22 October 2018 with Deputy Chief Medical Officer Prof. Gina Radford.

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[27] See for example: Pip Williams in “FOETAL ALCOHOL SPECTRUM DISORDERS: Future policy development on issues relating to FASD,” A Roundtable Discussion with FASD Stakeholders Convened and chaired by Professor Gina Radford, Deputy Chief Medical Officer National Liberal Club, London, 22 October 2018. http://www.nofas-uk.org/WP/wp-content/uploads/2018/11/20181022_Report_FIN.pdf

Conclusion

This report has highlighted significant areas of concern, demonstrating across-the-board confusion, inaction and mixed signals through the NHS and healthcare system with regard to FASD prevention, diagnosis, assessment and support.

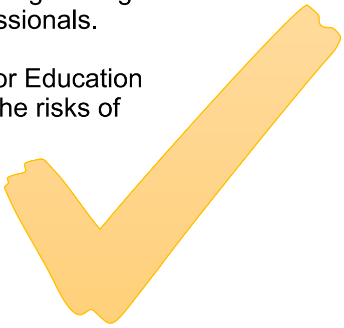
What it does not show is the desperation this situation creates in the lives of young women with FASD who are pregnant and living on the streets, in the lives of families who are at breaking point because schools and services see only behavioural issues because their loved one has never received proper assessment for underlying organic brain damage, in the lives of children who try hard every day to do what's right in a world that simply fails to meet their needs. There is heartbreak and trauma and family breakdowns underlying these statistics.

But the good news is this situation can and is changing.

Addressing FASD is one area where policy makers can have profound impact on the lives of their constituents. CCGs that get this right can revolutionise the care for an under-served population struggling with a neurodevelopmental disability. If government really has 'not an ounce of complacency,' then this is an area where transformative change can happen in our lifetimes.

Recommendations

- NOFAS-UK recommends a Parliamentary inquiry to explore the situation outlined in this report.
- NOFAS-UK calls on government to issue a Green Paper, using the consultative process to initiate a debate both inside and outside Parliament about the change needed to improve FASD prevention and services across government.
- NOFAS-UK calls upon the Department of Health, NICE, Royal Colleges and other relevant bodies to use their considerable expertise to help struggling CCGs and healthcare professionals train up on FASD and to better delineate pathways for diagnosis and support.
- There is an immediate need for CCGs to commission services for people with FASD, to ensure that health service providers understand the magnitude of the problem and to put in place oversight to track how they are making provision for the many and varied needs of those with FASD. Each CCG, as a start, should appoint a lead on FASD and arrange for FASD training via protected learning time.
- Improved record-keeping about FASD must be an integral part of any Department of Health action moving forward.
- The National Institute for Health Research should invest in research on FASD.
- Specific services should be commissioned for FASD and budgeted separately to ensure they are delivered. If it is considered more appropriate to provide for FASD needs through block commissioning of services, then expectations for services for adults and children with FASD must be specified clearly in the terms of that contract.
- Further research needs to be done to explore the level of understanding among relevant medical professionals and to improve training of all healthcare professionals.
- The Department of Health, Public Health England, the Department for Education and senior officials need to do far more to educate the public about the risks of FASD from alcohol consumption in pregnancy, and that this is should be a mandatory part of the PSHE curriculum in schools, with GPs and midwives raising the topic with patients from their teens onwards. All trusts need to consistently reference the CMO guidance to all patients. Posters with the guidance should be prominently displayed.



#HearOurVoices

Annexes

Sample questions sent to CCGs

Dear [x] Clinical Commissioning Group,
I am writing as a volunteer researcher for the National Organisation for Foetal Alcohol Syndrome-UK (www.nofas-uk.org) to make a request for information under the Freedom of Information Act. I am working in cooperation with an ad hoc group of leaders from the organisation and other experts to frame and shape this research project and to analyse the information we receive.
Background

In February 2017, Lord Boateng asked the government “what assessment they have made of the measures adopted in Scotland which provide guidance and support for children and young adults affected by foetal alcohol spectrum disorders.” Lord O’Shaughnessy replied that “Early intervention services can help reduce some of the effects of Foetal Alcohol Spectrum Disorders (FASD) and prevent some of the secondary disabilities that result. Responsibility for commissioning these services lies with clinical commissioning groups. [Hansard, Written Question HL5052, 10 February 2017]

This government policy was reiterated in July 2017 when Lord Campbell-Savours asked the government “what support they are providing for persons whose condition has been described as foetal alcohol spectrum disorder.” [Hansard, Written Question HL500 and Written Answer, 18 July 2017]

In response, Lord O’Shaughnessy for the government wrote that “It is recognised that Foetal Alcohol Spectrum Disorders (FASD) can have a significant impact on the early development of children, their behaviours and their life chances. Early intervention services can help reduce some of the effects of FASD and prevent some of the secondary disabilities that result. Responsibility for commissioning these services lies with clinical commissioning groups.” This was again repeated on 8 May 2018 by Steve Brine, Parliamentary Under-secretary at the Department of Health and Social Care. [Hansard, Written Question 139045, 8 May 2018]

The following conditions fall under the Foetal Alcohol Spectrum Disorder (FASD) umbrella: Foetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Alcohol-Related Birth Defects (ARBD), Foetal Alcohol Effects (FAE) and partial Foetal Alcohol Syndrome (pFAS)) or neurodevelopmental disorders linked to prenatal alcohol exposure (NDPAE)

Request for Information
In the light of these government statements that CCGs are responsible for commissioning services I would like to ask:
1)Please provide copies of any policies your CGG has on the commissioning of services for those with an FASD.
2)What services has your CCG commissioned to meet the ‘reasonable requirements’, as is your duty under Section 3 NHS Act 2006, of those in your area who have or may have Foetal Alcohol Spectrum Disorders as a result of antenatal exposure to alcohol, and what is your CCG doing to secure improvement in the physical and mental health of persons with Foetal Alcohol Spectrum Disorders and for the prevention, diagnosis and treatment of FASD (as is in your power under Section 3A NHS Act 2006)? Please release any information you hold concerning provision for:

a. prevention education following the Chief Medical Officers’ guidelines that the safest course is not to drink while pregnant or attempting to become pregnant;
b. diagnosis for both children and adults;
c. post-diagnostic care in the years 2013- 2018 from professionals including, but not limited to, paediatricians, GPs, nurses, psychologists, occupational therapists, speech and language therapists, mental health services and other disability support services to provide specialised intervention services for patients on the FASD spectrum across their lifespan?

3) Please release any information concerning how is your CCG exercising its duty (as specified under Section 14R NHS Act 2006) to securing “continuous improvement in the quality of services provided” to individuals with Foetal Alcohol Spectrum Disorders “for or in connection with the prevention, diagnosis or treatment” of FASD?
4) What is the budget for commissioned services for FASD in the current financial year? What was the budget in financial years beginning in 2013, 2014, 2015, 2016 and 2017?
5) Please release any agreed plans for service expansion for future years.

6) Has your CCG conducted, commissioned or assisted the conduct of research into any matters relating to the causation, prevention, diagnosis or treatment of Foetal Alcohol Spectrum Disorders, as is in your powers according to Section 5 NHS Act 2006 Schedule 1 (paragraph 13).
7) Does your CCG commission services from the National FASD Clinic? If so, what is the budget for this in the current financial year?
8) Please release any information concerning ways in which your CCG is fulfilling its duty (specified under Section 14Z, NHS Act 2006) to promote education and training related to FASD?
9) Do you have a lead person in your CCG on FASD? Please provide the name and role of the person responsible.
10) Please release any information concerning the steps are you taking or have you taken (according to your duty under section 14Z2 of the NHS Act, 2006), to involve individuals with FASD or their caregivers in "planning commissioning arrangements; in the development and consideration of proposals for change; in decisions affecting the operation of commissioning arrangements where implementation would have an impact on the manner in which services are delivered or the range of services available."?
11) How many inquiries/requests/letters have you received from medical practitioners or patients/families in your area related to FASD in the years 2013-2018?

If you are considering rejecting this request on the grounds of the costs of responding exceeding the statutory limits then please respond to as many of the numbered items as possible within the limit, in theorder they have been presented.

Thank you in advance for your answers.
Yours faithfully,

Sample questions sent to NHS Trusts

Dear [x] Trust,

I am writing as a volunteer researcher for the National Organisation for Foetal Alcohol Syndrome-UK (www.nofas-uk.org) to make a request for information under the Freedom of Information Act. I am working in cooperation with an ad hoc group of leaders from the organisation and other experts to frame and shape this research project and to analyse the information we receive.

Background
In February 2017, Lord Boateng asked the government “what assessment they have made of the measures adopted in Scotand which provide guidance and support for children and young adults affected by foetal alcohol spectrum disorders.” Lord O’Shaughnessy replied that “Early intervention services can help reduce some of the effects of Foetal Alcohol Spectrum Disorders (FASD) and prevent some of the secondary disabilities that result. Responsibility for commissioning these services lies with clinical commissioning groups. [Hansard, Written Question HL5052, 10 February 2017]

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In response, Lord O’Shaughnessy for the government wrote that “It is recognised that Foetal Alcohol Spectrum Disorders (FASD) can have a significant impact on the early development of children, their behaviours and their life chances. Early intervention services can help reduce some of the effects of FASD and prevent some of the secondary disabilities that result. Responsibility for commissioning these services lies with clinical commissioning groups.” This was again repeated on 8 May 2018 by Steve Brine, Parliamentary Under-secretary at the Department of Health and Social Care. [Hansard, Written Question 139045, 8 May 2018]

The following conditions fall under the Foetal Alcohol Spectrum Disorder (FASD) umbrella: Foetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), Alcohol-Related Birth Defects (ARBD), Foetal Alcohol Effects (FAE) and partial Foetal Alcohol Syndrome (pFAS)) or neurodevelopmental disorders linked to prenatal alcohol exposure (NDPAE)

Request for Information
In light of the above information I would like to ask you to provide:
1) Copies of any policies that the Trust has on the prevention of FASD, and on the diagnosis and post-diagnostic care pathway for patients with an FASD. Also your policy on the training of Trust personnel to manage patients with FASD.
2) Any information you hold on services your Trust provided for FASD for
a. prevention education following the 2016 Chief Medical Officers’ guidelines that the safest course is not to drink while pregnant or attempting to become pregnant;
b. diagnosis for both children and adults;
c. post-diagnostic care in the financial years beginning 2013, 2014, 2015, 2016, 2017 and 2018.
3) Information on the number of Doctors in your Trust who currently provide diagnostic and/or post-diagnostic services for FASD? Please provide their names and posts. Whether your Trust employs specifically trained professionals, including but not limited to nurses, psychologists, occupational therapists and speech and language therapists, to provide specialised services for patients on the FASD spectrum? If so, in what specialties, and how many? Please provide their names and posts.
4) Information on training provided to personnel in your Trust on FASD, or provided by others and accessed by your personnel.
5) Information you hold on whether your Trust sends patients for FASD diagnosis to the National FASD Clinic in Surrey (https://www.fasdclinic.com/)? Did your refer any patients to the National FASD Clinic in 2013, 2014, 2015, 2016 and 2017, and in 2018, and if so, how many in each year?
6) What was your budget for services for FASD in each financial year since that starting in 2013 and including the current financial year?
7) Please provide copies of any agreed plans you have to expand the budget or services in coming years.

If you are considering rejecting this request on the grounds of the costs of responding exceeding the statutory limits then please respond to as many of the numbered items as possible within the limit, in the order they have been presented.
Yours faithfully,

Summary of CCG Responses Received

CCG Responses

1) Name of CCG	2) FASD Policy	3) Prevention services	4) Diagnosis for children	5) Diagnosis for adults	6) Comments on diagnosis	7) Post-diagnostic care for FASD	8) 'Continuous improvement'	9) Budget in 2013 - 2018	10) Plans to expand services	11) Research on FASD	12) National Clinic	13) Education/training	14) FASD lead	15) Name and role of lead	16) Involve stakeholders	17) Requests received re FASD 2013-2018
Barnsley CCG	No	Yes	No	No	Nothing specific commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Basildon and Brentwood CCG	No	Yes	No	No	Diagnosis not directly commissioned by the CCG	No	Yes	No	No	No	No	No	Yes	Children's Commissioning Lead.	Yes	0
Bath and North East Somerset CCG	No	Yes	Yes	No	"Affected babies may be diagnosed at the RUH or later by community paediatricians within Virgincare." Nothing for adults	Yes	No	No	No	No	No	N/A	No	N/A	No	0
Berkshire West CCG	No	No	Yes	Yes	Mental Health, Learning Disability and Neurology "able to identify and treat the difficulties associated with FASD."	Yes	No	No	No	No	No	No	No	N/A	No	0
Bexley CCG	No	No	No	No	None commissioned	No	Yes	No	No	No	No	No	No	N/A	No	0
Blackburn with Darwen CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Blackpool CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Bradford City CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Brent CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Brighton and Hove CCG	No	Yes	Yes	Yes	Where an FASD is suspected a child will be referred to the Children's Development Centre for assessment by community paediatricians, and where a multi-disciplinary team can agree appropriate interventions and care. Neonatal cases can be referred to the Baby Unit where appropriate, and women at risk can be seen by the lead neonatologist. Older children/teenagers and young adults who come through the CAMHS route are usually referred to the National FASD Clinic.	Yes	Yes	Yes	No	No	No	Yes	Yes	Anne Foster, Mental Health and Child and Maternity Services Lead	No	Yes - 1 (2014)
Bristol, North Somerset and South Goucestershire CCG	No	Yes	No	No	Community health services are generally commissioned to provide diagnosis as appropriate. Nothing particular is commissioned for FASD.	No	No	No	No	No	No	No	No	N/A	No	0
Bromley CCG	No	Yes	No	No	Nothing commissioned but will entertain individual funding requests, and community services can diagnose.	No	No	No	No	No	No	No	No	N/A	No	0
Buckinghamshire CCG	No	No	Yes	Yes	Mental Health, Learning Disability and Neurology "able to identify and treat the difficulties associated with FASD."	Yes	No	No	No	No	No	No	No	N/A	No	0
Bury CCG	No	No	Yes	No	None specifically commissioned, but diagnosis available through paediatric services or learning disability service. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	Info not held
Cambridgeshire and Peterborough CCG	No	No	No	No	No specific diagnostic services commissioned	Yes	Yes	No	No	No	No	No	No	N/A	Yes	Yes
Cannock Chase CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	N/A	No	N/A	No	0

1) Name of CCG	2) FASD Policy	3) Prevention services	4) Diagnosis for children	5) Diagnosis for adults	6) Comments on diagnosis	7) Post-diagnostic care for FASD	8) 'Continuous improvement'	9) Budget in 2013 - 2018	10) Plans to expand services	11) Research on FASD	12) National Clinic	13) Education/training	14) FASD lead	15) Name and role of lead	16) Involve stakeholders	17) Requests received re FASD 2013-2018
Canterbury and Coastal CCG	No	Yes	No	No	Information not held	No	No	No	No	No	No	Yes	No	N/A	Yes	Info not held
Castle Point and Rochford CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Chorley and South Ribble CCG	No	No	Yes	No	No diagnostic service commissioned, but Community Paediatricians can diagnose if they are aware of FASD. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	0
City and Hackney CCG	No	No	No	No	Information not held	No	No	No	No	No	No	No	No	N/A	No	0
Coastal West Sussex	No	No	No	No	None commissioned, IFR possible	No	No	No	No	No	No	No	No	Falls under Planned Care Commissioning Team	No	Info not held
Corby CCG	No	No	No	No	Information not held	No	No	No	No	No	No	No	No	N/A	No	Info not held
Crawley	No	Yes	No	No	None commissioned but diagnosis possible through IFR	No	No	No	No	No	No	No	No	N/A	No	Info not held
Croydon CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Darlington CCG	No	No	No	No	None provided, stated to be responsibilityof local NHS Trusts	No	No	No	No	No	No	No	No	N/A	No	0
Dartford Gravesham and Swanley CCG	No	Yes	No	No	No specific services commissioned	No	No	No	No	No	No	No	No	N/A	No	Yes
Doncaster CCG	No	Yes	No	No	No specific service although children with developmental delay might be assessed. Women with substance abuse issues would be assessed. Children with general complex needs can be referred to Early Years. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	Info not held
Dorset CCG	No	No	No	No	None commissioned, paed and maternity services should work with specialist services to diagnose FASD. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	0
Dudley CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Durham Dales, Easington and Sedgefield CCG	No	No	No	No	No service commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Ealing CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
East and North Hertfordshire CCG	No		Yes	No	Provision of assessment and diagnosis on an individual basis for a number of children. No commissioned service for children. Nothing for adults.	Yes	No	No	No	No	No	Yes	No	N/A	No	Yes - 10 across the period
East Berkshire CCG	No	No	Yes	Yes	Locally commissioned services within Mental Health, Learning Disability and Neurology which are able to identify and treat the difficulties associated with FASD."	Yes	No	No	No	No	No	No	No	N/A	No	Info withheld
East Lancashire CCG	No	No	No	No	None commissioned, general services may diagnose	No	No	No	No	No	No	No	No	N/A	No	0

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East Leicestershire and Rutland CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
East Riding of Yorkshire CCG	No	No	No	No	None commissioned, but expect children to receive diagnosis through normal pathways; adults would receive treatment for consequences of drinking through normal services.	No	No	No	No	No	No	Yes	No	N/A	No	0
East Staffordshire CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
East Surrey CCG	No	No	No	No	See Guildford and Waverley answers	No	No	No	No	No	No	No	No	N/A	No	Info not held
Eastbourne, Hailsham and Seaford CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Eastern Cheshire CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Enfield CCG	No	Yes	Yes	Yes	Diagnostic pathway is through community paediatrics for a child, and possibly CAMHS. For an adult a GP would refer to adult services, not specified. Referral to tertiary specialist services (non-specified) can follow.	Yes	No	No	No	No	No	No	No	N/A	No	0
Erewash CCG	No	Yes	Yes	No	Nothing specific commissioned. Children seen as part of general developmental delay pathway. Nothing for adults.	Yes	No	No	No	No	No	No	No	N/A	No	Yes - 2 (2018)
Fylde and Wyre CCG	No	No	No	No	No specific diagnostic pathway for children, but would expect community paediatrics to diagnose. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	0
Gloucestershire CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Great Yarmouth and Waverney CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Greater Huddersfield CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Greater Preston CCG	No	No	No	No	No diagnostic services commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Greenwich CCG	No	No	No	No	No specific diagnostic service commissioned, although diagnosis is possible through general services under the block contract.	No	No	No	No	No	No	No	No	N/A	No	Info not held
Guildford and Waverley CCG	No	No	No	Yes	Diagnosis through arrangement with Surrey and Borders Partnership Trust (FASD Clinic).	Yes	Yes	No	No	No	No	No	No	N/A	No	Info not held
Halton CCG	No	Yes	No	No	No specific service for FASD, but additional needs services are expected to pick up children with the condition. Nothing for adults at all.	No	No	No	No	No	No	No	No	N/A	No	0

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Hambleton, Richmondshire and Whitby CCG	No	Yes	No	No	None commissioned	Yes	Yes	No	No	No	No	No	No	N/A	No	0
Hammersmith and Fulham CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Hardwick CCG	No	No	No	No	Nothing specific commissioned. Children seen as part of general developmental delay pathway. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	0
Haringey CCG	No	Yes	Yes	Yes	For kids, GP referral to paediatric services, for adults GP referral to tertiary services through IFR. None commissioned specifically.	Yes	No	No	No	No	No	No	No	N/A	No	Info not held
Harrogate and Rural District CCG	No	No	No	No	None commissioned, refer to local Trust	No	No	No	No	No	No	Yes	No	N/A	No	0
Harrow CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Hartlepool and Stockton CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Hastings and Rother CCG	No	No	No	No	No services commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Herefordshire CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Herts Valleys CCG	No	No	Yes	No	No specific service commissioned, but community paediatricians, acute paediatricians, DMO and others can diagnose. Nothing for adults.	Yes	No	No	No	No	No	No	No	N/A	No	0
Heywood, Middleton and Rochdale CCG	No	Yes	No	No	None commissioned, but diagnosis can be made through block contract services.	Yes	Yes	No	No	No	No	Yes	Yes	Charlotte Mitchell, Children's and Maternity Commissioning Manager	Yes	Info not held
High Weald Lewes Havens CCG	No	Yes	Yes	Yes	GP can refer to acute paediatric services or a tertiary expert if necessary. None for adults.	No	No	No	No	No	No	No	No	N/A	No	0
Horsham and Mid Sussex CCG	No	No	No	No	None commissioned but can be funded through IFR.	No	No	No	No	No	No	No	No	N/A	No	Info not held
Hull CCG	No	Yes	Yes	No	No diagnosis service for young people/ adults. Pregnant women are screened for alcohol use.	Yes	No	No	No	No	No	Yes	Yes	Karen Ellis, Deputy Director of Commissioning	No	Info withheld
Ipswich and East Suffolk CCG	No	Yes	No	No	None commissioned, but integrated Paediatric Service can support children with FASD. Nothing for adults	No	No	No	No	No	No	No	No	N/A	No	Info not held
Islington CCG	No	Yes	Yes	No	No specific service commissioned but referral through GPs to specialist services can be requested, with involvement of CAMHS if appropriate. Same for adults. Tertiary specialist services can be used on a case by case basis.	Yes	No	No	No	No	No	No	No	N/A	No	0

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Kernow CCG	No	Yes	Yes	No	Community Paediatric health service can diagnose. Do commission designated doctor for LAC and adopted children, including to assess likelihood of FASD.	No	No	No	No	No	No	No	Yes	Helen Childs, Childrens Health	No	0
Kingston CCG	No	No	No	No	None commissioned. Individual cases can receive funding on a case by case basis.	No	No	No	No	No	No	No	No	N/A	No	Info not held
Knowsley CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Lambeth CCG	No	No	No	No	No services commissioned, will accept IFR	No	No	No	No	No	No	No	No	N/A	No	Info not held
Leicester City CCG	No	No	Yes	No	Diagnosis for children through neonatal or children's neurodisability service.	No	No	No	No	No	No	No	No	N/A	No	0
Lewisham	No	No	No	No	None commissioned, although children may be diagnosed through standard services.	No	No	No	No	No	No	No	No	N/A	No	Info not held
Lincolnshire West CCG	No	No	No	No	No specific service	No	No	No	No	No	No	No	No	N/A	No	0
Linconshire East CCG	No	No	No	No	None commissioned	No	Yes	No	No	No	No	No	Yes	Angie Ashcroft, Head of Commissioning	No	0
Liverpool CCG	No	No	No	No	None commissioned	No	Yes	No	No	No	No	No	Yes	Alison Williams, Lead Commissioner for Women's and Children's Services	No	0
Luton CCG	No	No	No	No	No specific services commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Manchester CCG	No	Yes	Yes	No	Through paediatric services. Nothing for adults	Yes	Yes	No	No	No	No	Yes	No	N/A	Yes	Info not held
Mansfield and Ashfield CCG	No	Yes	No	No	None commissioned, but general services may diagnose through acute or community paediatricians. Nothing for adults.	No	Yes	No	No	No	No	No	Yes	Jane Selwyn, Maternity and Children's LEad	No	Info not held
Medway CCG	No	Yes	Yes	No	Children have been diagnosed by a regional service, and now locally. A neurodevelopmental pathway including FASD is being implemented. Nothing for adults.	Yes	Yes	No	No	No	No	Yes	Yes	Mary Mason, designated Clinical Officer for SEN	Yes	Info not held
Merton CCG	No	No	No	No	None commissoned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Milton Keynes CCG	No	No	No	No	None provided	No	No	No	No	No	No	No	No	N/A	No	Info not held
Morecambe Bay CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Nene CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Newark and Sherwood CCG	No	Yes	No	No	None commissioned but diagnosis possible through acute or community paediatricians	No	Yes	No	No	No	No	No	Yes	Jane Selwyn, Maternity and Children's LEad	No	0
Newcastle Gateshead CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held

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Newham CCG	No	No	No	No	None commissioned, would expect community paediatric services and child development services to diagnose children. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	Info not held
North Cumbria CCG	No	No	No	No	No service commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
North Derbyshire CCG	No	No	No	No	Nothing specific commissioned. Children seen as part of general developmental delay pathway. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	Yes
North Durham CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
North East Essex CCG	No	No	No	No	None commissioned	No	Yes	No	No	No	No	No	No	N/A	No	0
North East Hampshire and Farnham	No	Yes	Yes	Yes	Surrey and Borders Partnership Trust provides a diagnostic service on an IFR basis.	No	No	No	No	No	No	No	No	N/A	No	Info not held
North East Lincolnshire CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
North Kirklees CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
North Lincolnshire CCG	No	No	No	No	Community paediatricians can diagnose, but no specific diagnosis service commissioned.	Yes	No	No	No	No	No	No	No	N/A	No	0
North Norfolk CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
North Staffordshire CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
North Tyneside CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
North West Surrey CCG	No	No	Yes	Yes	Surrey and Borders Trust are commissioned to provide diagnosis though the FASD Clinic.	Yes	Yes	Yes	No	No	No	Yes	No	N/A	Yes	Info not held
Northern, Eastern and Western Devon CCG	No	Yes	No	No	None commissioned	No	Yes	No	No	No	No	No	No	N/A	Yes	0
Northumberland CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Norwich CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Nottingham City CCG	No	Yes	No	No	None commissioned	Yes	Yes	No	No	No	No	No	Yes	Mark Sheppard, Director of Acute Contracting; Maxine Bunn, Director of Contracting and Procurement	No	Yes - 1 (2016)
Nottingham North and East CCG	No	Yes	No	No	None commissioned	No	Yes	No	No	No	No	Yes	Yes	Mark Sheppard, Dorictor of Acute Contracting; Maxine Bunn, Director of Contracting and Procurement	No	Info not held

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Nottingham West CCG	No	No	No	No	None commissioned	No	Yes	No	No	No	No	Yes	Yes	Mark Sheppard, Director of Acute Contracting; Maxine Bunn, Director of Contracting and Procurement	No	0
Oldham CCG	No	Yes	Yes	No	Nothing specific commissioned but CAMHS, Learning disability, community paediatrics can all be involved in diagnosis. Nothing for adults.	Yes	No	No	No	No	No	Yes	Yes	Angela Walsh, Children's and Maternity Senior Business Partner Commissioner	Yes	Info not held
Oxfordshire CCG	No	No	Yes	Yes	Mental Health, Learning Disability and Neurology "able to identify and treat the difficulties associated with FASD."	Yes	No	No	No	No	No	No	No	N/A	No	0
Portsmouth CCG	No	Yes	Yes	Yes	Maternity services screen all children; children can be referred to community paediatricians via GP. Adults can be referred to specialist via GP.	No	No	No	No	No	No	No	No	N/A	No	0
Redditch and Bromsgrove CCG	No	No	No	No	None commissioned.	No	No	No	No	No	No	No	No	N/A	No	0
Richmond CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Rotherham CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Rushcliffe CCG	No	Yes	No	No	None commissioned	Yes	Yes	No	No	No	No	Yes	Yes	Mark Sheppard, Director of Acute Contracting; Maxine Bunn, Director of Contracting and Procurement	No	Info not held
Salford CCG	No	Yes	Yes	No	For young children specialist midwives would screen and direct to support services. Nothing for adults.	No	No	No	No	No	No	No	No	Stephen Woods, Head of Service Improvement Partnerships would be a first point of contact	No	0
Sandwell and West Birmingham CCG	No	Yes	No	No	No information held	No	Yes	No	No	No	No	Yes	Yes	Karmah Boothe swbccgcyp@nhs.net	No	0
Scarborough and Ryedale CCG	No	No	No	No	No commissioned services.	No	No	No	No	No	No	No	No	N/A	No	0
Sheffield CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Shropshire CCG	No	No	No	No	Diagnosis provided through general maternity or community paediatric services, nothing for adults.	No	Yes	No	No	No	No	No	Yes	Lead Commissioner for Children and Women's Services	No	0
Somerset CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
South Cheshire CCG	No	No	No	No	None commissioned. Local hospitals would be expected to provide diagnosis for newborns through maternity services.	No	No	No	No	No	No	No	No	N/A	No	0
South Derbyshire CCG	No	No	No	No	Nothing specific commissioned. Children seen as part of general developmental delay pathway. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	Yes - 2 (2018)
South Devon and Torbay CCG	No	Yes	No	No	None specific commissioned, neurodevelopmental services can diagnose FASD. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	Yes - 1 (2018)

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South Devon and Torbay CCG	No	Yes	Yes	No	No specific services commissioned, but FASD can be diagnosed through general developmental delay or behavioural services. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	Yes	0
South East Staffordshire and Seisdon Peninsula CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
South Kent Coast CCG	No	Yes	No	No	None commissioned	No	No	No	No	Yes	No	Yes	No	N/A	No	Info not held
South Lincolnshire CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	Yes	Andrew Rix, Chief Operating Officer	Yes	0
South Norfolk CCG	No	No	No	No	None comissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
South Sefton CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
South Tees CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
South Warwickshire CCG	No	No	No	No	No specific diagnostic services commissioned.	No	No	No	No	No	No	No	No	N/A	No	0
South West Lincolnshire CCG	No	Yes	No	No	No specific services commissioned	No	Yes	No	No	No	No	No	Yes	Anfrew Rix, Chief Operating Officer	Yes	0
South Worcestershire CCG	No	No	No	No	None commissioned. Expect general services to cover FASD needs, but have no figures on FASD.	No	No	No	No	No	No	No	No	N/A	No	0
Southampton City CCG	No		No	No	No services commissioned	No	No	No	No	No	No	No	No	None specific, general policy under Senior Commission for Maternity Tim Davis	No	Yes - 2 since 2013
Southend CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Southwark CCG	No	No	No	No	No services commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
St Helens CCG	No	Yes	Yes	No	Community paediatrics should provide diagnosis, but nothing specific. Nothing for adults.	Yes	No	No	No	No	No	No	No	N/A	No	Info not held
Stafford and Surrounds CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Stockport CCG	No	Yes	Yes	No	The CCG commissions specialist services which diagnose neurodevelopmental conditions including FASD. Can also provide assessment of adults and children with mental health conditions.	Yes	Yes	No	Yes	No	No	Yes	No	None specific but Gina Evans, Joint Commissioning Lead; Duncan Weldrake, Joint Commissioning manager (children and young people); Sarah Williamson, Assoc Director for Continuing and Complex Health Care	Yes	Yes
Stoke-On-Trent CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Yes - 1 (2018)
Surrey Downs CCG	No	No	No	No	None commissioned, see it as the responsibility of local CAMHS. Nothing for adults.	No	No	No	No	No	No	No	No	N/A	No	Info not held

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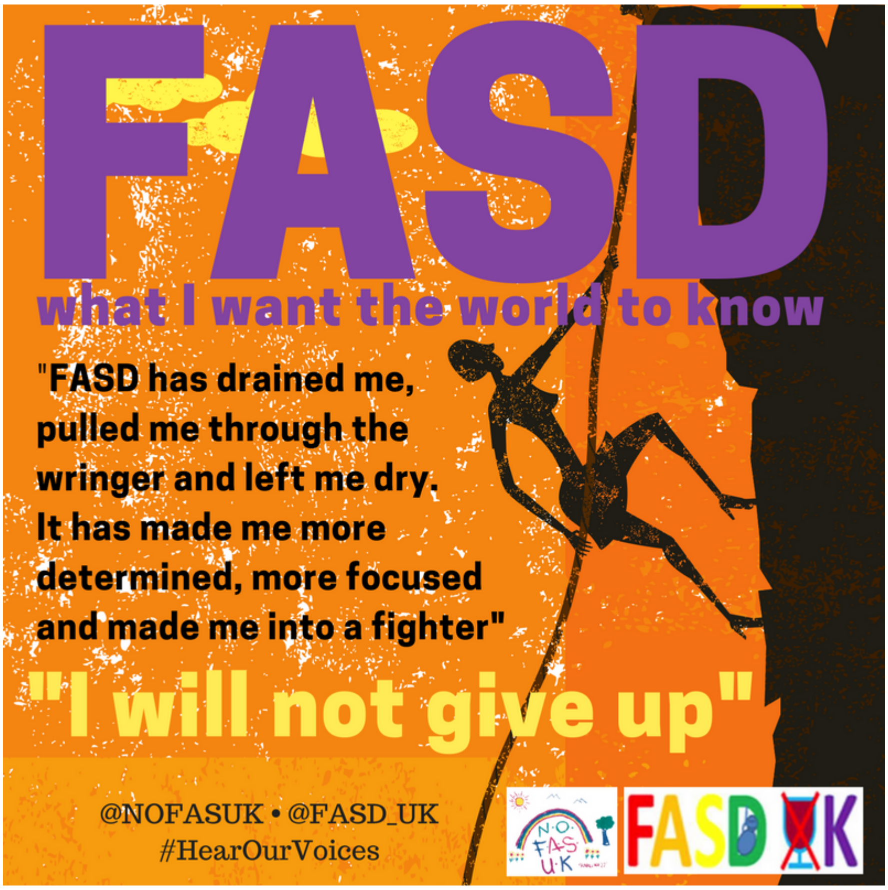
Surrey Heath CCG	No	No	Yes	Yes	Refer us to Surrey and Borders Trust for the Clinic, but no mention of whether they specifically commission this.	Yes	Yes	No	No	No	No	No	No	N/A	No	Info not held
Sutton CCG	No	No	No	No	No diagnostic service commissioned, will accept IFR requests.	No	No	No	No	No	No	No	No	N/A	Yes	Info not held
Swale CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Swindon CCG	No	Yes	Yes	No	No specific diagnostic service bu maternity services or community paediatricians may diagnose. Nothing commissioned for adults.	No	No	No	No	No	No	No	No	N/A	No	Info not held
Tameside and Glossop CCG	No	Yes	Yes	No	Maternity service use MAMA screening for awareness of FASD. Nothing for adults.	No	Yes	No	Yes	No	No	Yes	Yes	Debbie Watson, Asst Director of Population Health/maternity	Yes	0
Telford and Wrekin CCG	No	No	No	No	None commissioned, claim it is the local authority that is responsible.	No	No	No	No	No	No	No	No	N/A	No	0
Thanet CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	Yes	No	N/A	Yes	Info not held
Thurrock CCG	No	Yes	Yes	No	Nothing specific for FASD. "The CCG commissions specialist services to assess the needs of children presenting with developmental or conduct disorders." Nothing for adults.	Yes	Yes	No	No	No	No	No	Yes	Senior Children's Commissioner and Adult Mental Health Commissioner	Yes	Yes
Tower Hamlets CCG	No	No	No	No	No services commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Trafford CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Vale of York CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Vale Royal CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Wakefield CCG	No	Yes	Yes	No	None specific commissioned. Children can be diagnosed by paediatric services. Nothing for adults.	Yes	No	No	No	No	No	No	Yes	Senior Commissioning Manager for Children	No	Info not held
Waltham Forest CCG	No	Yes	No	No	None commissioned	No	No	No	No	No	No	No	Yes	Siobhan Hawthorne, Commissioning Manager for Children and Maternity	No	Info not held
Wandsworth CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
Warrington CCG	No	No	No	No	No specific service commissioned, would expect children to be diagnosed through developmental delays service.	Yes	No	No	No	No	No	No	No	N/A	No	Info not held
West Cheshire CCG	No	No	No	No	None commissioned	No	Yes	No	No	No	No	Yes	No	N/A	No	0
West Essex CCG	No	Yes	No	No	Diagnosis by specialist centre, not commissioned by CCG	No	No	No	No	No	No	No	No	N/A	No	Info not held
West Hampshire CCG	No	Yes	Yes	Yes	Diagnosis through IFR provided for children and adults following genetic testing, service provided by Surrey and Borders.	Yes	Yes	No	No	No	Yes	No	No	N/A	No	Info not held
West Kent CCG	No	Yes	Yes	No	Diagnosis through National FASD Clinic	No	No	No	No	No	No	Yes	No	N/A	No	Info not held

1) Name of CCG	2) FASD Policy	3) Prevention services	4) Diagnosis for children	5) Diagnosis for adults	6) Comments on diagnosis	7) Post-diagnostic care for FASD	8) 'Continuous improvement'	9) Budget in 2013 - 2018	10) Plans to expand services	11) Research on FASD	12) National Clinic	13) Education/training	14) FASD lead	15) Name and role of lead	16) Involve stakeholders	17) Requests received re FASD 2013-2018
West Leicestershire CCG	No	No	Yes	No	Diagnosis through a neonatal follow up or through general Community Paediatrics as part of neurodisability diagnosis. Nothing for adults.	Yes	No	No	No	No	No	No	No	N/A	No	Info not held
West London CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
West Norfolk CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	Info not held
West Suffolk CCG	No	No	No	No	None commissioned. Community Integrated paediatric Service can diagnose. Nothing for adults	No	No	No	No	No	No	No	No	N/A	No	Info not held
Wigan Borough CCG	No	Yes	No	No	None commissioned, children can be diagnosed through block grant funded standard paediatric, CAMHS, or learning disability services.	No	Yes	No	No	No	No	No	No	N/A	No	Info not held
Wirral CCG	No	Yes	No	No	No specific services commissioned	No	No	No	No	No	No	No	No	N/A	No	0
Wolverhampton	No	No	No	No	Maternity services commissioned in line with NICE guidelines (nothing about FASD) and nothing at all for adults.	No	No	No	No	No	No	Yes	No	N/A	No	0
Wyre Forest CCG	No	No	No	No	None commissioned	No	No	No	No	No	No	No	No	N/A	No	0

NOTE: Full responses to the FOI requests most easily can be found at www.whatdotheyknow.com by searching for the name of the CCG or NHS Trust and FASD.



FASD

what I want the world to know

"FASD has drained me, pulled me through the wringer and left me dry. It has made me more determined, more focused and made me into a fighter"

"I will not give up"

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