



Hear Our Voices

FASD STAKEHOLDERS SHARE THEIR EXPERIENCES WITH POLICY MAKERS

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Time to Address the Policy Gap

Foetal Alcohol Spectrum Disorders (FASD) are brain-based impairments that affect more people than autism but are little understood. In 2016, the UK Chief Medical Officers clarified guidance to say the “safest approach is not to drink alcohol at all” when pregnant or trying to conceive and yet this guidance is not consistently available throughout the NHS and has not seeped into all PSHE and Sex Education curricula.

Government recognised that “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.” And yet, despite the fact progress has been made in some areas (Scotland, the Northeast) there is an appalling lack of access to diagnosis and support in many areas of the UK creating a post code lottery with tragic outcomes for many.

Note: 'Fetal' is the international/medical spelling, 'foetal' is the UK usage. A glossary is on page 29.

This document includes input from more than 50 individuals and families affected by FASD. It is not scientific, it is anecdotal precisely because stakeholders are rarely brought into the discussions that impact their lives and futures.

Hear Our Voices is a project of the FASD UK Alliance, an informal coalition of FASD groups across the UK who seek to raise awareness of FASD. The report was prepared by the National Organisation for Foetal Alcohol Syndrome-UK (NOFAS-UK) in May 2018.

We draw policy makers' attention to two questions where parliamentary oversight could have great impact on the lives of many:

1. Are Clinical Commissioning Groups (CCGs) fulfilling their responsibilities regarding FASD? How can this be improved, perhaps via more standardised national protocols for diagnosis and care pathways as suggested by the BMA Report in 2007 (updated in 2016)?
2. Is the potential impact of the CMO guidance on alcohol and pregnancy being maximised?

Who We Are

This booklet summarises the experiences of more than 50 families across the UK affected by FASD. Here's a snapshot of how some of our contributors described themselves:

- ✿ Two exhausted bright confident parents battling the system for our adopted 13-year-old boy who's lived with us since 22 months; home-schooling because he cannot cope with mainstream education
- ✿ I am a legal guardian of a 4-year old boy who is struggling battling FASD and the system
- ✿ I am a 14-year old with FASD
- ✿ Mum to the most amazing, brave, creative & loving child who deserves support to reach his potential and not just become another sad statistic
- ✿ A retired paediatrician with two children one of whom is an adoptive daughter who is 14 years old and has FASD
- ✿ A grandmother
- ✿ We are a fun loving amazing empathic family that needs better understanding and support from the government

We are special guardians to a 9-year old with FASD. Our home is full of love, happiness and many challenges

- ✿ I am a full-time mother and career of five boys under SGO with FASDs and one birth son. These are all my boys and they deserve the support and recognition for their difficulties as any other child with a life-long disability
- ✿ Children's Panel Member and adoptive parent of two FASD sons (now 18 and 20) and two birth children, I work with children from birth to adulthood
- ✿ We have a birth son and adopted daughter, life is hard
- ✿ I am a single parent to two boys my eldest diagnosed with partial FAS in 2017 at the age of 9
- ✿ We are adoptive parents of a 15-year old girl. We had no idea she had FASD before she came to live with us or the adoption was finalised. We just acknowledge that it's a good job we love her, otherwise we couldn't carry on with caring for her
- ✿ Adoptive parent, now separated from my husband and employed full-time
- ✿ A happy but challenged family
- ✿ I am a longterm foster carer for a young person with FASD

What are Foetal Alcohol Spectrum Disorders (FASD)?

FASD is a spectrum which some call an “invisible disability”. Prenatal alcohol exposure at any time during pregnancy can alter brain structures and brain wiring, organ and bone development and other systems. How it affects each individual can vary greatly. While only approximately 1/9 of those with FASD have the facial features of Foetal Alcohol Syndrome, most with FASD have cognitive impairments. Over 400 conditions can co-occur with FASD. There is no proven safe amount of alcohol in pregnancy. FASD affects all populations. FASD and early trauma can be a very complex mix.

Diagnoses include:

- ◆ Foetal Alcohol Syndrome (FAS)
- ◆ Partial Foetal Alcohol Syndrome (pFAS)
- ◆ Alcohol-related Neurodevelopmental Disorder (ARND)
- ◆ Alcohol-related Birth Defects (ARBD)

Do the maths: 2% of 774,835 live births in the UK in 2016 = 15,497 children. FASD is estimated to affect even more.

The “stark reality is that a large number of children are born every year in the UK with lifelong physical, behavioural and / or cognitive disabilities caused by alcohol consumption during pregnancy.

“Worse still, there is a scandalous lack of support for these children, who live and grow up with the impact of their impairments without the educational, emotional and social support they require to fulfil their potential.”

- Professor Sheila the Baroness Hollins,
BMA 2007/2016

FASD - more prevalent than autism?

1 in 20 in Year 1 were diagnosed with FASD in a recent US study (of 222 cases, only 2 diagnosed previously). A Canadian study identified a 2-5% prevalence rate. (According to forthcoming studies, this may be higher in UK.) A US study found 29% of children in care have FASD (86% were previously undiagnosed). A Peterborough (UK) study showed 27% of Looked After Children referred for an initial health assessment had a diagnosis of FASD compared with 3% of all new referrals to community paediatrics and 75% of adopted children had been exposed to alcohol in utero. (*Sources, p 9.*)

“Alcohol is a teratogenic compound (ie a substance that interferes with the normal development of the embryo or fetus) that readily crosses the placenta...the fetus is totally unprotected from alcohol circulating in the blood system....The most severe effects are the intellectual disabilities associated with the adverse impact of alcohol on fetal brain development and the CNS (central nervous system).” BMA, 2007/2016

Diagnosis is Too Often a Battle

The first step toward accessing proper support is a diagnosis. There is a severe discrepancy across the UK in the experiences of those seeking a diagnosis. In some areas, they are told there are no commissioned services (despite government policy that the local CCGs are responsible for this). Many professionals lack proper training in recognising the wide spectrum represented by those with FASD. A diagnosis means the individual has organic brain damage. It changes the perspective from a 'naughty' child to one who can't do what is being asked, at least not without support. A diagnosis changes trajectories.

It took us years to get our daughter diagnosed. First CAMHS blamed it on my parenting - during an appointment, in front of our daughter. They then stopped appointments. Asked for referral to paediatrician. Saw one but she didn't know what FASD was and suggested we join a support group on line. I asked for a referral to a specific consultant out of area, and finally we got a diagnosis, 4 years later.

- Adoptive parent, Yorkshire and the Humber

Paediatrician refused to send adopted son for assessment repeatedly. We had to go above his head to the medical director who could see the need for assessment as this child was being expelled from and suspended from every school and missing

I was told by my son's paediatrician that a diagnosis for FASD would serve no purpose.

That it only helps to ease the mother's guilt about parenting.

-Birth Mother, South East

educational opportunities at 14. CCG exceptional referral committee agreed to fund assessment out of area as we had no diagnostic services in area. Diagnosis of ARND eventually came 15 months later after this child missed 9 months education. No funding for follow up services at all though.

- Adoptive Parent, Scotland

We followed too much professional advice that it was attachment disorder not FASD.

- Adoptive Parent, North West

My parents had to fund diagnosis as none available and lack of knowledge.

- Teen with FASD, South East

The process takes far too long.

- Adoptive Parent, Scotland

I have a foster child aged 13 but academically he is only 3 or 4 years old. He is already diagnosed with ADHD but has facial features of someone with FAS. His speech and issues with spatial awareness are getting worse, but everyone from social worker, CYPS to speech & language say he will never get a diagnosis.

- Foster Carer, North East

Despite my wife being a GP FASD expert who's taught on FASD at conferences, our (first) GP was extremely dismissive and our (first) community paediatrician was even worse, very reluctant to let us try melatonin despite years of battles at bed-time-"it won't work because he's not autistic". "He's not pre-verbal" (son had regressed to grunting during consultation, hiding on floor under wife's chair, eating biscuits and rocking).

- Adoptive Parent, East

Because my son did not present with any physical features of FASD, despite history of his birth mother drinking, his problems were assumed to be attachment issues only.

- Adoptive Parent, West Midlands

Professionals need up-to-date training. They need to drop the myth that FASD is only present with facial features.

- Grandmother,
Yorkshire and the Humber

I started looking into the possibility of my son having FAS or FASD due to behavioural problems and the fact I drank during pregnancy. I spoke with my doctor who put us forward for CAMHS and to see a Paediatrician. None of these people really had any idea about FAS/FASD. I was immediately told by the head Paediatrician that he did not have FAS as he didn't have any facial features. So, I asked about FASD, again I was told he did not have that as he didn't have facial features and I needed to stop trying to label my son. I expressed that FASD does not have facial features. I had also been honest about what I drank and when during my pregnancy. I then pushed to see a geneticist. We went to the appointment and I was told by the geneticist that he didn't have FASD due to no facial features, again I expressed that there were no facial features with FASD. The geneticist told me that he thought my son had the neurological damage but even with that he wouldn't diagnose due to him not having facial features. No matter who I spoke to, they didn't have a clue about FASD, how to diagnose it or what the symptoms are.

- Birth Mother, West Midlands

Although we had proof my son's birth mother drank significantly through pregnancy and he displayed lots of FASD-related behaviour and issues, the paediatrician and clinical psychologist were both wary of diagnosing. Psychologist said she had never come across it before!! And paediatrician said due to the adoption and associated issues (broken attachments, etc) it was too difficult to unpick! Clinical geneticist in the end was 'brave' enough to say it is FASD.

- Adoptive Parent, West Midlands

When our daughter was being assessed, the paediatric registrar said: "I've heard of FAS, but I don't know what FASD is?" We got to where we got to because we kept asking and educating. Our GP was fabulous. School was great, provided the support, in spite of the fact that the local educational psychologist seemed to fundamentally misunderstand the nature of FAS and FASD, having said, "Sometimes all these children need is a bit of support and they'll catch up".

- Adoptive Parent, North West

Initial GP told me that FASD couldn't be diagnosed after birth and that it was probably just mild autism that we wouldn't get any support for. I had to make another appointment to see a different GP and insist on a referral to community paediatrician.

- Adoptive Parent, West Midlands

We have been refused a diagnosis twice, once due to not understanding that a child can have a good weight and still have FASD and the second time due to lack of understanding that seizures are one of the primary conditions. She thought he might have something else as well and could not understand why FASD should be diagnosed.

- Special Guardian, East Midlands

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

- Adult with FASD, South West

We could not get the authority who placed my daughter to share the maternal notes with us. Our authority would not hear my concerns about FASD, blaming all my daughter's problems on attachment or our parenting style. We had to go privately to get the diagnosis done.

- Adoptive Parent, South West

It took me almost 9 years of struggling after getting SGO for my boys to even have them looked at for their issues. My 12-year old is still fighting for diagnosis. Even with proof of alcohol during his birth mum's pregnancies and with an IQ of 70 they are still refusing to diagnose -

leaving us frustrated and with him struggling on all aspects of his life.

- Special Guardian, North East

Referral for son was refused as no one commissioned to assess and diagnose FASD.

- Adoptive Parent, East

We were fortunate that the paediatrician spotted it on our first visit one year, post-placement with a diagnosis given a year later. On reflection the original paediatrician pre-adoption had enough

evidence to diagnose and follow up genetic tests, so two years with minimal support at school could have been avoided and better strategies used at home.

- Adoptive Parent, South East

We were initially told no FASD as no obvious physical features. We were later refused because, despite full range of social and emotional difficulties, she was "too tall"! Finally received a letter stating "diagnosis of ARND is best fit", which is now being reinterpreted as no diagnosis. Also told there'd be no point in a diagnosis as there were no targeted services.

- Adoptive Parent, North East

Our social worker got a referral to a clinical geneticist quickly and we were seen within expected time frame. However, the CCG would normally refer back to a paediatrician and when I asked my GP to accommodate for this I got a flat out refusal and, I quote "You have got your diagnosis, what more do you want?"

- Adoptive Parent, East Midlands

He did not receive a diagnosis until aged 10. This has now enabled him to access specialist teaching at specialist school which he should have had much earlier to maximise his potential. He has just moved school midway through Year 6. In my opinion there were signs he would need additional support in Year 2.

- Adoptive Parent, East of England

Stigma plays a huge part in the resistance to diagnose.

- Paediatrician/Adoptive Parent, North East

It's taken me over 2 years just to get a referral.

Health visitor knew nothing about it and told me she can see nothing wrong with him...fired her got a new

one and she is amazing. Also fought hard for a family support worker who came with me to appointments and because of her and new health visitor it's taken 6 months and now have also seen paediatrician and speech and language and hearing (failed all 3 tests, now seeing specialist) had genetics done and now waiting to see geneticist. Thinks it's disgusting how it was implied that I was pushy and a bad parent and when I knew more than them, I was over bearing and I needed to back off. Also found a lot of misinformation provided by professionals who only knew the basics. When corrected and shown documented detailed evidence on FASD/FAS you can see how displeased they were.

- Grandmother, Yorkshire and the Humber

I had to fight for a diagnosis of ARND for my adopted son. Then with two of my foster children I was told a label wouldn't benefit them.

- Adoptive and Foster Parent, North West

I was told by the geneticist that he couldn't have FASD as he didn't have "the look". At a follow up she commented on how much he'd grown - I told her, yes, 70th centile height, 50th weight - and THIRD centile head circumference. Finally did get FASD diagnosis as my daughter admitted poly use of drugs and alcohol in pregnancy; with almost no antenatal care it would have been impossible to get a diagnosis otherwise...

- Grandmother/Foster Carer, Wales

Sources (from page 4):

- Office of National Statistics, Live births in UK. <https://tinyurl.com/ONS2016Stats>
- "Alcohol and pregnancy: Preventing and managing fetal alcohol spectrum disorders," British Medical Association, June 2007 (updated February 2016)
- "Study of first-graders shows fetal alcohol spectrum disorders prevalent in U.S. communities," 6 February 2018. Available online: <https://www.nih.gov/news-events/news-releases/study-first-graders-shows-fetal-alcohol-spectrum-disorders-prevalent-us-communities>
- Two per cent of GTA [Greater Toronto Area] students likely have fetal alcohol spectrum disorder, new CAMH study shows, 10 April 2018, http://www.camh.ca/en/hospital/about_camh/newsroom/news_releases_media_advisories_and_backrounders/current_year/Pages/Two-per-cent-of-GTA-students-likely-have-fetal-alcohol-spectrum-disorder.aspx
- Chasnoff IJ, Wells AM, King I (2015) Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics* 135 (2): 264-70. Quoted in BMA, 2007/2016
- How foetal alcohol spectrum disorder affects the care system, *The Guardian*, 9 February 2016. <https://www.theguardian.com/social-care-network/2016/feb/09/how-foetal-alcohol-spectrum-disorder-affects-the-care-system>

GPs Identified A Need For Better FASD Information/ Guidance

- ✱ Only 31% of the GPs said they had in-depth education regarding FASD.
- ✱ Forty-seven per cent said it should be more thoroughly taught in medical school.
- ✱ Forty-one per cent said they have not received clear guidance from their local Clinical Commissioning Group regarding a pathway for diagnosis and support of FASD.
- ✱ Only 23% felt 'strongly confident' that all those with a Foetal Alcohol Spectrum Disorder are being diagnosed properly.

Between 22 August and 1 September 2017, OnePoll conducted online and mobile polling of 150 GPs in England on behalf of NOFAS-UK. Due to the charity's limited resources they were unable to conduct a more comprehensive study, but the answers received strongly suggest that the powers-that-be should look more comprehensively into GP training and awareness of issues related to FASD and the risks of alcohol in pregnancy.

Practitioner and Parent

I was both a practitioner and a parent. As a paediatrician I recognised my adopted daughter had a neurodevelopmental disorder and through personal research and training I came to recognise that this was FASD. I was working with looked after children for 25 years and as I learnt more and experienced living with a child with the disorder I started to recognise more and more children with FASD in the looked after population and children I was doing medical assessments on for adoption.

Over the last two years up to retirement I attempted to put in place a pathway for diagnosis and recognised and/or diagnosed over 200 children in the district. However, this was not welcomed by colleagues/other agencies despite it explaining many of the unmet challenges these children were facing. I recognised that we could not tick all the boxes in the newer diagnostic criteria from Canada and the USA but there was often sufficient evidence to start interventions and offer strategies (which in themselves are extremely helpful and not harmful even if the diagnosis is not FASD)...I am led to believe that children I painstakingly diagnosed and supported have subsequently had their provisional diagnoses revoked as I was unable to tick all the boxes.

It was hard to explain my awareness and insight into this condition born out of living with and struggling to meet the needs of a child with FASD.

In our district a major barrier to diagnosis is the resistance of mental health services to get involved with FASD. They claim it is an organic problem and will often not see the children. Yet we need psychological testing to diagnose and we know that over 90% of these children get mental health problems as secondary disabilities so this stance is unethical. We attempted to set up a multidisciplinary clinic as in autism but this was blocked. The separation of funding for children's physical and mental health needs has been in my experience/opinion very divisive in terms of collaborative working and has particularly impacted on Looked After Children and adopted children where we know the rates of FASD are highest.

My daughter has not got a formal diagnosis as it took me three years to seek through an agency I used to work with the confirmation of maternal drinking in pregnancy....I can now start the tortuous job of putting her through the diagnosis - nothing will change except this will protect her in the future. She already has her EHCP as she has learning problems but she will need a formal FASD diagnosis. She knows she has it so she understands herself better.

A client of mine (I am now a voluntary support worker) told me recently that a local mental health professional had said that they were not seeing children with FASD in CAMHS as this would "Open the floodgates and could not be resourced."

- Paediatrician (ret.)/Adoptive Parent,
North East



Accessing Support is Inconsistent and Slow

Families affected by FASD across the UK report challenges big and small in accessing support and/or benefits for health, education, social care, housing, and other financial support. Their lives are severely impacted by barriers they face when seeking to access Education and Health Care Plans (EHCP), therapies like Occupational Therapy or Speech and Language, assisted employment or internship schemes, financial support like the Adoption Support Fund or benefits like DLA, PIP, ESA, Universal Credit, housing, etc. The system can be cruel.

We eventually got support services, but it made things worse not better as they had no understanding and even blamed my care for his needs and put me through safeguarding.

- Special Guardian, East Midlands

School did not place my son on the SEND register when he was given a diagnosis. I made my own referral to speech and language and occupational therapy support was accessed privately and funded by post adoption support. School refused to apply for an EHCP and I have done that myself, currently in the process.

- Adoptive Parent, West Midlands

DLA went to appeal as they did not understand FASD. Primary school insisted she didn't need support despite ed psych, therapists, consultant and us all saying she did. Took 5 years to put in place.

- Adoptive parent, Yorkshire & the Humber

He ticks all the boxes of someone with FASD. He has ADHD and is in a school for children with social, emotional & mental health where most children have behaviour issues. As our foster son is so vulnerable he copies others behaviour. Hopefully if we could get FASD diagnosis we would be able to get his EHCP changed so he could go to a school that is better for him.

- Foster Carer, North East

Speech and language therapists had limited understanding of the complexities of FASD. They saw strong expressive language as an indication of strong comprehension which it isn't.

- Adoptive Parent, North East

Everywhere we go there is a lack of knowledge about FASD, so it's hard to get the right support. At school it's worst, teachers and support staff are not trained, and I am punished for the lack of understanding about my disability. It's not that I won't ... I can't and teachers don't get it. I have now been excluded because they can't meet my needs. If you have autism there are strategies in place. If you have FASD there is Nothing! Absolutely nothing.

- Teen with FASD, South East

School failed to acknowledge difficulties as she often shut down, causing no disruption despite a growing and significant gap academically.

- Adoptive Parent, Yorkshire and the Humber

Our son has a statement of special educational needs (SEN) but it was never fully implemented in school. The LEA refuses to assess our daughter for SEN because her scores in national tests are good enough. We intend to pay ourselves for her needs to be assessed by an Educational Psychologist in May/June before she goes to secondary school in September.

- Adoptive Parent, Wales

It became a full-time job for me compiling reports and arguing the case. We knew she would be extremely vulnerable at mainstream, possibly leading to exploitation, drug use and certainly deterioration in mental health. We have had no specific FASD support. We currently access support through Adoption Support Fund but the focus is on attachment and trauma.

- Adoptive Parent, South East

Apart from the last application we have always had to appeal to obtain Disability Living Allowance. Our initial application for an EHCP was refused and we had to go to mediation and then tribunal.

- Adoptive Parent, West Midlands

School were extremely unhelpful and clearly disbelieved us as parents until diagnosis came. Even then didn't take into account and we had to withdraw due to poor attendance (largely caused by not being accepted). Special school was no better, now home-schooling. DLA was surprisingly forthcoming but we're now veterans at advocacy and report writing.

- Adoptive Parent, East

We were told he did not need an EHCP as children with FASD are fine in school.

- Special Guardian, East Midlands

CAMHS told us my children were too complex for them and my eldest has now had a full psych assessment by Learning Disability (LD) CAMHS (this took me 4 years). Because his profile spikes so much and he scores so low on some areas but normal on others, they say they have to take an 'educated guess' at his IQ and they guessed at 4 points higher than the cut off for LD CAMHS involvement and he was discharged. The fight for support is relentless.

- Adoptive Parent, North East

Even for the little bit of adoption support allowance we get we have to prove each year he still has FASD!!!! It is permanent and irreversible!!!! And they want to see recent doctor evidence every year!

- Adoptive Parent, West Midlands

We got diagnosed at 7 years old. We have no support as it's not recognised where we are. There are no support groups. Primary education has been absolutely appalling. I have been personally abused by staff at school, I've been bullied and I have a safeguarding order on me. We have offered to help school and pay for assessment etc but no, they know best! So as it stands we are going to mainstream secondary school in September with no EHCP and no support.

- Adoptive Parent, West Midlands

I wasn't aware that I could claim anything?? When diagnosis was received, nothing was mentioned about any support.

- Adoptive Parent, North East

I have had trouble in accessing education support for my daughter as her school didn't even know what FASD is and she is the only one diagnosed in her school.

- Special Guardian, South East

Our daughter's end of primary and transfer to

Many children with FASD do not have a low IQ and so would not qualify for adaptive functional testing and yet these tests are essential for adolescents with FASD - they have apparent ability only and usually have significantly impaired adaptive functioning such that they cannot live independently. In my work I had great difficulty accessing mental health services and psychological testing for children. Other services (e.g. speech and language therapy, occupational therapy), pre-school teachers would accept my referrals but the systems were soon swamped by the numbers of children we were recognising. As yet, adult and transition services are not locally recognising the needs of these children but there are increasing numbers of individuals in all agencies who "get it" and do all they can to support the children and families.

- Paediatrician/Adoptive Parent, North East

secondary school was a trying time, and we did start the process to take our Local Authority to Tribunal, the submission had been made to the court, but the Local Authority accepted our preference for schooling, before our court date actually came up. At the transition meeting held at her primary school, everyone was in agreement that she should transfer to a

I have been fighting for nearly 3 years now to get my FASD diagnosis. It took me a very long time to get the help from DWP as I didn't have my diagnosis but with help from Mencap I got my PIP enhanced rate for care and standard for mobility. I am still struggling with work as they don't understand my needs properly. As a higher functioning adult, to doctors I am able to do things. This is what doctors don't understand.

- Adult/Mother with Suspected FASD, East

special school at the end of Year 5 and then continue at the special school for secondary. However, when the matter went to panel, it wasn't approved: mainstream with support was the Local Authority's only option. We commissioned (privately and at some significant cost) two reports: one from a neuropsychologist and one from a speech and language therapist, both clearly reflected our daughter's FASD profile. Our daughter is now very settled in a special school. She is a calmer, happier child. The noise and hustle and bustle of a large secondary school would have been overwhelming for her. We're fortunate, happy and settled ... until the next change comes when she's sixteen. For us, the issue is one of a general lack of knowledge and therefore, provision for children and people with FASD. We see the lack of knowledge everywhere. If, in a social or community setting you say that your child has autism, there is usually a general understanding and a degree of sympathy and support. If you say that your child has FASD, then there is nothing. Even though many people who are diagnosed with autism, may actually have FASD as the primary driver of their presentation.

- Adoptive Parent, North West

I get no help as can't get a diagnosis.

- Adoptive Parent, North East

I have personally experienced scary situations with both NHS staff and police who didn't understand FASD at all, putting me at risk. The NHS computerised information about FASD needs to be improved so doctors can access this quickly. NHS files could have an alert system indicating this person has organic brain injury. A nationally recognised medical alert bracelet might help. If under arrest, although protocol for the police is to do certain things on site of the scene, they need to reiterate it when back in the station when appropriate, perhaps with a third-party present, as the person with FASD won't (as in my case) remember.

- Adult with FASD, South

EHCP was extremely difficult to get and took about 2 years. No post-adoption support or funding and still fighting to get a disabled child social worker.

- Adoptive Parent, North East

The number of therapies we can access through the adoption support fund are frustratingly few. The only thing we could access was Theraplay, which was helpful but looking at my daughter's complex mix of needs, a mere drop in the ocean. And

During hospital stays, the staff were uneducated as to how FASD presents itself. They were therefore unable to meet my son's needs medically.

- Birth Parent, South East

Managed with extra support in primary but will not manage mainstream high. Only option to send into 'lion's den' to fail and compound mental health problems or home educate at significant personal cost to family as a whole.

- Adoptive Parent, East

certainly not the exact right therapy for her brain/mental state. Although we have been approved for respite we can't access it and no one has been assigned to help us since we were approved at the beginning of the year.

- Adoptive Parent, South West

No medical or social care professionals will acknowledge FASD. There is no expertise, so no specific services. CAMHS will not offer any specific therapy or services nor will they discuss the diagnosis with my daughter.

- Adoptive Parent, North East

No services in our area. Most with FASD/ARND have average or above IQ so they do not meet the criteria for adult social work services or supported housing. At one point respite was denied because our local authority thought the children being at school was respite enough for the family even though their own special needs code of practise specifically states the school should not be seen as respite for families.

We never did get any respite.

- Adoptive Parent, Scotland

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

- Adoptive Parent, North West

No help or understanding at school, even with an ECHP, which they don't follow, they still treat him as a naughty child and it's all about the punishment and no praise at all off them. Now he just has closed off from them and they blame him for not wanting to do his schoolwork. The school never

As a teacher educator I've talked to hundreds of trainee and practising teachers about the impact of FASD in the classroom.

For trainee teachers trying to learn about SEN generally and FASD specifically at the same time is a significant challenge. For

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

- Educator, West Midlands

thinks it their fault that they don't follow his care plan. CAMHS has also said as he's unique and has a bit of ASD, ADHD etc - they don't know what to do with him!!!! His FASD specialist has since retired and now we are banging our heads up the wall to get help. Have struggled to even get a repeat prescription for the past 2 months as nobody in our local council wants to take responsibility.

- Adoptive Parent, West Midlands

Unfortunately as our health visitor stated these children 'aren't good enough but they also aren't bad enough' - constant battle to engage services and they discharge almost immediately as again there is a lack of understanding of the needs of a child with FAS.

- Special Guardian, Yorkshire and the Humber



We have had to fight for 2 years to get the specialist education that he needs. The process of producing the EHCP was the most stressful thing we have experienced as a family, knowing his whole future hangs in the balance whilst the bureaucratic and impersonal and insensitive processes conducted by the local authority slowly grind away. This has been our very worst experience, truly awful and put enormous strain on our family and our son nearly to the breaking point of adoption disruption. Thankfully, we were educated enough to put a strong case together and fight his corner. How many other children are not so fortunate? At the point of breaking, we waited 5 months for support from social services. We still have no component to our EHCP from social care and struggle on with a disabled son with no respite or short break care that suits his needs. The health component to the EHCP is virtually non-existent despite our need to see paediatrician and psychiatrist on a regular basis, there seems no future planning in

CAMHS has been a challenge for us. My son was first seen at 7. They said he was too complex. Then when he got his diagnosis they said they had no pathway for FASD.

- Adoptive Parent, North West

It's overwhelming. You can clearly see your child's needs, but to many they are invisible.

- Foster Carer, Yorkshire and the Humber

consideration here. I am also very worried for our son as he matures, I feel he will fall through the cracks in services, will struggle to get benefits like PIP as his disability is invisible unless you know him. Despite our best efforts, I fear he will end up in the criminal justice system and we know our children are far more likely to end up in prison than the general population. Where there are good people like us working tirelessly to support him, this should be recognised and we should be assisted in that aim.

- Adoptive Parent, East of England

We have had speech and language, portage also did an in-depth assessment. When asked if they had any experience dealing with FASD/ FAS was told, "I have heard of it but never worked or assessed with anyone who has had it or suspected of having it." Makes for a difficult assessment as they don't know what to look for. Between the doctor's office and health visitor, our little one was failed. Health visitor notes were not followed up and he got lost in their systems.

- Grandmother, Yorkshire and the Humber

Social workers are still not trained in FASD. Adopted parents have been dumped on, left with no support at all. Our son has been excluded from school as they say

Having received a diagnosis of FASD there were no support services that we could access to support my foster child. I tried to get a sensory assessment via our local occupational therapy team, who told me they didn't do them. They had no understanding of FASD. I have tried to get assessment through speech and language, but they have discharged us as they don't understand FASD. Before our paediatrician retired she commenced my foster child on medication for ADHD. We have had to be referred to CAMHS so the medication can continue as someone needs to oversee it. I was told by the SENCO at our primary school, not everyone recognises FASD, it's like autism years ago, not everyone recognises the diagnosis. This was true of our Ed Psych, he was happy to mention trauma and attachment in the EHCP but only a sentence to FASD. I have had to fight for recognition of FASD, I am still fighting to get a sensory assessment. I don't know where to go to get an adaptive or executive functioning assessment as the Ed Psych didn't recognise the assessment. He said there wasn't a nationally recognised assessment so wouldn't do it. I am totally unsupported and on my own as our paediatrician has retired. She was the only professional we met who understood the condition and our challenges.

- Foster Carer, Yorkshire and the Humber

they can't reach his needs so where does he go now if there is no provision? After diagnosis there needs to a medical team in place to monitor, assess and support. There is nothing!

- Adoptive Parent, South East

Occupational therapy did assessment and report indicating significant sensory processing difficulties for both children, then discharged - no therapy for either and inadequate information in report to help with strategies. We had to pay for private assessment and then get our social worker to apply to Adoption Support Fund for funding for sensory integration therapy. Have been asking social worker for non-violent resistance training and attachment support for 2 years - still haven't got access to this. Live with what would be classed as domestic abuse if they were adults with no support. Had to apply for son's EHCP myself while he was out of school. Previous school admitted they couldn't cope and would have excluded but were put off by threat of us challenging this. We kept him on roll but taught at home for 2 months while education authority found suitable school. Son left traumatised by first school.

- Adoptive Parent, North East

My daughter is nearly 6-years old and has other health problems linked from FASD. She does have a lot of absence from school due to hospital appointments, illness and through tiredness as she has sleep problems. Her school are now unsupportive as she affects their attendance record and stopped our home/school communication book, use of sensory room, etc. - even though all are in her EHCP.

- Adoptive Parent, South East



Stated Government Policy

Early intervention services can help reduce some of the effects of Fetal Alcohol Spectrum Disorders (FASD) and prevent some of the secondary disabilities that result.



Responsibility for commissioning these services lies with clinical commissioning groups.

- Lord O'Shaughnessy, 10 February 2017, response to written question - HL5052 <http://bit.ly/2kdNiAV> (This policy has been repeated on other occasions.)

Impact on Individuals and Families Due to Limited or Non-Existent Support

We asked families to give us insights into how they are affected by the challenges they face in accessing diagnosis, assessment, support or benefits for FASD. Too often families struggle to find support, strategies and professional guidance for what can be a quite overwhelming constellation of symptoms and behaviours. The secondary co-morbidities that can arise from FASD are well documented - access to support can save individuals and their families great heartache. It can change futures. It also can save Government money if provided early and appropriately.

I have a child with autism who gets a lot more understanding in the wider community due to his condition being more 'mainstream'. I feel there is a taboo on FASD and the children afflicted. It is isolating and it makes you feel like you are exaggerating or whingeing.

- Adoptive Parent, East Midlands

Destruction of family life and preventing a child who could thrive and make a positive contribution if only basic (and cheap) support was available.

- Adoptive Parent, South East

Exhaustion. Secondary trauma for whole family. Depression. Anxiety. Impact on jobs.

Impact on family life. - Adoptive parent, Yorkshire and the Humber

We feel we are constantly fighting for support and this is increasingly frustrating.

- Adoptive Parent, West Midlands

Have felt forced into home-schooling because the system has been found wanting. This has impacted on our time, career development and energy levels. Very difficult to get any respite.

- Adoptive Parent, East of England

My marriage has broken down, I suffer from depression and barely have any energy, time or money to go out. 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! I have recently made a complaint about the lack

The hardest part of living with FASD is people's lack of understanding the complex needs of the child and what the family live with on a daily basis. This is particularly true of professionals we work with who just don't get what we have to live with every day. My daughter may be 13-years old but requires constant supervision to keep her safe".

-Adoptive Parent, Northern Ireland

of support to the Chief Executive of our local CCG and am awaiting their response.

- Adoptive Parent, South East

If we'd had an earlier diagnosis I'd have researched parenting strategies early.

- Adoptive Parent, South East

We are exhausted and on the brink of breakdowns. Mum has been in therapy, on anti-anxiety pills, dad is on the edge. Both of us are on the edge of losing it all the time. We are tired, emotionally, physically,

we have no time to ourselves to recover.

- Adoptive Parent, South West

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.

- Special Guardian, East Midlands

I fear for my foster child's future. I know he will need on-going support as an adult, most likely assisted living. Being unable to get an executive and adaptive functioning

The impacts are immense and have been cited as the cause of adoption breakdowns and multiple placement breakdowns in foster care. Children and carers need to know that there is something causing the problems and that it is not their parenting. Once the condition is diagnosed a lot of education can follow.

These children need to be parented differently due to their brain damage. Strategies are enormously helpful. My daughter now understands why she has the problems with her emotional de-regulations, her memory, her understanding of abstract, her maths and her behaviours. She is no longer as violent because both she and I understand and can work together to manage her problems - we focus on her strengths and no longer use withdrawal of these as her consequences.



Diagnosis opens the door to services and support. Without diagnosis they are "naughty children" and "bad parents". Many teenagers I met as a clinician thought they were going mad. For young adults who miss diagnosis as children the consequences are very serious with extremely high risk of mental health problems, addictions and custodial sentences although these young people are functioning at half their chronological ages such that there are significant risks of miscarriages of justice. Young people with FASD don't recognise risk or learn from consequences and jail is not the right place for them. Once in the criminal system its often hard for them to get out and recidivism rates are high.

- Paediatrician (ret.)/Adoptive Parent, North East

assessment I won't have a report that highlights his needs. Without a report from a professional his needs won't exist. As a carer your voice is not heard unless you have a report to back it up. Services for autism are often ring fenced, without an autism diagnosis I fear we will not meet the threshold for support, yet the needs of FASD and autism are very similar. I feel I have a vast knowledge and understanding of FASD yet when I meet professionals they have little or no knowledge of FASD. It's really hard to get across your needs in a short face to face appointment as FASD is so complex.

- Foster Carer, Yorkshire and the Humber

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.

- Adoptive Parent, North East

It's been a black hole of despair. To be told the only thing wrong with your adopted daughter is that she had me as her mother. It stressed me to the point of illness and anxiety. Everything is so much harder and takes so much longer and is more expensive.

- Adoptive Parent, West Midlands

It has affected my health as well as my daughter's. I am unable to work and our quality

Financial hardship for whole family.

- Adoptive Parent, East of England

CAMHS said he was too complex. When he got a diagnosis, there was no pathway for FASD.

- Adoptive Parent, North West



of life is affected. My daughter's self-esteem is affected and if it's not addressed professionally along with her anxiety issues I believe we will have a bigger mental health issue in the future.

- Adoptive Parent, East of England

It's very stressful and frustrating. Worried little one will be labelled as being naughty in school. Affects everyone in the family.

- Adoptive Parent, North East

I have found it really difficult to get anyone to understand my son. For anyone to listen to me and understand. This goes for doctors, paediatricians, CAMHS, geneticists, schools and everyone in between. We even had a woman visit my son in school who had just been trained in FASD, I believe she worked for LDS, she said there was nothing she could do for my child as he wasn't 'bad enough'. No one understands or has even heard much about FASD and its effects or how to cope

with someone who has this disability.

- Birth Parent, West Midlands

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 6 months of mounting violence it could have led to adoption disruption.

- Adoptive Parent, South East

The family became insular and isolated. Our only supports were other family members who gradually felt they could no longer safely help as FASD behaviours are so extreme and place others at risk. Relationships are strained, school was our only support along with only one professional who really wanted to learn about FASD. It was impossible for both parents to work. Indeed at one point there was only one parent in the house working part time as it was impossible to care for two FASD children who were placed hundreds of miles apart away from home and we were expected to transport them. It has been financially, emotionally, psychologically and physically draining. Everyone's health has suffered. FASD has families living in fear.

- Adoptive Parent, Scotland

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. My son's emotional state has deteriorated and my 24-year marriage is suffering.

- Adoptive Parent, North East

You imagine your child and how wonderful life is going to be once you have adopted. You don't for a second think about falling into a black hole and becoming invisible to the world.

- Adoptive Parent, West Midlands

Speech and language therapists discharged as my child could speak. Because she was assessed in an office with no stimulation/distractions she was assessed as needing no support. In a busy environment e.g. the classroom she is easily distracted and it's clear she doesn't

always understand what's said. 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

Isolated.

- Adoptive Parent, East of England

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.

- Special Guardian, Yorkshire and the Humber

Son traumatised by school to extent that psychiatrist wanted to put him on Risperidone. We opted to wait till move to nurture class - meds not needed. Daughter contains at school and is aggressive at home. Underachieving significantly but school won't support. Son was violent to point we considered splitting family up to keep siblings safe from each other - has settled since moving school. His school day ends at 2.15 - meaning mum has had to significantly reduce hours at work. Dad took redundancy as child need 1:1 adult attention - it is no longer safe for 1 adult to go out with both children. - Adoptive Parent, North East

Heightened anxiety and trauma in my son. Trauma in myself for having to see him not being given the help he needs. Extended time out of education.

- Birth Parent, South East

My son is occasionally violent to us as a family but we are still fighting to get him the medication we feel he needs.

- Adoptive Parent, West Midlands

The thing I've struggled with most is work, I mean I got there eventually and got the support I need, but it was really difficult.
- Adult with FASD, East

We have bought books to study and joined Facebook pages about FASD and met up with other mums in my area and it's the same stories over and over again. What others see as naughty are sensory issues as well as a lack of processing information. We educate ourselves to help littleman have a better life as we have realised this is a lifelong battle as it's not recognised here and the lack of education and specialist [provision] is diabolical.

- Grandmother, Yorkshire and the Humber

Severe delay in education. The gap between my son and peers has widened. Emotional impact on my son as he has meltdowns at home after holding it together all day at school.

- Adoptive Parent, North West

As a former virtual school head and having been foster parent and special guardian for 8 children with FASD, I see from many sides the urgency of more joined-up thinking from all levels of government and local services on how to ensure positive outcomes for those with FASD. At present the system doesn't work for our kids but causes more damage.

- Educator/Foster Carer, East

Very stressful for the rest of the family, disruption of all aspects of life. We cannot go out as a couple as we can't get a baby sitter for our adopted daughter (FASD) who is now 14 but can't be left unsupervised. She is visually impaired and can't see to safely cross a road but we can't get a peer mentor for her so she needs to come with us if we need to go out. We have no respite and feel exhausted.

- Adoptive Parent, North East

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 had ADHD so is in the right school even though he is not.

- Foster Carer, North East

We have been accused of being bad parents on many occasions due to behavioural meltdowns, that they cannot tell are due to processing issues.

- Special Guardian, North East

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

- Adoptive Parent, South East

She became extremely anxious and became a school refuser. Anxiety had a huge impact on self-worth, confidence, sleep.

- Adoptive Parent, Yorkshire and the Humber

There is an urgent need for local diagnosis of FASD and follow-up support by doctors. There is a need to recognise FASD as a disability so that children and adults with FASD can be helped to lead fulfilling lives, rather than being overlooked and forgotten.

- Adoptive Parent, Wales

The effect has been massive. I'm a single parent with no support from any professionals at all. One son was suffering in school and at home with up to 20 meltdowns a day. My eldest was suffering as I was so focused on this child and getting a

diagnosis/support for him. Our son with suspected FASD was violent towards his brother constantly.

We must acknowledge and learn from those pockets of innovation across the UK where pathfinder actions of some practitioners, alcohol harm prevention agencies and families have begun creating FASD support, training and services whilst waiting for a national response.

- Foster Carer, North East



As a family we were seriously struggling, I felt like I was drowning and wasn't sure how much longer I could carry on.

- Birth Parent, West

Messages for MPs

Individuals and families affected by FASD have been too long absent from policy debates that directly affect their lives, wellbeing and their future. It's time to start a dialogue. This is a snapshot of what they would like policy makers to know:

This is a growing issue & a ticking time bomb. There will be children with behavioural issues in schools which are not equipped to deal with them.

There are not enough special school places or suitable accommodation.

There is not enough respite for adoptive families. These children will fall through the net and end up in prisons, addicted to alcohol & drugs unless you act to do something about this now. Families need better support & the education system needs to wise up to this.

- Adoptive Parent, East of England

We need more consultants to diagnose, better support services, GPs to know what it is.

- Adoptive parent, Yorkshire and the Humber

It's classic situation where short-term investment would have massive long-term benefits with social care, NHS, education, prison system etc.

- Adoptive Parent, East of England

Parliament needs to listen to young people with FASD as schools and society don't get it and just watch us struggle and fail. I know this from personal experience.

- Teen with FASD, South East

Families are adopting children without the care system offering them the correct early interventions so the child can reach their full potential. Then too many families and children are destroyed by the system.

- Foster Carer, South East

Please, please listen and help the silent

voices of children, teens and adults with FASD.

Through no fault of their own they have to live with a neurological disability.

They and their families deserve and need a support system in place.

They have a right to diagnosis, education and a life. Think of the

economics! We need

national training to increase knowledge and understanding of this condition, starting at schools, education, medicine, social services judicial system. Make FASD a household name.

- Adoptive Parent, South East

Now is the time to make right the inertia of the past.

- Adopter, Birth Relative, South East

FASD is real. Support, education must now be prioritised. Failing to do so will be a far greater cost.

- Adoptive Parent, Yorkshire and the Humber

FASD needs to be recognised as a legitimate disability, as would autism or ADHD. Medical staff in particular need to be made aware on how our FASD children and adults need to have adjustments made and provision given.

- Birth Parent, South East

There is a real crisis and its happening now. FASD is real, families need diagnosis and support services now. Research the number of undiagnosed people in prison, in mental health services, children in SEMH schools. Look at ADHD, is it truly that or undiagnosed FASD? You need to plan for the future, children with FASD will need support for the rest of their lives. With support individuals can lead a happy fulfilling life, without they are likely to experience mental health problems, drug and alcohol abuse and enter the criminal justice system. Look at Canada and America, follow their lead and make our country one that recognises and supports those with FASD.

- Foster Carer, Yorkshire and the Humber

This is a serious issue, this is an epidemic in this country and it is ruining people's lives.

- Special Guardian, North East

Many children with FASD are in the care system or ex-care system. They leave care only to be disproportionately represented in the prison system. This is so unfair and needs urgent attention, as they are very vulnerable children and young people. All children who are in care should be

assessed for FASD as standard part of their medicals. This should be made mandatory. Then they can get the help they need earlier. Research in USA shows that outcomes are vastly improved with earlier diagnosis and support.

- Special Guardian, North West

It's an absolute disgrace. Drinking when pregnant harms the baby far more than if the birth mother takes drugs. The brain damage caused is irreparable and living with my adopted child, I see it daily and it's heart breaking.

- Adoptive Parent, North East

Neglecting FASD is false economy. If people with FASD don't get the support they need growing up and getting an education, surely many of them end up needing more support as adults.

- Adoptive Parent, South East

Having to fight for support when you are often struggling yourself is wrong. How would policy makers feel if it was their child? We wouldn't refuse to diagnose and

There are more children with FASD than with autism. It's preventable. It's a lifelong condition. It is soul-destroying for the child and for its guardians. It's time we were heard or you are going to have to face the consequences in future.

- Adoptive Parent, West Midlands

provide support for families of children with Down's syndrome or other similar conditions.

- Adoptive Parent, East of England

Accurate diagnosis is desperately needed to show the level of affected population, and manufacturers of alcohol should be taxed directly to fund research and support for FASD.

- Kinship/Foster Carer, Wales

Government needs to acknowledge the size of the problem and tackle the root cause. More importantly we need to ensure medical professionals and social care professionals are fully trained with specialist services being developed across the country for those with FASD. Clear guidelines need to be issued with regional

Come and spend a week here. See what we live with and what we are up against in getting the right support. Then you will understand.

- Foster Carer, West Midlands

centres for assessment and diagnosis. I have witnessed first-hand the devastation caused to a family by deliberately ignoring the issue of FASD because it's too difficult and costly to tackle.

- Adoptive Parent, North East

Give people with FASD and families priority for advice/support/housing/

medical treatment...If our children aren't with us in a loving kind empathetic family- where would they be??? Costing the government a fortune...

- Adoptive Parent, North East

My children are adopted and have already had a rough start to life. I feel the government is failing them by not supplying adequate provision for them.

- Adoptive Parent, East Midlands

As far as I can see there aren't policies. I'm a mother who drank during pregnancy, who told every Doctor, Paediatrician, Geneticist, CAMHS etc what and when I drank and I was still not listened to.

- Birth Parent, West Midlands

It needs to be talked about not hidden! It appears no one has the guts to discuss FASD in the mainstream. Put it out there for all to read 'there's no safe amount of alcohol in pregnancy'. Make it clear!!!

- Special Guardian, Yorkshire and the Humber

The professionals don't know enough about FASD and what our children actually need. It's equally as frustrating for a lot of the professionals.

- Adoptive Parent, North East

More research is needed, especially in courts and prisons as I am worried this is where she will end up.

- Adoptive Parent, East of England

My little one's medical record is as long as my arm and we were just fobbed off or mis-diagnosed. When I was shouting from the rooftops about FASD, they treated me like an idiot.

- Grandmother, Yorkshire and the Humber

Let me speak to you and tell you what it's like to raise society's children, as in our two adopted children who have FASD.

Society should provide

everything they need yet it didn't.

Government abandoned these children and continues to do so.

- Adoptive Parent, Scotland

These children and adults are amongst most vulnerable in our society. My daughter looks like a normal 11-year old approaching puberty but behaves [like] a toddler. She is at risk throughout her life of being a victim of abuse, exploitation as she likes to please and has no boundaries. We will have to supervise closely well into adulthood and this is only possible because she will be in a protected school environment. If she was going to mainstream we feel sure we'd lose her. Sounds dramatic but we've seen her behaviour around boys, men and teenagers.

- Adoptive Parent, South East

If time, effort & support are put in whilst our children are young, then it will

Simple preventative measures would have massive cost savings.

- Adoptive Parent, South East

ultimately save the NHS money (and save our families a lot of anguish) later on. The statistics for teens and adults with FASD who haven't had the right support when

young are shocking. The UK

Government needs to take a leaf out of Canada's book, as they lead the world in their research and support of FASD.

- Adoptive Parent, South East

Doctors should have to be trained and so should other professionals.

- Special Guardian, East Midlands

All Local Authorities / County Councils should routinely and regularly run information sessions/training sessions on FASD for adopters, foster carers, teachers and support workers. Awareness of FASD should be part of teacher training.

- Adoptive Parent, North West

By ignoring the devastation in-utero alcohol damage and FASDs have on individuals' lives, the way it wrecks and tears apart healthy family units, you are putting the future of society at peril. By ignoring the

adoptive families who you have implored to take in these children you are giving up on these

Thousands of children are being failed by the NHS due to the lack of a coherent policy.

- Adoptive Parent, South East

children. By refusing to support these families and refusing to acknowledge the problems they are facing, you are creating a future where fewer people will be willing to adopt, more children with FASDs will be born.

- Adoptive Parent, South West

People with FASD have many strengths. Thousands of families across the UK are trying to help loved ones maximise their potential. We implore Government to address their lifelong needs comprehensively.

- Adoptive Parent, East of England

People need knowledge, professionals need teaching. Mental health needs an FASD pathway. The prison justice system needs to be aware of FASD and gain understanding. Parents and people with FASD need a support system. So many people are being let down because of the epidemic that is FASD in this country. Funding and knowledge is needed.

- Adoptive Parent, North West

We should be ashamed of the harm we are causing to our children. We will have a significant number of adults with FASD and once this happens its harder to get interventions in place. I believe all taxes gained from alcohol sales should be channelled into services for those affected. Minimum pricing should

be raised as in Scotland. In Canada alcohol can only be sold in liquor stores, not in newsagents, corner shops and supermarkets. There are so many ways this can be tackled and it must beby Government.

- Paediatrician (ret.)/Adoptive Parent, North East

Early intervention is the key to help my children succeed. Yes, it costs you money but the long-term cost to health, education and support services without early intervention will cost so much more.

- Adoptive Parent, North East

Acronyms (please see p. 4 for FASD diagnoses)

- ASD - Autism Spectrum Disorder
- CAMHS - Child and Adolescent Mental Health Services
- CCG - Clinical Commissioning Group
- DLA - Disability Living Allowance
- EHCP - Education, Health and Care Plan
- ESA - Employment and Support Allowance
- LDS - Learning Disability Services
- LA/LEA - Local (Education) Authority
- OT - Occupational Therapy
- PIP - Personal Independence Payment
- SEMH - Social, Emotional and Mental Health
- SENCO - Special Educational Needs Coordinator
- SGO - Special Guardianship Order



Promote the Chief Medical Officers' Guidance

The 2016 CMO Guidance stating clearly that if you are pregnant or trying to become pregnant, the "safest approach is not to drink alcohol at all" was an extremely positive step forward, but it has not filtered far enough into society, nor is the message consistently advocated, taught, and distributed. As of May 2018 NICE still has not updated its website, for example (<https://www.nice.org.uk/guidance/cg62/chapter/1-guidance>). This is unacceptable and contributes to confusion.

* It needs to be embedded into society that it's too dangerous a risk. As a woman I feel we don't know enough about what could happen. We know it's not good, but we aren't educated on how bad it is.

* Speak about risks openly, the same as smoking. People can still make own choices, but they are informed choices.

* It needs a national campaign. We have them for smoking in the past, for crossing the road, we have 5 a day, we have the healthy eating, low sugar ones. It's simple, we aren't saying don't drink, we are just saying don't drink if you are pregnant or trying to conceive.

* Retraining for all health practitioners, even if only a short session cascading down the organisation.

* Better labelling on alcohol.

* In the USA they have signs up in the women's toilets, why not here?

* How about sending info in post to all women when they register with a midwife. Posters in antenatal areas.

* Prospective adopters certainly need a lot more information. Adoption agencies must be compelled to make this information available to adopters.

* Training of doctors/midwives so a consistent message is out there.

* Information provided to people trying for babies and when people find out they are pregnant.

* All GPs to issue advice to women of child bearing age and on display at surgeries.

* Start with schools, educate teenagers during sex education and keep covering it. Show them the damage alcohol can do to a foetus and the lifelong disabilities and health needs the babies are left with.

* Advertising campaign, public health information, interviews with affected families & people with the condition.

* A constant definite message should be given out by all professionals. It's astounding that people still think there is a 'safe' limit.

* Part of curriculum at school.

* Health visitors, midwives and nurses - training for pregnant women.



- * Make addiction/detox services readily available in every community.
- * National advertising campaigns in supermarkets, any outlet selling alcohol, all community buildings and medical service providers.
- * Make FASD a household name.
- * Get the bloody message out there: No drinking in pregnancy, it causes permanent brain damage and neurological disorders.
- * Pubs should have posters up.
- * Make advice even more explicit and include in all other public health guidance.
- * Supportive campaigns - less stigma but visible
- * More and better training of doctors, nurses, midwives, teachers, social workers etc - new recruits and continuing professional development.

* School should provide both girls and boys with a lot more information about the risks of drinking alcohol in pregnancy. Boys need to know so that they can support their girlfriends/ future wife during their pregnancies and help to sustain positive healthy behaviours.

* It should be highlighted in the media with no contradictory messages being given out that one or two drinks are OK. Educate editors

of programmes like This Morning and other popular tv shows. Include in soap operas. More documentaries on FASD. Use actors with FASD.

- * Use alcohol tax and duties to cover costs of services and prevention awareness.
- * I recently went to my local maternity hospital with my pregnant daughter. There was not one poster or information leaflet about FASD. People still think it's OK to drink in pregnancy.
- * It should be taught in schools, colleges and universities. Most people think that it's only alcoholics that give birth to children with FASD, this way of thinking is very misguided.
- * National media, BBC, etc. should promote more information about the long term effects of drinking during pregnancy.
- * Educate judicial service.
- * Posters in schools, hospitals, doctors, pubs, restaurants, anywhere.



* Public information advertisement should be bombarded across the country to make pregnant women and their support network/families fully aware of the risks.

* In Scotland a huge public health campaign was undertaken - together with countrywide training - why is England so far behind them?



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

YouTube Channel: FASD UK Resources

CONTACTS

UK & European Birth Mothers – FASD

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FASD Alliance Ireland (an all-Ireland sister alliance)

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FASD Awareness South East

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E. Hertfordshire and Area FASD Support Network

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FASD Dogs UK

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FASD Network UK

Support groups throughout the North East
www.fasdnetwork.org • Maria Catterick,
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A coalition of groups and individuals from across the UK united together for positive social change for those affected by Foetal Alcohol Spectrum Disorders (FASD). Affiliates include small local, regional and virtual groups as well as some of the country's longest standing national organisations devoted to FASD, with links to international networks.

fasd-uk.net • fasd-uk@live.com • @FASD_UK

FASD Northwest

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