All Party Parliamentary Group on FASD

INITIAL REPORT OF THE INQUIRY INTO THE CURRENT PICTURE OF FASD IN THE UK TODAY

December 2015

About the APPG on FASD

The All Party Parliamentary Group on FASD was set up in June 2015 to address the growing issue of FASD in the UK and to enable Members of both Houses to have a platform from which to encourage debate and influence policy on this key public health matter, with a view to continue to raise awareness of FASD, to seek both a reduction in prevalence of this condition and the establishment of appropriate support mechanisms for those affected by FASD.

The APPG is Chaired by Bill Esterson, MP and secretariat services are provided by The FASD Trust.

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***as at 09/12/15**

Acknowledgements

We would like to thank all the groups and individuals who submitted written and oral evidence to the inquiry. Where individual testimonies have been used in this report, key details have been changed to ensure anonymity.

This report has been written by Julia Brown and Stefan Lang of The FASD Trust on behalf of and in partnership with the APPG Members.

Disclaimer

The facts presented and views expressed in this publication are those of the APPG Members and the content has been agreed by Members. The content is not necessarily endorsed by the political parties of the Members of the Committee or The FASD Trust and its associated projects, Oxford Foundation for FASD (www.oxfordfoundation-fasd.com) and FASD in Education (www.fasdineducation.co.uk).

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Foreword

Foetal Alcohol Spectrum Disorder (FASD) is a life-long condition caused when a person is exposed to alcohol in the womb, leaving the affected individual with a range of physical, behavioural and cognitive difficulties.

The World Health Organization estimates that at least 1% of the global population is affected by FASD. Our Inquiry concluded that there is an urgent need for a UK prevalence study, and highlighted that some sections of UK society are more likely to be disproportionately affected by FASD, such as children who are in foster care or have been released for adoption. The implications of this for both governmental policy and local authority practice are one key area this reports highlights for further consideration.

The argument is that FASD is theoretically 100% preventable if all pregnant women are given clear advice regarding the potential risks posed to their unborn child if they drink alcohol during pregnancy. However, the point was also made that some babies may already have been affected before their mothers even know they are pregnant, and since approximately 50% of births are unplanned, it would be impossible to prevent completely. The Inquiry heard evidence of a Danish study which found that once national guidance had been changed to a clear no alcohol in pregnancy message, they saw an increase from 69% to 83% of women choosing to abstain from alcohol during their pregnancy. This supports one of our major recommendations arising from the evidence presented during the Inquiry that NICE, the Royal College of Obstetricians, the Royal College of Midwives and the Department of Health should all give the same message of “no alcohol in pregnancy is best for baby and you” and advice must also say that women who are trying to conceive should avoid alcohol completely. As the Inquiry discovered, this advice is given in many other developed countries, including the USA, where such an unambiguous message has been given since 1981.

We believe that a high proportion of children with a variety of behavioural difficulties both in childhood and later adult life are the victims of FASD. This is not only tragic for them and their families but imposes substantial social and economic costs on wider society. More research needs to be done to substantiate this link, but we are confident that this is the case from what evidence is already available both from Britain and elsewhere and from what our witnesses have told us. Such children in Canada are described, perhaps somewhat unkindly, as ‘million dollar babies’.

Another clear strand that emerged from our Inquiry is that whilst more children are being diagnosed with FASD, and at a younger age, there is still a major gap in appropriate support and advice post-diagnosis. As the first generation of children diagnosed with FASD are now becoming adults, we hope this report will serve as a catalyst for the Government and adult service commissioners to consider closely how they are going to support not only the current generation of adults with FASD, but the many others likely to follow.

The issue of the number of young people with FASD who come into contact with the criminal justice system was related in some depth during the Inquiry; we hope in 2016 to explore this phenomenon in more detail through the APPG.

To both myself and the Members of the APPG, there are strong economic arguments for advocating abstinence during pregnancy and thus reducing the prevalence rates of FASD in the UK. The cost of implementing clear public health messaging when compared to lifetime costs of supporting a person affected by FASD are vast, the latter costing our economy millions of pounds.

We therefore hope that Ministers, Government and other bodies will study our recommendations closely and we are hopeful of their positive response.

Bill Esterson, MP

Chair of All Party Parliamentary Group on FASD

December 2015

CONTENTS

Introduction

Background

Following its launch in June 2015, the Members of the APPG decided that it would be helpful to the work of the group to begin by having a clear understanding of the current picture of FASD in the UK today. Therefore over the summer a Call for Evidence was issued and the Members were pleased with the response received not only from many parents and carers of children with FASD but also from individual professionals, public bodies, organisations and companies.

Inquiry & Evidence

Written evidence was received by the Members and the Members then held a private session with a group of parents and carers, a young man in his early twenties affected by FASD and a boy aged nine with FASD.

On 3rd November 2015 and 10th November 2015 the Members heard Oral Evidence in Public from the following:

Martin Clarke, TACT

Anne-Marie Winstone, Research Midwife, Addenbrookes Hospital

Dr Raja Mukherjee, Consultant Psychiatrist, Surrey Borders NHS Partnership Trust

Professor Sir Al Aynsley Green

Brian Roberts, Former Virtual Head Teacher and FASD Trainer

Joanna Buckard

SAB Miller plc

British Pregnancy Advisory Service

A separate document, Appendix I, contains the written submissions from organisations and professionals. Appendix II contains anonymised versions of the submissions from affected individuals and their parents / carers.

Next Steps

The APPG Members will now use the evidence received and this initial report to inform their work over the next year and they intend to consider certain aspects in more depth, with the aim of issuing further specific recommendations.

Pregnancy & Alcohol

The Inquiry highlighted two prevailing views regarding alcohol and pregnancy. The British Pregnancy Advisory Service (BPAS) voiced the opinion that women must retain the right to make their own choices and that it is unreasonable to “scaremonger” and frighten would-be mothers by warning them of the potentially devastating consequences of drinking alcohol during pregnancy. Anecdotal evidence was cited to suggest that some women seek terminations because of a concern that their unborn child will have been affected by their drinking alcohol during the early stages of pregnancy. It was noted by all who presented evidence that many women remain unaware of their pregnancies for some time and therefore this was a potential cause for concern.

Other submissions to the Inquiry sympathised with this view. RCOG in their written evidence commented, “We must acknowledge that the majority of women drink responsibly, and that a ban on alcohol consumption during pregnancy may instil feelings of guilt in sensible, rational individuals”.

The APPG Members agree that women do indeed have the right to make their own choices, however, emphasise that this choice should be predicated upon medical science, with all the appropriate empirical evidence made available to prospective mothers. However, Members also take the view that when women drink in pregnancy they are not just responsible for their own health but that of another potential human being who can be damaged for life with serious and often tragic implications for themselves but also with ramifications and ongoing costs for wider society.

In this respect it was argued that the UK should fall in line with international best practice, which advocates that alcohol should be avoided if a woman is pregnant, think that they might be pregnant, or are trying to conceive.

To enable women to be able to make a decision about whether they think it appropriate to drink alcohol during pregnancy, whilst avoiding creating undue stress by issuing dire warnings, clear advice based on medical research is crucial. A comparative example is the clear message given by governmental departments that smoking during pregnancy affects the foetus and therefore should be avoided. The same transparent guidance should be provided with regards to alcohol consumption and pregnancy.

Of particular importance in providing prospective mothers with advice that allows them to make an informed decision are midwives, several of whom contributed to the evidence of the Inquiry.

One professional noted that Substance Misuse Midwives, historically in place to support women who have drug habits, are seeing an increase in referrals for women who have problems only with alcohol.

In spite of this, the available evidence pool suggests that many midwives are uncomfortable giving advice about alcohol. A study questioning 200 midwives in East Anglia found that only 60% of respondents asked women about their drinking habits, one-third provided information on alcohol during pregnancy on a regular basis, 30% advised against binge drinking during pregnancy and just 11 respondents felt confident in raising the issue of FASD. Indeed, only 10% were aware of what FASD was. This is astonishing and deeply worrying and something which must be rectified as a matter of urgency with rigorous programmes of education for all women of child-bearing age and medical staff at every level. It is noteworthy that in Canada girls even in primary education are made aware of the dangers to babies of drinking alcohol in pregnancy.

It was reasoned that this lack of awareness and uncertainty mainly stems from the unclear guidelines provided by professional and governmental bodies such as NICE and the Department of Health which, whilst warning of the potential for alcohol to harm a foetus, do not stipulate that women should abstain from drinking during pregnancy. This is contrary to the guidance provided in other countries such as the USA which, since 1981, has advocated abstinence ("no alcohol is safest for baby and you").

How, the Members asked, could midwives provide women with clear advice to make informed choices when they themselves were getting contradictory information? The British Medical Association, in contrast to NICE and the Department of Health, advocates abstinence during pregnancy.

Illuminatingly, 93% of the midwives in the East Anglia study indicated that they would be comfortable advising abstinence to their patients if this was the consistent message from the governmental level downwards. In the absence of such clarity, they are afraid to offer such advice.

This inability to offer women the means to make informed choices about drinking during pregnancy is largely the result of a lack of British-based research on FASD and the failure of government departments and service providers to acknowledge the widespread mainly international research that has already been carried out.

Medical Perspective

The Inquiry highlighted the urgent need for a thorough UK-wide Prevalence Study to ascertain the number of people with FASD living in the UK. Such a study has been campaigned for by a handful of medical professionals for several years and is crucial to better inform local and national Commissioners, whilst also enabling them to assess the impact of prevalence reduction interventions in the future.

Testimony was provided by Dr Raja Mukherjee who was a member of the Steering Group for the World Health Organisation (WHO) on FASD, which formulated a protocol for conducting prevalence studies in various locations across the globe. The UK, as a "first nation" in terms of healthcare, would be expected to fund its own prevalence study but to date proposals by Dr Mukherjee and various colleagues for the UK have been rejected.

Dr Mary Mather noted that a search for "fetal alcohol" in an archive of world-wide medical publications produced more than 14,500 articles. Virtually none of these papers were written in the UK. This lack of research inhibits the production of definitive guidance in Britain and has led to unconsidered and diverse opinions about alcohol, where every professional has a different view and pregnant women are left confused and uncertain. However, this research base can only be sufficiently expanded once the scale of the problem is known. Therefore the Members are clear that the absence of a prevalence study is hindering the research necessary to increase the knowledge base of those who count (i.e. medical professionals dealing with pregnant women and children).

Several testimonies highlighted the fact that there needs to be appropriate training and national standards adhered to amongst medical professionals in relation to FASD. Without such standardisation there is the scenario, currently realised, whereby many medical professionals have an inadequate knowledge base. Indeed, it was noted that “a little knowledge can be dangerous” with medics making wrong assumptions about FASD. A classic example is that in the absence of a child displaying the classic facial features associated with full Foetal Alcohol Syndrome (FAS), doctors are inclined to discard FASD as a potential diagnosis. This, despite the fact noted by Dr Mary Mather, that over 85% of children damaged from prenatal alcohol exposure have no physical birth defects.

This lack of in-depth knowledge means that children with FASD are usually given multiple inaccurate diagnoses. Many are diagnosed as having ADHD, atypical autism, an attachment disorder or a conduct disorder. As such, the appropriate support mechanisms are rarely put in place and parents/carers are left frustrated and confused.

In-depth knowledge will only come about through indigenous research, supported by a national prevalence study. This will subsequently allow for improvements in prevention, supportive treatments and service planning. Everything is interlinked.

Perhaps because of the absence of a comprehensive prevalence study, and a lack of general awareness amongst governing departments and bodies, there is only one FASD clinic in the UK (run by Dr Mukherjee in Surrey). Despite being within an NHS Foundation Trust service the clinic is currently not properly funded so that many parents and carers have to pay personally in order to access its diagnostic and assessment capabilities. Not only that, but the waiting list for a full assessment is considerable, with few referrals given (and therefore funds available) from local councils or other NHS Trusts unfamiliar with FASD.

Other medics are attempting to run FASD Clinics within their normal community clinical schedules and some separate work is being carried out in Ayr, in Scotland, but all of this is under-funded and unrecognised.

Whilst the NHS and other bodies continue to not see FASD as a priority, more sustainable NHS funding routes will continue to be inaccessible.

The FASD Trust, in conjunction with Dr Mukherjee and others, have proposed a three-tier system of diagnostic and support services, with a national hub, regional centres and local support, which fits the NHS service delivery model.

Post-diagnostic support is also required to enable individuals to reach their full potential and also for others to understand how the individual with FASD functions so that non-medical support can be tailored accordingly.

All of the medical professionals that provided evidence to the Inquiry acknowledged that a vicious circle exists whereby adequate training and clear guidance on FASD across the services is absent. This is due to a lack of in-depth and consistent research in the UK on FASD, which itself is dependent upon knowing the scale of the problem; this in turn requires a thorough prevalence study to be undertaken, yet such a study is currently not being funded because of the lack of research providing clear scientific evidence on diagnostic criteria.

Despite the overwhelming scientific research carried out in countries overseas, particularly Canada and the USA, the key stakeholders in the UK are remaining deaf to these studies, insisting upon a national evidence-base yet unwilling to provide the funding for the research that will provide it.

This inadequate evidence base has restricted knowledge and awareness of FASD not only in the medical profession but across all relevant service providers in the UK. Those most affected by the incoherent and inconsistent guidance resulting from this insufficient knowledge pool are families, carers and, of course, those with FASD.

Those Most Affected - Parents, Carers and People with FASD

Numerous submissions were received from families affected in some way by FASD (see Appendix II). Additionally, a small group, including a child and a young adult with FASD, attended Parliament to meet with the Members.

Common themes emerged from both the written and oral evidence received by the Inquiry.

Concerns were expressed by all families that parents – with no medical training - have to explain the diagnostic nuances of FASD to medical staff. The FASD Trust has received written assurances from the Department of Health that funding has previously been allocated to medical training specifically to ensure the issues around FASD are covered, but those present indicated that evidence of this is yet to be found.

This lack of awareness of FASD extends across the board, with people having to explain their own difficulties or that of the child they are caring for to their own extended family, their neighbours, the school and a multitude of others who are involved in their lives.

The spectrum of FASD was also noted, how it affects one person more significantly than others, and how the visibility of impact can vary depending on the school or social setting.

The emotional impact was also revealed with reports of those affected by FASD withdrawing from society, feeling suicidal and becoming extremely unpredictable, especially when faced with misunderstanding in the community. This, in turn, places great stress on parents and carers, with many of them having experienced periods of isolation and ill-health.

Many parents stated that a national standard was required regarding diagnosis and commissioning of support services. It was noted at the closed private oral evidence session, that those in the room had obtained a diagnosis as early as one-month old or as late as ten-years old, or had no formal diagnosis at all. It was noted that even within the same family, a diagnosis was obtained at differing ages due to the "chance" of which professional a child was referred to see, with too many people being given an inconclusive answer. This is a completely inadequate and incoherent diagnostic system, which has a "knock-on" effect for families, especially when trying to access help from non-medical services (e.g. schools).

Post-diagnostic support from statutory services for affected individuals and their families, including from the NHS, was described as either negligible or inconsistent and often inappropriate. For example, children were referred to Child and Adolescent Mental Health Services (CAMHS), which predominantly provide psychotherapy / counselling, not necessarily of value to the child with FASD who has "behavioural problems" stemming from organic brain damage.

The issue of support in school for children with FASD was raised and the difficulties many experience as their children are academically bright enough for a mainstream environment but socially and emotionally repressed in comparison to their peers. Many children with FASD fail academically as they cannot manage in the school environment, rather than due to any academic deficiency.

Concerns were voiced by all parents and carers about the vulnerability of those with FASD as they move into adulthood, where they cannot meet societal expectations and norms and where they can easily be exploited by criminal gangs and sexual predators. Evidence was heard of how some families have suffered the horrific consequences of their adult children being exploited and drawn into the criminal justice system. Lack of support for adults with FASD was highlighted as a major theme, a continuation of the inadequate support mechanisms for children and adolescents.

There was a marked consistency across the evidence submitted by parents and carers of those affected by FASD. A clear conclusion is that the UK currently offers inadequate provisions for FASD diagnosis, therefore failing to put in place the requisite support structures required for these children at an early age. This in turn places an enormous burden on parents and carers for being the sole provider of support, putting great strain on their physical, emotional and financial capacity. Repercussions include marital breakdown, bankruptcy and neglect of other "unaffected children". In many cases, the lack of societal and governmental support has led to the children with FASD being placed into/returned to the adoption and fostering system which, as the next section demonstrates, causes its own problems.

Social Care and FASD

The evidence received from parents and carers indicated the significant proportion of children in the care of the local authority or adopted who are affected by FASD.

Internationally, the research indicates that 30% to 50% of children in foster care are potentially affected by FASD. In the UK, Dr G Gregory's audit in Peterborough (published in the CoramBAAF Journal of Adoption & Fostering, October 2015) found that 34% of children referred to a community clinic for looked after health assessments and 75% children referred for adoption medicals had a history of prenatal alcohol exposure.

If the figures across the UK are the same as they are in Peterborough – and anecdotal evidences suggests that they may be – then this has major implications for Government policy on adoption. In essence, adoption in the UK could be said to have become predominantly a family finding service for children with FASD.

The Oral Evidence presented by Martin Clarke from TACT highlighted the importance of raising awareness amongst social workers so that they can forewarn potential adopters before placing a child. The survival of placements is sometimes tenuous, without confusion arising because of abnormal child behaviour that has not been attributed to an identifiable cause. Whilst only 3-5% of adoption placements break down, 25% are always "on the verge" and undiagnosed conditions can be the factor that causes a final disruption.

The FASD Trust at their helpline have noted over the past year an increase in calls from potential adopters wanting to receive more information prior to deciding whether or not to proceed with adopting a child with FASD whom social services wish to "match" them with. Whilst this is clearly a step in the right direction, there are still too many children being placed for adoption without adopters or their adoption support workers fully understanding the implications of FASD.

Martin Clarke raised the issue of the increasing number of special guardianship orders being granted, often to people of an older age. Frequently these are grandparents looking after grandchildren as one of their own children has an alcohol (and/or drug) problem. There is concern that without the right information and support for these carers, the children will simply "bounce" back into the care system.

Foster Carers are another important part of this framework of support for children in care. It is vital that foster carers are aware of FASD and understand how to care for an affected child / young person.

Information sharing is key. It is vital for the future wellbeing of the child / young person that any data about their mother's alcohol consumption during pregnancy and its possible implications are shared with all who have responsibility for the child / young person. It is important that social workers, foster carers, adopters and any substitute carer are fully informed and thus able to properly support the individual.

There are implications, of course, for adults with FASD and therefore adult social care. As awareness of the condition is slowly rising, a number of young adults concerned that they may have FASD are coming forward themselves, seeking medical support and diagnosis. As awareness is increasing about FASD amongst the adoption community, many are realising the struggles they have faced are due to the fact their now adult child has FASD. (One couple adopted their son at 7 weeks old; he is now 37 and has just been diagnosed with FASD).

There is a large cohort of young people who have been diagnosed with FASD over the last 12 years, who are now young adults, and they require support for life. However, many fall outside the current parameters of adult social care. FASD is often referred to as an "invisible disability" as it is brain function which is affected, not necessarily intelligence levels (IQ) or physical features. Another subtle factor of FASD is those affected have good expressive language skills so appear highly verbal and accomplished, which masks their poor receptive language skills and inability to follow instructions or complete simple tasks. This contradiction is very often misunderstood by social care and medical services.

Adult social care urgently needs to address the issue of how it supports those with FASD, what kind of support they need and how, within budgetary constraints, it is possible to support and safeguard these vulnerable adults.

Education

The testimonies provided suggest that, as far as education goes, children with FASD often cope at nursery and foundation stage. However, by the time that they reach about year 6 and the end of key stage 2, the gap between them and their peers is glaringly obvious, even for children on the lower end of the spectrum. Primary schools tend to have excellent pastoral, wrap-around care, but the move to the "independence" of secondary school is when many children with FASD tend to be failed educationally.

One of the biggest issues in school is the lack of awareness amongst staff regarding FASD. If the condition is not identified, then there are too many misconceptions about the child's capability to learn. Teachers do not have appropriate expectations and lack the knowledge and skills to adequately encourage the children to learn, particularly when the child has not received a diagnosis (the difficulty of which is alluded to above).

As a result of the lack of awareness and support within the education system, too many children with FASD end up being home-schooled. As former virtual school head Brian Roberts notes: "Too many children affected by FASD have disrupted education, far too many have permanent exclusions largely because they cannot meet the expectations of the schools and it is very tiring for professionals to maintain conditions which promotes appropriate learning. This is despite the clear guidance on meeting the needs of children with medical conditions. If a child is not in school, then they can't learn. Therefore, it is vital that schools change their expectations of affected children and this cannot happen without much greater understanding".

The APPG Members intend to return to the issue of Education and FASD in the New Year as this important thread was mentioned by many parents and carers and Members believe the potentially significant number of children in school with FASD must be causing major impact and affecting the UK's ability as a nation to raise educational standards, particularly if the needs of a large sub-set of pupils are not being met.

Economic Impact

The Inquiry heard evidence of the “hidden” economic impact of FASD. Families where the parent is unable to work as it is impossible to maintain full-time (or even part-time) employment while caring for a child with FASD. The constant calls into school; the multiple appointments, telephone calls, emails and meetings with different professionals; the endless forms for EHCPs, benefits or other support; the frequent bouts of illness or other physical problems requiring yet more hospital visits; the non-existent respite; it all adds up to a 24/7 role.

Many children and young people with FASD qualify for Disability Benefits. Their parents / carers who are unable to hold a job, end up claiming additional benefits. Many adults with FASD are unable to hold down a full time job, or gain any employment at all. Therefore there is significant national impact in terms of lost tax earnings and drain on welfare resources.

There are also the more instantly quantifiable costs. Brian Roberts said in his evidence that the cost to the education system for children in care is estimated at £100m last year. It is costing some local authorities £3,000 a week to support children with FASD, making it an approximate total £150,000 a year per child. These costs are often elevated due the fact that the child’s FASD has not been properly diagnosed or understood thus an inappropriate – and highly expensive – support option is sought.

Costs are also passed to the NHS, as these children require input from a multi-disciplinary team drawn from paediatrics, speech & language therapy, occupational therapy, physiotherapy, psychology and psychiatry services, educational psychology, teaching / learning support assistants. In addition, about one third have heart defects requiring surgery or on-going treatment; a significant number have major dental issues, problems with their eyesight, bladder problems requiring support from incontinence services and a proportion have walking difficulties meaning they require wheelchair services.

Those born with FASD are often born premature, thus requiring specialist services at birth. Some have significant feeding difficulties requiring them to be “tube fed”, which again costs in terms of specialist nursing, medical and equipment all provided by the NHS.

As yet the cost to the UK criminal justice system has not been quantified, but the Canadians estimated that around 35% to 45% of their prisoners have FASD. The APPG intend to explore this matter further in 2016.

The other cost in the UK is that of children’s social care and the family courts. It has been noted already that the individual children who are costing local authorities the most are often the ones who are most significantly affected by FASD.

Unsurprisingly, the Canadians call children with FASD, “The Million Dollar Babies”.

The Alcohol Industry and FASD

Evidence was received from several large companies within the drinks industry, all of which displayed their commitment towards reducing FASD prevalence rates and giving women suitable advice about the perils of drinking when pregnant.

One of the key means through which the drinks industry can, and does, raise awareness about the harm of alcohol consumption for foetus is bottle labelling. Nearly all alcoholic drinks bottles/cans in the UK (about 91%) carry a warning about drinking during pregnancy.

However, it was acknowledged that this labelling is different to that seen in countries overseas. For instance, bottle labelling in Canada, the USA and South Africa, amongst others, is both mandatory and provides a far more severe warning message about the potential effects of alcohol consumption during pregnancy.

Contributors from the drinks industry stated that the more tepid warning labels in the UK are because of the current NICE guidelines (and similar) which do not specifically advocate abstinence during pregnancy. The key for the drinks industry is to comply with national regulations and guidance and this happens to be weaker in the UK than some countries abroad, explaining the smaller and less explicit labels.

The Members emphatically advocate a mandatory label size and message on all alcoholic drinks containers that women should avoid alcohol during pregnancy. The urgency of creating clear guidelines through governmental departments is therefore clear, because without this the drinks industry will not comply with the safest message.

The impression gathered is that, in many respects, the drinks industry is being more proactive than some government departments and commissioning bodies. SAB Miller representatives testified that their company tries to provide additional information about the potential harm of alcohol in pregnancy through links to websites. They take a holistic approach starting with raising awareness through labelling, providing links to additional digital resources to increase awareness and understanding. Additionally, overseas they have funded programmes in alliance with healthcare stakeholders to change social attitudes and norms. Many of these programmes have been undertaken with success in South Africa and Europe.

SAB Miller indicated that the most successful awareness raising programmes had occurred in countries where engagement between the drinks industry, NGOs and political bodies at a local, regional and national level occurred, with continuous feedback from all groups. They had not seen this in the UK.

It is imperative, in the Members' opinion, that the goodwill of the drinks industry is harnessed through clear government and healthcare guidance to establish a supportive partnership between the potential source of FASD and those bodies ultimately responsible for dealing with its consequences.

International Perspectives – How Far Behind is the UK?

As was demonstrated by every contributor to the Inquiry, whatever field they worked in, the UK finds itself considerably behind other developed countries when it comes to raising awareness, offering clear advice and putting in place appropriate support mechanisms to reduce the prevalence and mitigate the consequences of FASD.

This situation was even more explicitly addressed in the evidence presented by Professor Sir Al Aynsley Green. In particular, he demonstrated the comprehensive approach of the Canadians to managing the FASD issue. He noted that in Canada there exists a concerted political will to combat FASD at both a federal and provincial level, particularly following the realisation that 35-45% prison inmates have FASD symptoms and that FASD issues cost the country between approximately $1.5bn and $2.2bn a year.

This comprehensive political will, in his and the Members' opinion, is absent from UK governance at a national and local level. Yet the extent of the issue is potentially greater in the UK, exacerbated by the British drinking culture and the lack of awareness over FASD, which is expounded upon earlier in this report. As has occurred in Canada, there is a pressing need for economists in the UK to measure the societal impacts of FASD, as well as healthcare professionals and politicians. The Members hope that the formation of this APPG and the publication of this report will be another step forward in altering this position, gathering support for such an endeavour.

In Canada the government took a firm stance advocating abstinence during pregnancy which led to a change in societal attitudes. This position was emphasised from an early age by teaching even young children that drinking during pregnancy can damage a baby and the Canadians have even established a national programme called "Roots of Empathy" to teach healthy holistic attitudes.

There are five federal level programmes explicitly dedicated to FASD in Canada with large funding bases, dedicated research bodies and expert input. Funding for research in the UK is minimal, with no resources set aside by governing bodies and departments for nationwide research programmes.

Pregnant women in Canada, Denmark, France, Norway, Israel, Mexico, Australia, Ireland, New Zealand, Spain and the Netherlands are now advised to abstain completely from alcohol. There is an apparent reluctance in the UK to follow the message of this growing international coalition, partly because of the lack of British research and a consistent evidence base with clear recommendations along the lines advocated overseas. Without government support, however, this research is impossible and therefore there is a perpetuation of unclear guidelines.

Clinically, too, the UK is a long way behind its international partners. In Canada and the USA, multidisciplinary teams based on models in wider neurodevelopmental services are available at the local and regional level, whereas only one such institution exists in the UK (Dr Mukherjee's Surrey clinic), to which funded referrals are extremely rare.

Again these crucial support services require the government and departmental bodies to recognise the scale of the FASD problem in the UK, taking Canada's lead by commissioning regular prevalence studies to determine whether preventative action is working and to ensure that suitable management procedures are put in place for those already affected.

What is most disconcerting is that, despite the extensive international evidence and clearly-demonstrated prevention and management strategies put in place in countries such as Canada, those in the UK with the power to mirror such achievements appear reluctant to do so.

Conclusion

Our Inquiry has demonstrated the tangible personal, societal and economic impacts of FASD, the devastating affects the disorders have on families, carers, social workers and even those in the medical profession unable to make their voices heard.

Despite all this, the evidence presented demonstrates that the UK is lagging far behind similarly-developed countries across the globe when it comes to implementing effective prevention and management guidelines, services and strategies to confront the challenges posed by FASD.

A handful of dedicated and knowledgeable professionals have succinctly demonstrated the work that needs to be done to elevate the UK response to FASD to a level comparable with Canada and the USA, in particular. Both these nations have shown the positive impact of promoting strict abstinence guidelines for women during pregnancy, backing up this message with an extensive research base, public awareness campaigns, clear messaging on alcohol bottles and ingrained training policies for all professionals likely to be able to give advice to prospective mothers.

In instances where children are affected by FASD, countries such as Canada and the USA have put in place clinical and emotional support structures from the local to the national level, ensuring that no family is prohibited from accessing the help they need to give their child the best possible opportunity to thrive in spite of their condition. Such a support structure is sorely absent in the UK and will not be rectified until the government and its affiliated bodies recognise the severity of the issue – proving the local pilot programmes and anecdotal evidence through a properly-funded national prevalence study – and make raising the awareness of FASD a clear national health priority.

It should not be the responsibility of parents and carers to fight for support services for their children – whether they are clinical, educational or judicial – when their entire lives already revolve around providing a stable environment in which these young people can flourish.

Nor should it be left to a select group of medical, social and educational professionals – in addition to the small number of under-staffed and under-funded national charities – to create an ad hoc support structure for what could be a significant minority of the population.

Tackling FASD requires a governmental response. Without this even the very credibility of FASD as a national issue will continue to be overlooked by a wide segment of the population, ensuring that those at a regional and local level able to contribute to its effective prevention and management will be disinclined to act.

The original clinical diagnosis of FASD was made in 1973. Our Inquiry has shown that in the four decades since then, the UK as a whole has still barely acknowledged its existence. This cannot be considered the fault of individuals who in most cases are unaware of the full implications of drinking alcohol during pregnancy. Rather, it appears to be the result of institutional malaise and dismissiveness from those in authority and with the ability to lead change. Countries that could be described as similar to the UK have set precedents for challenging the devastating consequences of FASD and these precedents have been largely ignored by the political and medical hierarchy in this country with the result that, as far as FASD is concerned, our response to date can only really be described as non-existent and not even comparable to that of a “developing nation”.

Unfortunately, it would appear that whilst everyone has ignored the issue, the problem has merely increased in size and impact on society, and the Members of the APPG are clear that decisive, swift action needs to be taken to stem the incidence of FASD, to assess properly the extent of the condition and to put in place appropriate diagnostic and support mechanisms for those living a lifetime with the consequences of FASD.

Initial Recommendations

As a result of this Inquiry, the Members of the APPG are making these initial recommendations. The APPG Members fully intend to make further specific recommendations during the course of 2016, but believe the actions below should be considered now.

1. *That the Academy of Royal Colleges, NICE and the Department of Health all give out clear consistent advice to pregnant women, those trying to conceive (and those who suspect they may be pregnant), "no alcohol in pregnancy is best for baby and you".*

2. *That the Department of Health and Public Health Bodies give consideration to a public health campaign raising awareness of FASD.*

   We draw attention to the example in Nottingham North, led by the Rebalancing (Early Intervention) Programme where Public Health have made tackling FASD / Pregnancy & Alcohol one of their top 3 priorities.

3. *That Government engage further with the alcohol industry, giving consideration to mandatory size and wording of labelling on alcoholic products advising pregnant women and those trying to conceive to abstain from alcohol.*

4. *That all medical establishments, including GP's surgeries, hospitals, etc, should be required to display prominent notices warning of the dangers to the unborn child of drinking alcohol in pregnancy and at the time of conception.*

5. *That a compulsory element of the National Curriculum is introduced to inform school children about the dangers of drinking alcohol in pregnancy and at the time of conception.*

6. *That urgent consideration is given by the Government into commissioning a UK wide to ascertain the prevalence of FASD.*

   Until the true scale of the prevalence of FASD is fully known and understood, Government – both national and local – and service commissioners will continue to have difficulty responding to the issue, including future planning and providing appropriate levels of service.

7. *That the Government and all the relevant Royal Medical Colleges look to Agree and Adopt a National Referral, Diagnostic and Care Pathway and the NHS provide appropriate funding for initiatives such as the clinic in Surrey led by Dr Mukherjee.*

   The APPG Members draw attention to documents such as the British Medical Association's Report on FASD, originally published in 2007 with a revised edition due out in 2016 and the UK Medical & Healthcare Professionals Forum on FASD Consensus Statement on Recognising, Diagnosing and Managing FASD in a Clinical Setting (published by The FASD Trust, Oxford in February 2013), in which UK medics set out their suggestions for their envisionment of such a Pathway.

8. *That Government, Local Authorities and Relevant Professional Bodies review policy & practice on Adoption, Fostering, Special Guardianship and Children's Social Care taking into account the estimated high levels of children coming into contact with them who have FASD.*

   In particular, comprehensive training must be provided to social workers and other staff so they are fully aware of the issue of FASD; adoption / fostering / SGO preparation must cover what FASD is and how to adapt parenting strategies accordingly and post-adoption support must be appropriately tailored to meet the needs of children with FASD and their parents / carers.

9. *Revision is required to all national curriculums and training programmes within the healthcare, educational and social work fields to ensure that FASD is taught during initial professional training and subsequently through continuing professional development.*

   The common thread from many parents is that they are the "experts" and from professionals that they feel like they are only a small percentage within their discipline who are aware of FASD. It is a topic which must be included in initial training for anyone in the caring or educational professions and we recommend that all such training establishments and bodies revisit their curriculum to ensure FASD is adequately covered. Furthermore, the many qualified practitioners require access to expert training on FASD to enable them to improve their knowledge and understanding of FASD and adapt their practice accordingly.

10. *Those responsible in Government and local authorities for adult social care need to urgently review their current response to those affected by FASD and look at their planning for future provision.*

11. *The Department for Education, OFSTED and other educational bodies need to look at the impact FASD is having in UK classrooms.*

    The APPG intend to revisit this issue in 2016 in more depth, but would urge Government to engage with the UK charitable sector's programmes – for example FASD in Education - as well as giving consideration to learning from Governments overseas, particularly the programmes implemented by the Canadian Government.

12. *The Ministry of Justice needs to consider the impact of FASD within the Criminal Justice System.*

    Data needs to be gathered which gives a clearer picture of how many in prison are affected by FASD. The APPG intend to visit this issue in 2016 as well, to look at how and why those with FASD become involved with the criminal justice system. Consideration must then be given as to how this can be prevented.