

## FASD: the current situation in the UK

### *What do we know?*

It is 45 years since FASD was first named in a *Lancet* article by Jones *et al.* (1973). FASD represents a syndrome with a range of physical and neurological damage caused primarily by the mother consuming alcohol whilst pregnant. Whilst historical records identified the effects of prenatal alcohol, dating back many years (Warren and Foudin, 2001), current evidence would suggest there remains limited knowledge regarding FASD. Both the UK general public and healthcare professionals appear to have heard about FASD but there was little depth to the knowledge about this condition (Mukherjee *et al.*, 2014, 2015). This leaves many individuals and their carers with very poor access to expert help (APPG, 2016).

Clinical services for FASD in the UK are limited. These include both diagnostic and therapeutic services, both specialist and generic. Other than the BMA Board of Science review, which included a gap analysis of services and recommendations by the UK Parliament All Party Group on FASD (APPG, 2016; BMA, 2016), there is no UK legislation to guide FASD service delivery. Epidemiological studies in the UK have not been, as yet, adequately completed. Whilst health episode statistics and passive surveillance have been conducted showing low rates of reporting (Morleo *et al.*, 2011; Watts, 2015), this is known to under report accurate levels (Roozen *et al.*, 2016). To date, no active ascertainment study, where people go and actually seek the condition out and considered the best way to identify prevalence in such disorders, has been conducted in a UK population (BMA, 2016). Wider studies around the world where these approaches have been conducted, rates vary between populations studied. The most recent reports suggest up to 5 per cent of the population may be affected (May *et al.*, 2018). As a result, this means some professional groups suggest the condition is too common to require a specialist services. In opposition to this, the lack of knowledge of how to diagnose and manage the condition, suggests a specialist service is needed. This paradox means that many people with FASD fall between gaps in existing service provision and expertise (Mukherjee *et al.*, 2013, 2015).

### Identification and risk

Several problems regarding identification arise. First, who should diagnose this condition, and second, when should it be identified. Reporting of alcohol exposure in pregnancy remains the remit of primary care, obstetrics but primarily midwifery. Unfortunately there appears to be a postcode lottery with regards to the questions asked and the level of information collected by these professionals. For example, it is insufficient to simply ask a woman if they drink. Beginning questioning with "Are you teetotal?" may be a better way to begin the conversation with a mother as it normalises the discussion. It is only if people are teetotal that there is no risk. Therefore, if a positive answer is given to this question, no further information about alcohol exposure if required as there is no risk. If the answer is in the negative, in that the woman will normally drink alcohol in keeping with the majority of the UK population, it allows a conversation about their normal drinking patterns to take place not just about that consumed in pregnancy. This is potentially a better approach than the pejorative question about whether they drink in pregnancy or not. Also, as has been demonstrated, an individual's understanding of alcohol consumption levels can vary greatly (Mukherjee *et al.*, 2012).

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Many people underestimate, especially when pouring their own drinks, just how much alcohol has been consumed (Mukherjee *et al.*, 2012). Further, because patterns of drinking behaviour have changed, for example, with preloading of alcohol at home, the risk of harm also increases (BMA, 2008). This means more accurate assessment of alcohol exposure histories are required by the practitioner. This should be recorded not only in the maternal notes, but also in the child's summary notes which allows future practitioners to access this information. In many places this does not occur (BMA, 2016).

Paediatricians will often follow up the younger age group; however, it is clear that FASD presentations vary by age, as does the suitability of tools to identify them. At a younger age the difference between normal developmental trajectories and those seen in FASD, do not necessarily differ greatly. As most standardised tools are normed against the general population, when the gap is not great, differences may not be evident. As such it is important that those identified as high risk for FASD are followed up initially by primary care and if issues arise secondary care professionals such as paediatricians or psychiatrists. This may not be until later years when the differing developmental trajectories become more obvious, but for some later in life the history of alcohol exposure during the pregnancy may be missing. Unfortunately, it is not yet possible to identify those individuals who are at the highest risk of developing later disorders. It is only possible to identify where high risk exposure has taken place. When considering that studies have identified over 40 per cent of the UK population consuming alcohol during pregnancy (Popova *et al.*, 2017), it becomes essential that more work is undertaken to identify early markers that may better correlate with later diagnostic presentations.

The most common presentations for FASD remain behavioural (e.g. inattention, conduct issues or social communication issues) and educational (e.g. failure to progress, difficulties with math and lower than expected achievements). Whilst it is not the remit of teachers to diagnose, work undertaken in primary school settings has identified that teachers who are able to recognise difficulties and support referral to specialist diagnostic services can lead to better outcomes (Blackburn *et al.*, 2010). Behavioural presentations are often, especially in older children, the remit of Child and Adolescent Mental Health Services. Unfortunately, similar to paediatricians, there is a significant lack of understanding regarding these presentations and how making a diagnosis can alter the management strategies (Mukherjee *et al.*, 2015).

Neurodevelopmental and behavioural outcomes such as autistic spectrum disorders but especially attention deficit hyperactivity disorders and conduct disorder are common (Mukherjee, 2016; Mukherjee *et al.*, 2011; Popova *et al.*, 2016). Despite this, because of the absence of physical stigmata for the majority, these children and later adults, remain hidden in plain sight. A systematic review identified 428 separate comorbid conditions linked to FASD (Popova *et al.*, 2016). People with FASD often are referred to be seen for the comorbid presentation rather than the FASD itself. Once again, this explains why so many cases are missed.

The "So What" question also remains. Unless there is a rationale why making the diagnosis alters treatment, for many, the argument remains that it is a diagnosis that is not worth making. This is especially when considering the associated stigma (Mukherjee *et al.*, 2013, 2015).

Increasingly, however, there is evidence to suggest that managing individuals, who are diagnosed with FASD, will alter due to this diagnosis. Examples of this are increasing. A recent consensus statement highlighted alternate treatment pathways for those diagnosed with comorbid ADHD (Young *et al.*, 2016). Another example is that in people with FASD, the ability to condition and process information differs from typical neurodevelopmental profiles (Kodituwakku, 2009). Their response to standard parenting is thought to therefore be less effective (Mukherjee *et al.*, 2013). This means that FASD does not fit with the established referral and management pathways for typically developing children. Therefore, many fall through service gaps and end up unsupported or receiving therapeutic approaches that do not have the anticipated benefits. Families have described always having to fight to get help and being the experts, having to always update professionals rather than consulting professionals who know more than they do (Mukherjee *et al.*, 2013). This needs to change.

## Clinical structures and the way to change

Clinical structures in the NHS within England are set in a series of clinical commissioning groups (CCG). These are consortia of general practitioners defining what their areas should deliver in terms of service. Whilst these were established to focus on local needs, anecdotal evidence and reports to parliament suggests they often focus on areas of clinical need they are familiar with, leaving emerging conditions, such as FASD unsupported (APPG, 2016). These conditions may often fall under the radar and services are not commissioned as a result. Yet if internationally suggested prevalence rates for FASD are to be believed, then in the UK it is likely that FASD is presenting to services, but not being recognised.

Evidence would suggest that for many people with FASD, access to diagnostic and therapeutic services where the needs of people with FASD is properly understood by professionals is nigh on impossible (APPG, 2016; Mukherjee *et al.*, 2013). Despite these issues, structures exist within the NHS that would allow rapid development and support for people with FASD with only a minimum increase in cost, and far greater cost saving, when compared to the estimated lifetime cost of FASD as a whole (Popova *et al.*, 2012).

The hub and spoke model of service delivery, one where central specialist services offer consultation and support to regional and then subsequently local services, was described by the BMA (2016) Board of Science. This model exists already in many specialties. It allows individuals local access to support and engagement without the need to travel to national specialist services and can be seen closer to their place of residence. It also allows expertise to be available to local clinicians to support their decision making, when the experience locally is not available. This would be an effective approach to implementing and supporting this potentially common condition which would be unsustainable for a highly specialist service on its own. These discussions around service development are commencing between specialist and secondary care services, as well as in some areas with wider commissioning groups. These remain in their infancy, and in many places have yet to begin.

FASD appears to be rising up the agenda in many areas for clinicians, commissioners and even government. In the UK, there are various interested clinicians now beginning to work in the subject area. Scotland, for example, has established its own service, embedding service modelling examples from Canada and England into its own processes to offer not only a diagnostic service for FASD, but also some wider ongoing support to individuals and their families. Clinicians from this service are also now beginning to support other clinicians around Scotland (Mcgruer and Shields, 2018; NHS, 2018). It was through the engagement with government, who as direct commissioners of service in Scotland, were able to make an identified need, a realistic deliverable service. This initially began as a service pilot, later becoming a fully established and funded multidisciplinary clinic. It will only be through central coordination by NHS England or specialised commissioning, to help raise the profile of FASD, as well as take the funding issues out of the equation for many CCG areas, that eventually these issues and this condition will become well understood. The Scottish example shows that only then can it be devolved to a CCG successfully. At this point in time there is insufficient knowledge in the different English regions, leaving a postcode lottery of service delivery (APPG, 2016). Without local clinicians being better up-skilled and aware of the true burden posed by FASD, it will not be possible for the debate around how to minimise harm and support those affected to happen.

## Conclusions

Raising awareness of FASD continues to be a primary need across multiple professional groups. It is hoped that by educating clinicians, the public and politicians about the presentation, prevalence and complex management needs of this condition can then begin to be addressed.

With the correct will and support the UK is well set up to address this condition rapidly. A concerted effort by those interested from government, to commissioners and with the support of clinicians can areas begin to model change. That will allow the services to be established elsewhere. Essentially this will allow change to spread to wider regions from the places of initial

interest to generic access. The National Specialist FASD clinic began as a specialist interest. Now it is able to support a few others clinicians who have shown the seeds of interest. Without this desire by the few to influence the many, those affected by FASD as a group of vulnerable individuals will continue to face a wide range of lifelong challenges.

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