

# Health and Adult Social Care Overview and Scrutiny Committee

BRIEFING NOTE – No. 5/21

Date: 3 March 2021

Briefing paper to: All Members of the Health and Adult Social Care Overview and Scrutiny Committee

Purpose: To update the Committee on key issues and work relating to Foetal Alcohol Spectrum Disorder (FASD) in Kent and Medway

## **Background:**

### What is Foetal Alcohol Spectrum Disorder (FASD)?

*“FASD is an umbrella term for a set of disorders caused by the consumption of alcohol by a mother whilst pregnant. These conditions range in diversity from the full presentation of foetal alcohol syndrome, involving a characteristic set of facial features combined with growth and neurocognitive deficits, to a range of conditions affecting the neurobehavioural presentations of the condition without all these features.”<sup>1</sup>*

There is no particular treatment for FASD, and the damage to the child's brain and organs cannot be reversed. However, research shows that early intervention can improve a child's development<sup>2</sup>.

### What is the prevalence of FASD?

There is a paucity of data detailing the prevalence of FASD across the UK. This is due to challenges in bringing data sets together for diagnosis, for example alcohol consumption during pregnancy and linking growth deficiency and cognitive issues. Recent research has determined that the UK rates are broadly consistent with the upper limits of some European studies, which recorded FASD prevalence estimates in the region of 1% to 5%. This is in line with the Scottish Intercollegiate Guidelines Network, which estimates that 3.2% of babies born in the UK are affected by FASD. This is three to four times the prevalence rate of Autism in the UK.

It is important to note that there is documented evidence that the rate of FASD can be significantly higher within certain sections of the population, for example those experiencing high degrees of social deprivation and poverty.

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<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1472723/>

<sup>2</sup> <https://www.nhs.uk/conditions/foetal-alcohol-syndrome/>

## National Guidance and Plans

The 2019 Department of Health and Social Care publication “*funding for FASD interventions*”<sup>3</sup> outlined the Government’s commitment in this area. Following significant Stakeholder engagement, The Department of Health and Social Care is considering improvements in the following five areas:

- Focusing on prevention
- Improving education and awareness relating to FASD
- The whole system impacts and approach to FASD – health, education, social care, employment and the benefits system, and criminal justice
- Improving processes for diagnosis and treatment
- Improving data and intelligence relating to FASD prevalence

As a part of these improvements, the National Institute for Health and Care Excellence (NICE) will be producing a set of Quality Standards relating to FASD. Whilst consultation on these Quality Standards has been completed, the publication has been delayed as a result of the COVID pandemic, with a current revised publication date of 30 July 2021. These Standards will cover five areas from recognition and prevention, noting down of alcohol histories in the child notes, access to diagnoses and diagnostic pathways, comprehensive neurodevelopmental assessments in all those suspected and finally a proper system of post-diagnostic support. This will therefore require the development of pathways to improve service for this condition in the UK.

### Key Local Issues:

There are a number of key issues relating to FASD across the Kent and Medway system, many of which are mirrored across England. These include:

- Knowledge and understanding relating to FASD amongst the general public and within the workforce more widely are poor. A significant level of training and awareness-raising is required to enable the cultural changes that are necessary for improvement in this area.
- Inconsistent ways of recording alcohol intake during pregnancy, either within health or social care. Professionals such as midwives and social workers deliver public health advice and guidance throughout the course of their work, however at present there is no agreed systematic way that alcohol intake and advice relating to alcohol intake during pregnancy is delivered and recorded.
- Health providers across Kent and Medway currently have not been commissioned to provide services that routinely assess, diagnose and support children and families where there is suspected FASD. It is therefore possible that children and young people with undiagnosed FASD, who also have physical health needs, do not always have their care joined up in their

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<sup>3</sup> <https://www.gov.uk/government/publications/funding-to-support-work-around-foetal-alcohol-spectrum-disorder>

best interests. Some children with FASD may not meet the diagnostic criteria for other diagnosable conditions such as ADHD and ASD and would therefore be discharged from services without the full package of support that an individual with FASD would require.

Although referrals can be made to the national centre in Surrey, this is at additional cost and would likely require an Individual Funding Request (IFR) to be undertaken.

- Many services that support children and families are likely to be supporting some needs associated with FASD, however this will currently be in an unstructured way that may not always be optimally designed to improve outcomes for those with FASD.

These issues are not unique to Kent and Medway. National reports into FASD have identified that there are very few areas within England where the issues of prevention, identification and support of FASD have been effectively managed.

*Current Local System and current work to address the issues identified:*

Due to historical commissioning arrangements, there are four different providers of community paediatric services across Kent and Medway; Kent Community Healthcare NHS Foundation Trust (KCHFT), East Kent University Hospitals NHS Foundation Trust (EKUHFT), Medway Foundation Trust (MFT) and Medway Community Healthcare (MCH). In addition, North East London NHS Foundation Trust (NELFT) provide neurodevelopmental assessment and diagnostic services for older children throughout Kent and Medway.

Due to the close comorbidity with neurodevelopmental conditions, community paediatric teams are well placed to support children and young people with FASD. These providers are all engaged in the systems for improvement outlined in this briefing note.

*Current work to address the issues identified:*

**FASD System Partnership Group:**

A Kent and Medway FASD System Partnership Group has been established, and the inaugural meeting was held in December 2020. This Group consists of representatives from Social Care; Maternity Systems; Education; Policing; Voluntary organisations; Public Health; Parent/Carers and other partners. It is anticipated that this group will expand over time.

The Partnership Group has developed and signed off the Terms of Reference and it has been agreed that there are three key areas for initial focus, which are in line with the NICE Quality Standards - namely:

1. Prevention
2. Communications and Engagement
3. Workforce Mapping and Training

Task and Finish Groups have been established for each of these. Each group has a wide representation of partners and will be developing and leading an action plan relating to its specific area of focus and reporting back into the Partnership Board on a quarterly basis.

The aims are to raise awareness of FASD amongst the workforce and wider population; to ensure models of prevention are embedded across systems, and to upskill staff in identification and post-diagnosis support.

The task and finish groups will aim to make necessary system changes in readiness for the implementation of the NICE clinical guideline in July – for example by linking with the Kent and Medway Local Maternity System.

### **FASD Business Case:**

In addition to this work, NHS Kent and Medway CCG are in the process of developing a business case to ensure that local services are trained in assessment and diagnosis of FASD. This includes ongoing advice and guidance from the national centre in Surrey, and the opportunity to refer children and young people with the most complex presentations to the national centre for further diagnostic support.

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