Report of the Executive Director for People and Neighbourhoods

Stockport Family and Safeguarding Partners

Foetal Alcohol Spectrum Disorder (FASD): working in partnership to improve and develop FASD prevention, diagnosis, and support in response to the NICE FASD quality standards.

1. Purpose of report

- 1.1 Foetal Alcohol Spectrum Disorder (FASD) is the leading known preventable intellectual disability and is only caused by prenatal alcohol exposure. For too long FASD has nationally and internationally been a hidden disability.
- 1.2 This report outlines a brief overview of the causes and impact of FASD and describes Stockport's response to the FASD NICE quality standards published in 2022 Overview | Fetal alcohol spectrum disorder | Quality standards | NICE

2. Background

- 2.1 FASD results when prenatal alcohol exposure affects the developing foetus, causing damage to the developing brain and body. FASD is the only known preventable disability, if there were no alcohol exposed pregnancies there would be no babies born with FASD. FASD is a spectrum, each child and adult with FASD is affected differently. FASD is at its core a lifelong neurodevelopmental condition, with over 400 identified co-occurring conditions (National Organisation for FASD, 2025).
- 2.2 The reason alcohol exposed pregnancies need to be prevented is because alcohol is a teratogen. Teratogens cross the placenta and cause malformations to the unborn foetus. Therefore, alcohol passes freely into the foetus' blood stream and causes harm to brain cells, damage to a foetus's nervous system, organs and limbs. The dangers of an alcohol exposed pregnancy exist throughout the whole nine months of pregnancy (National Organisation for FASD, 2025)
- 2.3 Historically, there has been a focus in the assessment and diagnosis of FASD on the presence of sentinel facial features. As our knowledge continues to expand it is now evident within numerous studies that sentinel facial features are only present in a small minority of cases, less than 10% of all diagnosed children. Therefore, FASD needs to be understood as a whole-body diagnosis (SIGN, 2029; NICE, 2022).
- 2.4 FASD is a full-body diagnosis, a multifaceted spectrum of disorders that can include more than 400 known co-existing conditions including the impairment of the frontal lobe (brain) which impacts on a child's working memory. Impairment to the frontal lobe and therefore executive function of the brain is why many children with FASD present with similar characteristics to autism and ADHD (National Organisation for FASD, 2025).

- 2.5 A child with FASD may also suffer from physiological impairments and defects, such as kidney damage, heart defects, visual impairment including blindness and congenital malformations of the spine (Burd,2016).
- 2.6 The groundbreaking publication on the prevalence of FASD by the University of Salford, estimates that FASD affects 1.8% of children in Greater Manchester. In Stockport that equates to over 5,000 children and young people living with FASD (Greater Manchester Integrated Care Partnership).
- 2.7 FASD is associated with lifelong disabilities which, if unsupported, can lead to wider secondary consequences. Children may be diagnosed with ADHD, ASD, as having behavioural problems or as having had poor parenting. Studies suggest that without the correct support an individual is more likely to have a range of issues including mental health problems, trouble with the police, homelessness and difficulty with social relationships and employment (Alex & Feldmann, 2012; Landgren, et al., 2019; Rangmar et al., 2015;).
- 2.8 'Early diagnosis and support for families affected by FASD can prevent or mitigate adverse secondary outcomes, such as school exclusions, poor job prospects, and mental ill health' (McCarthy et al., 2021: 2278).
- 2.9 Studies have shown that children and young people with FASD are overrepresented in the youth justice system, statutory children's social care, becoming looked after, placement breakdowns, school exclusions and in incidents of inappropriate sexual behaviours. In many cases, people with FASD require lifelong assistance from a wide range of services including health, mental health, education, criminal justice, substance use services, social care and many others. Hence, it is recognised that FASD has a substantial economic effect on any society (Gilbert et al., 2016: Coates and Gilbert, 2024).
- 2.10 The risk to young people growing up with FASD that has gone undiagnosed, is the absence of understanding from professionals and therefore fully informed and tailored care plans.

3. NICE FASD quality standards and Stockport's response

- 3.1 The standards are as follows:
 - Quality Statement 1 Pregnant women are given advice throughout pregnancy not to drink alcohol.
 - Quality Statement 2 Pregnant women are asked about their alcohol use throughout their pregnancy and this is recorded.
 - Quality Statement 3 Children and young people with probable prenatal alcohol exposure and significant physical, developmental or behavioural difficulties are referred for assessment.
 - Quality Statement 4 Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment if there are clinical concerns.
 - Quality Statement 5 Children and young people with a diagnosis of foetal alcohol spectrum disorder (FASD) have a management plan to address their needs.

3.2 Launch of the Stockport multiagency FASD advisory board



- 3.3 In October 2023 Stockport launched the FASD advisory board, an event attended by colleagues from across Stockport including public health, children's services, youth justice, midwifery, health visiting, school nursing and beyond. The event was organised by Stockport Family Workforce Development and Stockport Safeguarding Children's Partnership.
- 3.4 Stockport's advisory board was the first of its kind in England and since its launch, we have been contacted by several neighbouring local authorities for advice and guidance on how they too can implement what we have been able to achieve in Stockport.
- 3.5 Following the launch event, quarterly FASD advisory board meetings have been held and chaired by Eleanor Hirst- Head of Safeguarding and Learning and Principal Social Worker and supported by Dr Hannah Todman- Stockport Family Workforce Development. The Terms of Reference for the Board are as follows:
 - Strategic oversight of the areas for improvement as outlined in the NICE FASD quality standards.
 - A multi-agency forum to ensure partnership working across Stockport Family and partners in working to achieve improved outcomes for children and young people pre and post FASD diagnosis.
 - A forum to identify and seek to problem solve potential barriers to the delivery of areas of improvement.
 - Oversight of the implemented changes, with financial planning and advise on potential funding opportunities.
 - Support for sustainability of the implemented changes
 - Evidence of Stockport's commitment and legal responsibility in meeting the NICE FASD quality standards.

Please see this video - Walk Along With Me

4. Success to date

- 4.1 Stockport was recently named as an example of best practice in a nationally published report by National FASD (2024). The report named 'Not 'Commissioned: Systemic confusion in NHS services for alcohol, pregnancy and FASD' sought to evidence the changes Integrated Care Boards, NHS trusts and local authorities have implemented since the publication for the NICE quality standards.
- 4.2 'The report shows that the majority of NHS Integrated Care Boards and NHS Trusts are missing a golden opportunity to protect baby's brains and futures with their slow, non-strategic and uncoordinated responses to the 2022 NICE Quality Standards on Foetal Alcohol Spectrum Disorder' (National FASD, 2024). The report outlines the success of the advisory board and highlights Stockport as a "pocket of hope and example of good practice".
- 4.3 In particular, the report notes the success of the ICB in influencing a changed practice in relation to FASD 'This ICB has taken the lead nationally in establishing best practice and their response indicates the depth of their response to NICE QS 204. This ICB demonstrates the kind of systemic change that other ICBs should be exploring' (National FASD, 2024)
- 4.4 Louise Burns- Stockport Family 1001 days critical days lead and Emma McDonough- Principal Lead for Health, Stockport Family/ Stockport Foundation Trust, have led on the development of an Alcohol Exposed Pregnancy (AEP) pathway that was established in 2022. There has been a sharp focus on AEP within midwifery and joint working with Stockport's Mosaic 'Young Peoples Drug and Alcohol Service', to ensure accurate messaging to all pregnant women. Through the AEP pathway, midwifery has worked closely with Mosaic to ensure support, advice and guidance to pregnant women.
- 4.5 Training for all midwives and health visitors has been provided and completed between 2022 and 2023. FASD training remains a strategic priority and is scheduled to be refreshed and regularly updated, in line with developments in knowledge across Greater Manchester.
- 4.6 Information about AEP's are now routinely recorded on a child's health record both within midwifery and health visiting records. This is to ensure evidence of an alcohol exposed pregnancy is recorded to support the future assessment and diagnosis of FASD. Health colleagues are working closely with all who attend the FASD advisory board.
- 4.7 Stockport now has two paediatricians who have completed the full assessment and diagnostic training with Professor Raja Mukherjee- national expert and Roisin Reynolds- GM strategic lead population health. Dr Lucy Barnes- Paediatrician, attends the advisory board and has been instrumental in supporting colleagues.

5. Influencing national change

- 5.1 Dr Hannah Todman and Fran Davies- Project Manager Maternity, Children and Young People, have led discussions with the head of Bounty Media, in response to the inaccurate information within bounty packs given to expectant mums in relation to alcohol during pregnancy. The Head of Bounty Media has now accepted that the messaging within the current packs is at best confusing and in places misguiding and not in line with the chief medical officer's guidance, of no safe time and no safe amount. Confirmation has now been received that any new prints of the bounty pack will include clear messaging on the risk of an alcohol exposed pregnancy.
- 5.2 Through the advisory board, connections have been made with Dr Karen McEwan, Clinical lead for children's and maternity and Fran Davies, Project Manager Maternity, Children and Young People (Stockport), and this has enabled the dissemination of FASD knowledge and training opportunities. In September 2024, Dr Hannah Todman successfully delivered FASD training to over 100 GPs in Stockport.
- 5.3 The feedback from this training evidences how needed this knowledge was:
 - 'It will definitely change my practice and thinking about FASD when considering neurodiversity'
 - 'I will now consider FASD in diagnosis and now routinely ask about alcohol use during pregnancy'
 - 'FASD is not something I have considered when children are presenting with ASD/ADHD behaviour, I will explore the possibility of FASD'
 - 'I will now consider FASD with adult patients and be curious about alcohol exposed pregnancies'
- 5.4 Increased partnership working with colleagues in public health through the advisory board has led to FASD knowledge and the drymester campaign being distributed across Stockport's civic complex and in primary health care settings, including sexual health clinics.
- 5.5 Specialist training has been provided to adult treatment services by Dr Hannah Todman, ensuring that practitioners are now informed about FASD and are confident to have sensitive conversations with service users about alcohol exposed pregnancies.
- 6. FASD and developments within early help and family hubs, Led by Cheryl Hanson-Stockport Family Workforce Development.
- 6.1 Information of FASD is now included in the Solihull Approach 2 day foundation training and community of practice sessions. This includes the impact of alcohol exposed pregnancies on the developing foetus with particular reference to the prevention of alcohol exposed pregnancies through sensitive and compassionate conversations with parents.
- 6.2 Alcohol exposure in pregnancy is now discussed as part of embryonic development section within the Special Educational Needs and Disability training, which is mandated for children's social workers and family help workers.

6.3 A focus on the first 1001 days is embedded in Family Hubs training content for Neighbourhood and Prevention induction training programme and alcohol exposed pregnancies and FASD is now included in this programme.

7. FASD training

- 7.1 A programme of training to support increased knowledge of FASD across the workforce has been led by Dr Hannah Todman. On international FASD awareness day in September 2024, two learning circles were delivered to colleagues across Stockport children's and adults services reaching **90+** Practitioners.
- 7.2 In response to a growing understanding of the prevalence of FASD in young people within our criminal justice system, specialist training has been provided to our youth justice service by Professor David Gilbert, a leading national expert in FASD and the criminal justice system.
- 7.3 Dr Hannah Todman has delivered specialist FASD training to the following services:
 - Speech and Language therapy service
 - Occupational health and Physiotherapy,
 - SENCOs approx. 50
 - Fostering service- whole service
 - Foster carers- x 50 and Residential care teams
 - Edge of care and intensive support service- whole service
 - FASD training embedded in our new social work Learning and Development programme.
- 7.4 The distribution of knowledge through training and through the advisory board is now widespread regarding knowledge of FASD and the consultation offer.
- 7.5 1:1 consultations have been going well with positive outcomes for children and young people. In 2024 we provided 1:1 support to;
 - 3 social workers
 - 2 supervising social workers,
 - 2 foster carers
 - 3 SENCO's

8. Financial and Risk Assessment Considerations

8.1 There are no financial and risk assessment considerations associated with this report

9. Legal Considerations

9.1 There are no legal considerations associated with this report

10. Human Resources Impact

10.1 Ongoing commitment from partners in One Stockport to engage with and be part of this work.

11. Equalities Impact

11.1 The work to raise awareness and develop clinical and non-clinical pathways for children affected by FASD is helping us extend our reach to marginalised and disadvantaged individuals to enable a more inclusive borough. By working closely with senior leaders in health, local authority, education, criminal justce and the VCFSE, we are working together to raise awareness and prevent FASD and where FASD is present, provide appropriate support to the child and family. This includes identifying and addressing the unique needs of individuals and families living with FASD. communities, ensuring that support is inclusive and non-stigmatising.

12. Environmental Impact

12.1 There are no environmental considerations associated with this report.

13. Conclusions

- 13.1 Foetal Alcohol Spectrum Disorder (FASD) is a diagnostic term which describes the impact of an alcohol exposed pregnancy on the developing foetus. The impact of an alcohol exposed pregnancy needs to be understood far beyond the impact in utero, as FASD is a lifelong condition which can impair all aspects of a child's development and have lifelong consequences.
- 13.2 FASD has long been referred to in literature as a hidden disability, due to decades of legislation and policy indifference. The implementation of the NICE quality standards have tipped the balance and though this hasn't resulted in any additional funding from central government, local authorities do now have a duty to respond to this guidance.
- 13.3 Despite limited resources, Stockport has worked in partnership across health, social care, education, early help services. Stockport's commitment and aspiration to respond to the nice FASD quality Standards is evidenced through the launch of the FASD advisory board along with the work that has been done to develop clinical pathways, raise awareness, train, develop and support professionals and in turn children and families.
- 13.4 Stockport is the first local authority (as highlighted by the Greater Manchester integrated health partnership) to implement an advisory board and as such we are recognised as a beacon of hope and an example of best practice in a recent national report. We continue in our endeavour to spread the word to prevent alcohol exposed pregnancy's, to educate our workforce and communities and respond to the needs of children growing up with FASD. Our FASD journey is in its infancy and there is still much more to do.

14. Recommendations

- 14.1 Children and Families Scrutiny Committee are asked to note and comment on the report.
- 14.2 For further information please contact:

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