

HEALTH SCRUTINY PANEL

A meeting of the Health Scrutiny Panel was held on 20 December 2016.

PRESENT: Councillors E Dryden(Chair), S Biswas (Vice-Chair), J G Cole, A Hellaoui, B A Hubbard, J McGee, G Purvis and M Walters

ALSO IN ATTENDANCE: Maria Catterick - FASD Network,
Graeme Nicholson - Health Improvement Specialist(Best Start and Families) Public Health Middlesbrough,
Michelle Conley - South Tees CCG,
Mark Burdon Commissioning Manager (Mental Health) - South Tees CCG

OFFICERS: C Breheny

APOLOGIES FOR ABSENCE Councillor C Hobson.

DECLARATIONS OF INTERESTS

None Declared

1 MINUTES - HEALTH SCRUTINY PANEL - 22 NOVEMBER 2016

The minutes of the Health Scrutiny Panel held on 22 November 2017 were submitted and approved as a correct record.

2 FOETAL ALCOHOL SPECTRUM DISORDER (FASD)

In June 2016 members of the public were asked to provide potential topics for consideration by the panel. In response the FASD Network had brought this issue to the panel's attention. FASD was a condition linked to drinking alcohol in pregnancy and was thought to be the leading cause of preventable learning disabilities.

Nationally there was a lack of diagnostic and intervention services to support families affected by FASD and there was a widespread lack of knowledge amongst professionals. It was more prevalent than autism but attracted no specialist provision.

The panel had agreed to consider FASD to assess the scale of the problem in Middlesbrough and consider the support that was/needed to be provided. Representatives from Public Health and the South Tees CCG had been invited to attend the meeting to provide an overview of the topic for Members. The panel was advised that there were a number of key issues to highlight in respect of FASD including the following key points:

- FASD was the most common, non-genetic cause of learning disability in the UK
- The true prevalence of FASD in the UK was not known, however it was estimated to be well in excess of 1 per cent of all live births.
- The condition was preventable if a mother abstained from alcohol during pregnancy.

The Health Improvement Specialist explained that there were a number of symptoms that characterised FASD including an abnormal appearance, short height, small head size, poor co-ordination, low intelligence, behaviour problems and problems with seeing or hearing. Profound facial features and a flat nasal bridge were also prominent features in the most developed versions of FASD. However, some symptoms were quite subtle and the Lancet Journal advised that FASD had 428 potential impacts. The point was made that given these facts it was quite alarming that the condition received hardly any media exposure.

The representative from the FASD Network explained that the condition was officially recognised in the UK in 1973. However, as far back as 1725 the Royal College of Physicians noted that children born to mothers who drank alcohol during pregnancy displayed the aforementioned symptoms. FASD was a condition that had been ignored for hundreds of years and until recently the UK government was the only government in the world to still

endorse any level of drinking during pregnancy. Labelling was another issue and the small symbol currently displayed on bottles of alcohol at present was viewed by FASD as inadequate. It was stated that the UK was quite far behind other countries in their estimation of prevalence, with other countries estimating the true prevalence to be between 3 and 7 per cent. In 2015 an All Party Parliamentary Group (APPG) for FASD highlighted the true harm caused by the condition and sought to raise awareness of this issue. In response to a query it was advised that it is not known at present how much alcohol causes FASD.

In terms of FASD in Middlesbrough it was stated that although there was no local study to document the prevalence of the condition it was anticipated that Middlesbrough would be higher than 1 per cent of all live births. There were approximately 2000 children born each year in Middlesbrough which equated to 20 births per year or 1,300 cases from the standard population figure. It was stated that many children with FASD end up in the care system and are either fostered or adopted. Often there was no clear diagnosis and no information was recorded on the child's health file to indicate the potential for FASD. Children were instead diagnosed with ADHD or attachment disorder due to distinct separational loss or behaviour differences. However, no one was looking back to what was happening during early pregnancy. Research in the USA and Canada estimated that raising a child with FASD came a cost £1million per year.

In 2015 a research carried out in Peterborough revealed that a third of looked after children referred for a health assessment had the condition, and three quarters of children undergoing adoption medical assessments had the potential of FASD as their birth mother had a history of alcohol. The cost to the health, social care and justice systems were significant but insufficient robust research had been undertaken in the UK to give an accurate indication of FASD prevalence. The number of hospital admissions in 2014/15 for the major conditions by socioeconomic decile for the broad measure indicated that for conditions related to pregnancy and childbirth the higher the level of disadvantage by decile the higher the number of admissions. The latest data, which was published on 2nd December 2016, indicated that women in the most deprived areas were four times more likely to be admitted to hospital than those in the least deprived. The management of pregnancy in the least deprived wards was particularly important. In respect of the number of units that were classified as harmful it was advised that 6+ units in one sitting was labelled as binge drinking, which equated to two glasses of wine. Middle class professionals could equally be affected by this issue.

In terms of the national picture it was explained that in terms of guidance there was no clear UK evidence base around the prevalence or how to best support those with FASD. There were no National Institute of Clinical Evidence (NICE) guidelines and the best available research data was contained within the Public Health England Regional Healthcare Needs Assessment, which was undertaken in August 2016. There was no register held by GPs on the number of patients diagnosed with FASD and very few people had the condition marked on their medical records. A lack of clarity over how hospitals code diagnosis was a further issue that needed to be addressed. The panel was advised that further research and a clear clinical pathway for diagnosis was needed in Middlesbrough. The FASD Network representative expressed the view that action was needed and there was worldwide evidence to demonstrate what measures made a positive difference.

The Health Improvement Specialist advised that Public Health had a good relationship with the local anti-natal and midwifery services. Midwives routinely asked questions around alcohol use and carried out alcohol screening tests during pregnancy. It was accepted that the information gleaned by midwives was dependent on the mothers providing an honest response and many mixed messages on drinking during pregnancy prevailed.

The FASD Network representative stated that FASD remained a serious issue for public health and the public needed to be made fully aware of this preventable condition. The numbers of people being diagnosed with FASD was not representative of the harm that this condition caused for families affected.

Reference was made to the local picture and the Health Improvement Specialist advised that a specific work stream for FASD had been established in Middlesbrough approximately eighteen months ago. As a result a local campaign had been launched around the dangers of

drinking during pregnancy and health visitors as well as midwives now discussed alcohol consumption during pregnancy at universal visits. A Member of the panel expressed the view that awareness raising needed to be undertaken in schools to ensure young people were aware of the dangers of drinking during pregnancy. It was stated that the evidence suggested that drinking alcohol during the first ten days of pregnancy was a risk factor even though at this stage many women might not have known they were pregnant. The risk of harm to the baby was, however, likely to be low if a woman had only drunk small amounts of alcohol. In February 2016 the UK Chief Medical Officer (CMO) revised national guidelines to outline that:-

- If you were pregnant or planning a pregnancy, the safest approach was not to drink alcohol at all to keep risks to the baby to a minimum.
- Drinking in pregnancy could lead to long-term harm to the baby, with the more you drink the greater the risk.

It was highlighted that if it had been clearly documented that a woman drank heavily during pregnancy or it was suspected that this was the case she would receive special maternity care and the baby would receive dedicated support. In terms of FASD diagnosis one element of the assessment focussed on the child's and this was not easily identifiable at birth. Often it was the case that Paediatricians did not want to label a baby with FASD, however, if a brain scan was undertaken organic brain damage could be mapped and diagnosed.

The panel queried how knowledgeable GPs were in respect of the condition and the FASD Network representative advised that the Department of Health's guidance on this issue was that professionals were responsible for their own professional development. FASD was not included as part of any of the formal training undertaken by Social Workers or Teachers. The FASD Network was regularly approached by parents that were concerned their child had this condition and were only then given a diagnostic sheet and advice on what to do next. The point was made that GPs, Social Workers and Teachers were coming into contact with a child regularly and the referral system needed to be there to signpost parents to the right person.

The panel was informed that often it was not until a child reached the age of 7, 8 or 9 that the difficulties they experienced became apparent and the connection with possible alcohol exposure in the womb was made by professionals. Many adopters were unaware that the development of this condition was a possibility for their child and the difficulties the family experienced were often put down to issues of attachment. The point was made that a full medical assessment was undertaken when a child was adopted. However, the information on mother's medical records remained with the mother's GP practice and it was very difficult for another GP to access that data. It was explained that at the point of adoption the child becomes a new person and it was acknowledged by the panel that there were some areas of national policy that the panel cannot affect. The FASD Network representative advised that in an effort to provide this information to adopters some Health Visitors were recording the information in the child's red book.

In terms of the work undertaken locally to promote the preventative message and inform women and men of the dangers involved in drinking during pregnancy a Teeswide campaign had been launched. FASD awareness day was held on 9 September 2016 and supported by Right Balance. The panel was shown infographics on FASD, which showed the risks and key facts on which the campaign had been built. Reference was also made to a specific piece of work which had been undertaken with a group of professionals and a cohort of mothers. Opportunities to further this work were being explored whilst the campaign posters had been displayed in shops, pubs and restaurants throughout Middlesbrough. The Council's Licensing Team had fully supported the campaign and in line with the new licensing objectives every responsible licensee should be backing the campaign.

It was acknowledged that there were numerous factors that contributed to a child developing FASD and mother's own nutritional health at the time of her pregnancy was another important factor. Given the serious nature of the condition the panel was of the view that the wording featured in the poster campaign should be stronger, as with the guidance issued by the Chief Medical Advisor. The point was made that 50 per cent of all pregnancies were unplanned and that this was a whole population issue. It was also explained to the panel that alcohol freely

crosses the placenta during pregnancy and it was a direct supply to the baby. There was reduced risk to the baby after the first trimester, however, there was also a need to protect the future babies of the town by educating people of the risks involved.

The question was put to the CCG as to why, given the fact that people will continue to develop FASD, had a paediatric service not been commissioned on a population basis. Families in Middlesbrough have had to access services from elsewhere including the national FASD clinic and Yorkshire. The point was made that the FASD Network was still waiting for two Paediatricians at South Tees NHS Trust, fully trained in FASD, to sign off on a diagnosis. All Local Authorities had a named Looked After Children (LAC) Paediatrician and it was often the person in that role who specialised in FASD given that they were the most skilled and knowledgeable in dealing with LAC. It was confirmed that efforts had previously been made to engage Paediatricians in the South Tees but unfortunately these had not been successful. The FASD network was hosting a Training Day at South Tees NHS Trust in February and it was hoped that the event would be well attended. The view was expressed that there was also a wider issue in that even where clear pathways were in place one of the difficulties with FASD was what support a child would access following diagnosis. FASD was a condition diagnosed by exclusion and therefore it was more difficult to diagnose.

The Health Improvement Specialist advised that FASD was mentioned in the most recent review of the Joint Strategic Needs Assessment (JSNA), as well as the Alcohol Harm Reduction Strategy 2017 - 2022, which was due to go out for public consultation very soon. The FASD Network representative advised that there was support that could be provided for a child diagnosed with FASD. For example, with regard to developmental support the child may need extra support with their reading. National research on this issue has already demonstrated the type of support which provides a good outcome for the child. The point was also made that it maybe a case of revamping existing systems to support children with FASD. The panel was informed that 95 per cent of children with FASD had a co-occurring mental health condition. Post diagnosis support was needed for the child's whole lifetime and once a diagnosis had been given the child often flourished with the right support. The point was made that recognition of the condition early on could result in the child's sensory and learning needs being met and managed rather than behavioural issues resulting in school exclusions.

The FASD Network representative advised that a diagnosis shifted the entire support provided to the child and once obtained the child was on the right path to accessing the support the child needed. The suggestion was put forward that structurally there was the potential to use existing CAMHS systems by broadening the umbrella term used to include neurodevelopmental conditions for which support to the child was provided. It was acknowledged there was, however, also a need for training to be provided in order to increase capacity. In terms of diagnosis the point was made that the diagnosis of FASD was not time consuming in itself. The difficulty was with the co-ordination of the various medical assessments that needed to be undertaken including an Occupational Therapy Assessment, Speech and Language Assessment and Cognitive Assessment. Reference was made to other countries and the fact that in Canada a team model was in place in order to pull together the required evidence together prior to sign off by the Paediatrician.

Reference was made to the potential damage of not 'getting this right' and it was explained that FASD involved difficulties with sensory processing as a result of organic brain damage. The knowledge and evidence was out there to show which 2, out of a possible 1100 medications were most effective in managing FASD. However, children mistakenly diagnosed with ADHD could end up with additional issues, as a result of taking prescribed antipsychotic medication and there was a real need to get this right.

During discussion the following points were made:

- There needs to be improved pathways of care for FASD as the present arrangements are not 'hitting the spot'.
- Diagnosis remains a stumbling block and the majority of authorities have 2 Paediatricians to sign off on a diagnosis of FASD.
- A FASD training event for Paediatricians at South Tees NHS Foundation Trust was scheduled for 8 February 2017.

- It was a false economy not to commission support for FASD.
- Information provided on the NHS website advising that 1 or 2 units of alcohol in pregnancy was still acceptable needed to be changed.
- The message of not drinking any alcohol during pregnancy was a clear one.

The panel queried how the FASD Network representative had become involved in supporting children with FASD. It was explained that as a Foster Care the representative had fostered over 40 children, 9 of whom had FASD. At present the FASD Network representative was supporting over 1100 families locally who had children with the condition. These were described as some of the most exceptional families you could meet. The FASD Network representative stated that she was very grateful the panel was considering the topic and that Members had been so patient and outraged about the subject, as well as feeling that scrutiny could have an impact. The point was also made that the Health Improvement Specialist had championed FASD over the last eighteen months and was leading the way in generating interest amongst professionals.

AGREED as follows:-

1. That an invitation be extended to the Director of Public Health, the South Tees CCG, South Tees NHS Foundation Trust, the Local Medical Committee and FASD Network representative to provide further information on this topic at the panel's next meeting.
2. That the Executive Member for Education and Skills be invited to attend the panel's next meeting to provide information on the advice / education provided in schools on the dangers of drinking during pregnancy.
3. That an extract of the information on FASD contained within the Joint Strategic Needs Assessment (JSNA) be presented at the panel's next meeting.
4. That efforts be made to ascertain who is responsible for transferring health data from the Looked After Child's (LACs) file to the adoption medical assessment.