HEALTH SCRUTINY PANEL

A meeting of the Health Scrutiny Panel was held on 28 March 2017.

PRESENT: Councillors Councillors E Dryden (Chair) and A Hellaoui and J McGee

ALSO IN ATTENDANCE: Leon Green - Public Health Intelligent Specialist
Maria Catterick - FASD Network

OFFICERS: Fiona Alexander - Principal Educational Psychologist
Graeme Nicholson - Health Improvement Specialist (Best Start and Families)
Jane Wilson - Head of Service - Looked After Children, Placements, Children with Disabilities
Caroline Breheny - Democratic Services Officer

APOLOGIES FOR ABSENCE Councillors C Hobson, B Hubbard, G Purvis and M Walters
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DECLARATIONS OF INTERESTS

None declared

1 **MINUTES - HEALTH SCRUTINY PANEL - 28TH FEBRUARY 2017**

The minutes of the Health Scrutiny Panel meeting held on 28 February 2017 were approved as a correct record.

2 **FOETAL ALCOHOL SYNDROME DISORDER - FURTHER EVIDENCE GATHERING**

The purpose of the meeting was to hold a further evidence gathering session on the topic of FASD and a number of representatives were in attendance to contribute to the discussion. The Public Health Intelligence Specialist had been requested to provide a briefing on prevalence estimates for Foetal Alcohol Spectrum Disorders (FASD) in Middlesbrough. A briefing paper had been prepared and was presented to the panel.

The panel was advised that the evidence highlighted that despite reducing in recent years, the rate of alcohol-related admissions for women aged under 40 years in Middlesbrough remains higher than the English average.

In 2014/15, which was the latest statistical data available there were 144 admissions for alcohol related conditions for women in this age group, a rate of 199.7 per 100,000. The Middlesbrough rate is 66% higher than the England rate of 120.4 per 100,000. These figures suggested that rates of alcohol misuse in women of childbearing age in Middlesbrough were likely to be higher than the England average.

Reference was made to the admissions data for Foetal Alcohol Syndrome (dysmorphic) and it was explained to the panel that Hospital Episode Statistics record reasons for admission to hospital in England. There were coded using a global coding system developed by the World Health Organisation called the International Classification of Diseases (ICD). The tenth revision of the classification was currently in use, known as ICD-10. In England, hospital admissions were coded with a primary diagnostic code and up to nine additional diagnostic codes. In the ten years for which data was available routinely, the maximum number of admissions in a year was 30 and for each of the most recent five years there were between 10 and 13 admissions annually. Middlesbrough data was not available due to such small numbers. It was acknowledged that given FASD was a syndrome disorder it would be rare for it to be listed as a primary reason for admission to hospital.

The Health Intelligence Specialist advised that routine reporting for all diagnostic codes was only available for the last three years. There was considerable increase in the number of cases compared to primary diagnosis only. In 2013/14 there were 25 times as many admissions for primary and all diagnosis including Foetal Alcohol Syndrome but even with 300

to 350 admissions in England, the admission figure for Middlesbrough may only be one. The point was made that the national data showed a gap in understanding of the quantity of FAS. In terms of estimating the prevalence of FASD in England it was advised that there was no accurate measurement. Local understanding of incidence (the number of new cases occurring in a given time) and prevalence (the total number of people in the population) was unknown. Estimates could be made using research gathered elsewhere and applying it to Middlesbrough's population. However, such estimation was subject to certain assumptions and prone to error, which lead to uncertainty in the estimates.

Assumptions included:

i. The original research was robust
ii. The research population was sufficiently similar to the local population for meaningful comparison
iii. The rate of FASD did not vary much with time

It was advised that in making use of research from elsewhere the estimated number of new cases (incidence) of FAS and number of school aged children with FASD (prevalence) in Middlesbrough was as follows (based on research included in a 2016 report by the British Medical Association):-

- Based on the low estimate of FAS incidence (USA) of 0.5 per 1000 live births and a high estimate of 7 per 1000 live births the incident rate would equate to an estimated number of between 1 and 13 new cases annually based on the dominator of 1,925 live births per annum.
- The FASD prevalence (USA and W Europe) of school-aged children in Middlesbrough based on a low estimate of 2 per cent and high estimate of 5 per cent would equate to a prevalence of between 406 and 1016 cases based on the denominator of 20,313 children in Middlesbrough aged 5-16.
- Further research from Italy on 6 year old children showed a prevalence of FAS between 4 and 12 per 1000 live births. This figure equated to a prevalence of between 81 and 244 children based on the denominator of 20,313 children aged 5-16 in Middlesbrough. The FASD prevalence (Italy) rate i.e. including all Foetal Alcohol Spectrum Disorders equated to between 469 and 1,272 children in Middlesbrough. The Public Health Intelligence Specialist made the point that in summary, these combined studies provided the following estimates for Middlesbrough:-

Foetal alcohol syndrome (FAS)

- Between 1 and 21 cases diagnosed annually
- Between 12 and 244 school-aged children

Foetal alcohol spectrum disorders

- Between 34 and 111 cases diagnosed annually
- Between 406 and 1,272

It was emphasised that with these estimates, it needed to be recognised that:

- Foetal alcohol syndrome (FAS) represents a fraction of all foetal alcohol spectrum disorders
- There was a high degree of uncertainty in these estimates
- There maybe differences between the study populations and Middlesbrough
- There was little understanding of the number of adults living with FAS and FASD

Reference was made to the data included in the draft copy of Middlesbrough's Alcohol Harm Reduction Strategy 2017-2022, which included the statement that 23 children were diagnosed with FASD at James Cook University Hospital (JCUH) in 2013-14. There had also been a near doubling in children diagnosed with FASD at James Cook University Hospital since 2006-07. In the year between 1 April 2013 and 31 March 2014 there were 27 females admitted to JCUH with conditions wholly attributable to alcohol consumption within 9 months of having given

birth.

The Health Improvement Specialist (Best Start and Families) updated the panel to advise that since then the data had been revisited and the service was not confident that this data was accurate, as multiple IDC-10 codes had been included. That section of the report had been rewritten and a copy of the update be provided to the panel in advance of the next meeting.

For comparative purposes the FASD Network representative advised that in Gateshead the Looked After Children's (LAC) Paediatrician had re-examined the LAC case files and identified as part of this study 200 children with FASD. Reference was made to the Peterborough study and it was advised that two audits of children were conducted in a community Paediatric clinic setting. The first audit counted the number of children seen during a period of two-and-a-half years between April 2010 and August 2013, where there was a clear prenatal history of alcohol exposure. The audit also looked at how many children may have Foetal Alcohol Syndrome (FAS) or FASD. Seventy-two children were given such a diagnosis within the time frame. The second audit reported on children looked after and children put up for adoption during a 12-month period from January 2013 to December 2013. It reported a history of prenatal alcohol exposure in 55 out of 160 health assessments for looked after children (34%) and in 34 out of 45 medicals for adoption (75%).

The panel was informed that as part of the Peterborough's Safeguarding Children's Board training programme a new course on Foetal Alcohol Syndrome Disorders (FASD) had been included. One of the key aims and learning outcomes of the course was to enable participants in recognising FASD and securing the earliest possible intervention. The session was delivered by a Consultant Community Paediatrician in Peterborough, who held a lead Clinical role for Children in Care and was Medical Advisor to the Adoption Panel in Peterborough.

The Chair expressed the view that in light of the findings of the study in Gateshead and Peterborough the Council owed it to Middlesbrough's Looked After Children to undertake a piece of work on FASD in partnership with the Looked After Children's Paediatrician. Otherwise our young people were potentially not receiving the services they should be. The issue of labelling children with FASD was raised but the view was expressed that to ensure children were receiving the right support this issue needed to be examined. The Head of Service for Looked After Children advised that an issue, which did need to be considered was that any work undertaken on this would need to be focused specifically on FAS, narrowed down and not cover the full FASD spectrum, as this alone would be a significant piece of work.

Reference was made to Public Health England proposing to undertake some work in the North East on establishing prevalence rates. However, this opportunity had not been taken up by the authority, although it was acknowledged that Public Health would welcome some good quality local data on this issue. The Principal Educational Psychologist was asked for her views on reviewing Looked After Children's case files. The panel was advised that in respect of reviewing information retrospectively the difficulty the Educational Psychology service faced was that the service had been on a downward spiral since 2010. The service was only now starting to be rebuilt and as of September 2017 the priority would be to rebuild relationships with schools and undertake more work directly with young people.

In response to a query the Head of Service for Looked After Children advised that screening for children at risk of FASD needed to be embedded into the care system. Where children were identified as being potentially at risk of FASD this needed to be investigated further through a referral to a Paediatrician. Looked After Children were a cohort with a high probability of FASD prevalence and the panel's consideration of this topic had raised the profile of this issue. The view was expressed that this was the first forum in Middlesbrough to have taken a thorough look at this issue with all agencies around the table. It was suggested that an expert group of the professionals involved in the panel's review should be established to take this work forward in 2017/18.

Reference was made to the current screening arrangements for Looked After Children for FASD and the view was expressed that there needed to be a way of red flagging, as soon as possible, any likelihood of FASD along with what action needed to be taken. It was advised

that a very robust screening tool template had been developed and encompassed if a child had SEN or if there had been any risks to the child such as exposure to alcohol in utero. It was emphasised that these issues should be picked up at the initial assessment stage but given the low numbers of children diagnosed with FASD locally, the systems in place needed to be revisited. The question was posed as to whether it could be to a child's detriment to be diagnosed with FASD. However, the view was expressed that every potential issue a child may encounter should be picked up as early as possible for the benefit of both the child and adoptive parents. Issues such as exposure to alcohol in utero should be flagged up specifically in a child's permanence report to ensure that when the child reaches 8, 9 and 12 the evidence is contained in their case documentation.

The Chair posed the question as to the so what effect. Did having a diagnosis have any positive implications for families who were caring for a child with FASD? The point was made that as a result of the recognition of the condition health services were better able to target support. The Specialist Nurse for Looked After Children would be able to flag FASD / FAS on the system as a possible issue from 1 April 2017. Reference was also made to a recent study undertaken in Northumbria, which involved taking the bloods of 500 women at 18 weeks of pregnancy. The results for hazardous substances consumed in utero was 1 per cent. The research undertaken in Northumbria was offered to Middlesbrough and the cost was in the region of five thousand pounds. The Health Improvement Specialist advised that a decision was taken that the authority would reassess its decision to undertake a similar piece of work following the findings in other areas. The view was expressed that a prevalence of 1 per cent in Northumbria was not comparable with Middlesbrough's figures. Reference was made to the findings of the international community where prevalence figures ranged from 3 to 6 per cent of the population.

The Health Improvement Specialist advised that over the last 18 months the Council had concentrated on promoting the prevention agenda. However, it was clear that from the evidence gathered there was insufficient data on children potentially at risk of FASD following birth and there was a need to see a shift forward in service provision. The Head of Service for Looked After Children advised that if services were aware from the outset that the cause of the child's health issues were due to exposure to alcohol in utero there would be an increased focus on dealing with these difficulties in the early years. The support offered once a child was diagnosed with a condition were more focussed and early intervention in areas such as Speech and Language, Occupational Therapy and provision of Psychological Assessments all needed to be conducted in advance of obtaining a diagnosis. From an Educational Psychologist's perspective it was advised that it was always helpful to have the causal factors. The point was made that FASD had a very spikey profile and a child would require a Psychologist's support during the transition phases including moving to secondary school and college. The FASD Network representative advised that families with a child who has FASD would be delighted to have that support but there were issues with capacity. The Principal Educational Psychologist advised that capacity was an issue and although by September 2017 the service would have a full complement of staff consideration needed to be given to the use of Clinical Psychologists, along with Educational Psychologists.

During discussion the following issues were raised;

- Regardless as to whether a child had been diagnosed with Autism or another neurological condition Educational Psychological support would be expected at primary and secondary level. Children in Year 5 and children in Year 9 known to have such conditions were identified and support arrangements built in.
- It had been reported that people were struggling to obtain Educational Health Care Assessments and were often looking at standard provision for their child.
- At present agencies maybe equipping families with generic parenting skills when bespoke programmes were needed. FAS would need to be identified as the issue in order to target it.
- If there was evidence to indicate that the prevalence rate for FAS locally was 20 births per year all services should be expecting those numbers coming through the system. The question was posed as to how would that factor affect the way services worked? The view was expressed by representatives around the table that a local study would be worthwhile.

The Chair put the point to the panel that it needed to be sure that any recommendations the panel put forward were done so for the right reasons. In light of this factor the view was expressed that the panel was in favour of the following:-

- A study, which included bloods being taken around a mother's ‘booking in' appointment so prevalence rates could be established.
- The tweaking of system improvements to ensure that any LAC child with the potential of developing FASD was flagged on the system early on.
- A proposal to be put to Council that a specific piece of research be undertaken in Middlesbrough / Tees Valley on FASD – at present although systems were in place these were not actually helping children with a high probability of FASD.
- Training on FASD to be offered through the Local Children's Safeguarding Board (LSCB), which could also be counted towards an individual's Professional Development Programme.
- That National Institute of Clinical Excellence (NICE) Guidance on FASD for clinicians be requested. The guidance would provide a standard protocol for diagnosis, which demonstrated evidence based practice.
- Reference was made to a comment expressed during discussion that obtaining a joined up Educational Health Care Plan for a child was more difficult now than it had been previously. The Principal Educational Psychologist advised that if this was the case it would need to be flagged up, as this would be another piece of work that would need to be looked at.

In terms of securing funding for a specific piece of research on FASD in Middlesbrough to be undertaken reference was made to the following options:-

- The FUSE partnership - an alliance with the University could have research interest opportunities that were worth exploring.
- The Royal College of Public Health had various grant funding opportunities that could potentially be accessed.
- External grant funding including the DCLG Communities Fund, which provided funding to Local Authorities working with community groups to deliver solutions to entrenched social issues could be considered. .
- The Chair requested that efforts be made to establish as to whether any of the above funding opportunities could be explored in order to ensure that the research work could be undertaken.
- The Chair thanked all of the guests for their attendance and valuable contributions.

AGREED as follows:-

1. That the panel's next meeting focus on the shaping of the recommendations for this review.
2. That the rewritten section of Middlesbrough's Alcohol Harm Reduction Strategy 2017-2022 on 'Alcohol use during pregnancy' be provided to the panel in advance of the next meeting.
3. That the Heath Improvement Specialist contact the Royal College of Public Health to establish as to whether there was any possibility of the organisation supporting a specific piece of research on FASD in Middlesbrough.
4. That the information received be incorporated in the panel's final report on this topic.

3 **ANY OTHER BUSINESS**

GP Provision in Middlesbrough

Confirmation had been received from the University of Newcastle to advise that all Medical Training previously undertaken at the Stockton Campus of Durham University had been transferred to Newcastle. The Chair queried the implications for GP Training Placements locally and it was requested that a response from the Local Medical Committee on the implications for the Tees Valley be requested. The Mayor had also raised this as an issue of concern and an update was required.

Health Inequalitites - Increasing Breastfeeding in Middlesbrough

Reference made to the panel's previous review on the topic of Health Inequalities - Increasing Breast Feeding in Middlesbrough. The Chair requested that an email audit be undertaken to ensure that Breast Feeding friendly facilities were accessible in all Council buildings.