

MIDDLESBROUGH COUNCIL

FINAL REPORT OF THE HEALTH SCRUTINY PANEL

FOETAL ALCOHOL SYNDROME DISORDER (FASD)

AIMS OF THE INVESTIGATION

1. The aims of the investigation were:
 - To examine current service provision for children with FASD / probable FASD to assist in identifying and planning for future service demand.
 - To ensure any child with FASD / probable FASD receives the right support at the right time and can access that support in Middlesbrough.

TERMS OF REFERENCE

2. The terms of reference for the scrutiny panel's investigation were as follows:
 - a) To investigate the prevalence of FASD in Middlesbrough.
 - b) To give consideration to the issues of diagnosis, prevention, early intervention and new pathways to care for FASD.
 - c) To examine the support currently available for children with FASD and their families.

BACKGROUND INFORMATION

Foetal Alcohol Syndrome Disorder (FASD)

3. In June 2016 members of the public were asked to provide potential topics for consideration by the panel. In response the FASD Network brought this issue to the panel's attention. FASD is a condition linked to drinking alcohol in pregnancy and is thought to be the leading cause of preventable learning disabilities. Nationally there is a lack of diagnostic and intervention services to support families affected by FASD and there is also a widespread lack of knowledge amongst professionals. The condition is more prevalent than autism but attracts no specialist provision. The panel agreed to consider FASD by assessing the scale of the problem in Middlesbrough and considering what support should be available to children with the condition.
4. In terms of the national picture there is no clear UK evidence base around the prevalence or how to best support those with FASD. There is no National Institute of Clinical Evidence (NICE) Guidelines and the best available research data is contained

in the Public Health England Regional Healthcare Needs Assessment, undertaken in August 2016. No form of register is held by GPs on the number of patients diagnosed with FASD and very few people have the condition marked on their medical records. A lack of clarity over how hospitals code diagnosis also needs to be addressed.

5. There are a number of key issues to highlight in respect of FASD:-
 - FASD is the most common, non-genetic cause of learning disability in the UK
 - The true prevalence of FASD in the UK is not known, however it is estimated to be well in excess of 1 per cent of all live births.
 - The condition is preventable if a mother abstains from alcohol during pregnancy.
6. FASD is characterised by a number of symptoms 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 are also prominent features in the most developed versions of FASD. Other symptoms of the condition are quite subtle and the Lancet Journal has advised that FASD has 428 potential impacts. Given these facts it is quite alarming that the condition receives hardly any media exposure.
7. Until recently i.e. February 2016 the UK government was also the only government in the world to still endorse any level of drinking during pregnancy. Labelling is a further issue and the small symbol currently displayed on bottles of alcohol to discourage pregnant women from drinking is perhaps inadequate. The UK is 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. It is not known at present how much alcohol causes FASD.

Prevalence of FASD locally

8. There is no local study to document the prevalence of FASD in Middlesbrough but it is anticipated that it would be higher than 1 per cent of all live births. There are approximately 2000 children born each year in Middlesbrough which equates to 20 births per year or 1,300 cases from Middlesbrough's population figure. Many children with FASD end up in the care system and are either fostered or adopted. Often there is no clear diagnosis and no information recorded on the child's health file to indicate any potential for FASD. Children are instead diagnosed with ADHD or attachment disorder due to distinct separational loss or behaviour differences. However, no one is looking back to what was happening during early pregnancy. Research in the USA and Canada estimates that raising a child with FASD comes in at a cost £1m per year.
9. In 2015 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 misuse. The cost to the health, social care and justice systems are significant but there is insufficient robust research in the UK to give an accurate indication of FASD prevalence.

10. FASD is mentioned in Middlesbrough's most recent review of the Joint Strategic Needs Assessment (JSNA), as well as the Alcohol Harm Reduction Strategy 2017 – 2022. The data included in the draft copy of Middlesbrough's Alcohol Harm Reduction Strategy 2017 – 2022 included the statement that 23 children were diagnosed with FASD at James Cook University Hospital (JCUH) in 2013-14. It also stated that this equated to a near doubling in the number of children diagnosed with FASD at JCUH since 2006-07. However, this data has since been revisited and the Public Health Team is no longer confident that the data is fully accurate, as multiple IDC-10 codes were included. That section of the report has been rewritten as follows:-

The true prevalence of FASD is not known, however it is estimated to be prevalent in more than 1% of all live births in the UK and North East research in 2016 also showed the same prevalence. This means we can estimate for Middlesbrough that at least 20 babies born a year will be affected FASD. Diagnosing FASD can be hard because there is no specific medical test and there are also other disorders, such as ADHD (attention-deficit/hyperactivity disorder), which have similar symptoms to those seen with FASD."

11. In the year between 1 April 2013 and 31 March 2014 27 females were admitted to JCUH with conditions wholly attributable to alcohol consumption within 9 months of having given birth. The number of hospital admissions in 2014/15 for the major conditions by socioeconomic decile for conditions related to pregnancy and childbirth also show the higher the level of disadvantage by decile the higher the number of admissions. The latest data, which was published in December 2016, indicates that women in the most deprived areas are four times more likely to be admitted to hospital than those in the least deprived. The management of pregnancy in the most deprived wards is particularly important. In respect of the number of units that are classified as harmful 6+ units in one sitting is labelled as binge drinking, which equates to two glasses of wine. Middle class professionals can equally be affected by this issue.

Prevention of FASD in Middlesbrough

12. Middlesbrough Council's Public Health Team has a good relationship with the local anti-natal and midwifery services. Midwives routinely ask questions around alcohol use and carry out alcohol screening tests during pregnancy. It is accepted that the information gleaned by Midwives is dependent on the mother providing an honest response to the questions and many mixed messages on drinking during pregnancy prevail.
13. In 2015 a specific work stream for FASD was established by the Public Health Team in Middlesbrough and as a result a local campaign has been launched around the dangers of drinking in pregnancy. Health Visitors and Midwives discuss alcohol consumption during universal visits. The evidence suggests that drinking alcohol during the first ten days of pregnancy is a high risk factor even though at this stage many women might not know they are pregnant. The risk of harm to the baby is, however, likely to be low if a woman has only drunk small amounts of alcohol. In February 2016 the UK Chief Medical Officer (CMO) revised the national guidelines to outline that:-

- If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all to keep risks to the baby to a minimum.

- Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk.

14. If it has been clearly documented that a woman is drinking heavily during pregnancy or if it is suspected that this is the case she will receive special maternity care and the baby will receive dedicated support. In terms of FASD diagnosis one element of the assessment focusses on the child's emotional development, which is not identifiable at birth. Often Paediatricians do not want to label a baby with FASD, however, if a brain scan is undertaken and organic brain damage can be mapped the condition may be diagnosed by a Geneticist. However, often it is not until a child reaches the age of 7, 8 or 9 that the difficulties they experience become apparent and the connection with possible alcohol exposure in the womb is made by professionals. Many adopters are unaware that the development of this condition is a possibility for their child and the difficulties the family experience are often put down to issues of attachment.

15. A Teeswide campaign has been launched to promote the preventative message and inform women and men of the dangers involved in drinking during pregnancy. FASD awareness day was last held on 9 September 2016 and is supported by Right Balance. The following infographics on FASD show the risks and key facts on which the campaign has been built:-



16. A specific piece of work has also been undertaken with a group of professionals and a cohort of mothers. There are numerous factors that contribute to a child developing FASD and mother's own nutritional health at the time of pregnancy is another important factor. It has been shown that alcohol freely crosses the placenta during pregnancy and there is a direct supply to the baby. There is reduced risk to the baby after the first trimester, however, there is still a need to protect Middlesbrough's unborn babies by educating people on the risks involved. Opportunities to further this work are being explored whilst the campaign posters have been displayed in shops, pubs and restaurants throughout Middlesbrough. The Council's Licensing Team has fully supported the campaign and in line with the new licensing objectives every responsible licensee should be backing the campaign.

17. The point was also made that the Health Improvement Specialist has championed FASD over the last eighteen months and is leading the way in generating interest amongst professionals. However, it was highlighted that the area where families are having difficulties is in obtaining a diagnosis of FASD and often spend years trying to get a diagnosis. In South Tees there appears to be an obstacle on the health side, as parents report that they have been on this journey for quite a few years. The FASD representative accepted there are challenges in the diagnosis of FASD but obtaining a diagnosis and accessing post diagnostic support are important for children and families. The FASD Network representative expressed the view that further research and a clear clinical pathway for diagnosis is needed in Middlesbrough.
18. A number of measures have been identified that have a positive impact on outcomes for the children following a diagnosis:-
- There is support that can be provided for a child diagnosed with FASD. For example, with regard to developmental support a 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.
 - It is recognised that 95 per cent of children with FASD have a co-occurring mental health condition. Post diagnosis support is needed for the child's whole lifetime and once a diagnosis has been given the child often flourishes with the right support.
 - Recognition of the condition early on can result in the child's sensory and learning needs being met and managed rather than behavioural issues resulting in school exclusions.
 - A diagnosis shifts the entire support provided to a child and once obtained the child is on the right path to accessing the support the child needs.
 - There is the potential to use existing CAMHS systems by broadening the umbrella term used to include neurodevelopmental conditions. It was acknowledged there is, however, also a need for training to be provided in order to increase capacity.

Canada's gold standard model

19. In terms of diagnosis the view was expressed by the FASD Network representative that the diagnosis of FASD is not time consuming in itself. The difficulty is with the co-ordination of the various medical assessments that need to be undertaken including an Occupational Therapy Assessment, Speech and Language Assessment and Cognitive Assessment. Reference was made to worldwide research and the fact that in Canada a Multi-Disciplinary Team (MDT) approach is in place in order to pull together the required evidence prior to sign off by a Paediatrician.
20. Reference was made to the potential damage of not 'getting this right' and it was explained that FASD involves difficulties with sensory processing as a result of organic brain damage. The knowledge and evidence is out there to show which 2, out of a possible 1100 medications are most effective in managing FASD. However, children mistakenly diagnosed with ADHD can end up with additional issues, owing to prescribed antipsychotic medication and therefore there is a real need to get this right.
21. The panel queried where it should look for the gold standard in FASD diagnosis, care and support. It was advised that Canada is seen as an exemplar with Diagnostic Clinicians, Occupational Therapists, and Speech Language Therapists working

collectively. There are also Case Managers pulling all of the documentation together. The child would see each practitioner for an assessment, those practitioners would come together once a month and establish whether it was a diagnosis of FASD or not. The turnaround was quite quick and it would be followed up by a post diagnostic plan.

How FASD affects the care system

22. Many children diagnosed with FASD are children in the care system and Looked After Children (LAC) Paediatricians are often the most familiar with this condition. For cases where there are very obvious facial characteristics children tend to be diagnosed with FASD by a geneticist. Across the North East and North Yorkshire there are 1 or 2 named Paediatricians that would rule in or out FASD as a possible diagnosis. For example, there are 2 in North Tees, 2 in Durham, 1 in Gateshead and 1 emerging in Sunderland. The FASD Network expressed the view that a named Paediatrician in the South Tees would be helpful in moving the issue forward locally.

23. The Head of Service for Looked After Children provided an insight into the department's experience of working with children diagnosed with FASD / probable FASD.

How many looked after children in Middlesbrough have been diagnosed with FASD?

24. In the UK accurate identification of FASD is not yet as consistent as in some other countries such as the US and Canada, but it has been estimated that in Western countries as many as 9 per 1,000 live births involve children affected by Foetal Alcohol Syndrome (FAS), Partial Foetal Alcohol Syndrome (PFAS) or Alcohol Related Neurodevelopmental Disorder (ARND). Of the children concerned, 10 -15 per cent are affected by FAS, 30 to 40 per cent by PFAS and nearly half by ARND. However FASD can be misdiagnosed as ADHD, oppositional defiant disorder (ODD), conduct disorders amongst others.

25. In Middlesbrough:-

- A major issue is that there are a limited numbers of Paediatricians prepared to diagnose FASD in our surrounding areas.
- There appears to be more children coming through the system with a diagnosis of FASD that require an adoptive placement. However, these children are typically from the southern regions of the UK.
- There are currently 441 Children Looked After by Middlesbrough – of whom only 3 have a diagnosis of FASD, which is a lot less than in other areas.
- At present the data team cannot produce a report to reflect this information but could, if the information was in there to pull through.
- It was possible and probable that there are Looked After Children who are not diagnosed – training and briefings have been and will continue to be rolled out for Social Workers, Foster Carers, Connected Persons, Carers and Adopters to raise awareness.
- Many of Looked After Children are 'diagnosed' as having problems with their emotional health and some with behavioural issues – all of which are responded to as part of their health assessment and plan. In short – the presenting issues are managed whether or not their source is related to parental alcohol misuse.

26. What type of support are these children accessing and is support available to their families / foster carers?

- A year's worth of drop in sessions from the FASD Network have been secured by Middlesbrough Fostering Team to provide support to carers.
- FASD is now a 'stand alone' topic on the Adoption Preparation Group
- Children's Social Workers are being encouraged to include ANY information in the Child's Permanence Report (CPR) about alcohol consumption during pregnancy which could be vital to diagnosis in the future.
- Maria Catterick (FASD Network) has produced a checklist for GPs and other health practitioners to assist in their 'ruling in or out' of FASD. This had been shared with prospective adopters during their preparation.
- CAMHS Looked After Children's service are not currently working with any children/young people with FASD – though many of the children with whom they ARE working (41 currently) may have the 'wider effects' of FAS. The Local Authority is keen to see CAMHS working with more LAC children, as previously the figures have been around 70-75 and ideally the Local Authority would wish them to be higher. It is anticipated that the numbers will be higher next quarter. Psychologist support is provided should a child's referral cite FASD as an issue.

27. The Head of Service explained that she has spoken with a very experienced Foster Carer about her long term support of a young person with FASD and she provides the following insight:-

- Without a clear diagnosis there is very little support available
- Doctors are reluctant to diagnose either because they do not want to label a child with FASD OR because they don't know enough about it
- There was no local 'specialist' to diagnose the young person in her care
- Training on FASD (then) meant travelling to London – this is NOT the case now
- Emphasis should be on the WIDER effects of alcohol upon the child and not solely the syndrome as this would capture many more children e.g. impulsive behaviour

28. When asked what would have helped, the carer said;

- Specialist medical knowledge – locally
- Better Social Worker knowledge
- Understanding of the changing needs and 'presentation' of children who have FASD as they grow and develop
- Specialist schools are essential

29. In terms of whether FASD had been raised as an issue of concern by adopters via the After Adoption Support Team no specific concerns have been raised. However, there are children who have been diagnosed post placement (with Adopters and Foster Carers) because of the skill and knowledge of their adopters - who knew what to ask and what to request.

30. Are Social Workers regularly working with children in Middlesbrough that they suspect have FASD?

- In the Children with Disabilities team there are only 5 children (and they are NOT looked after) out of 200 cases with probable FASD i.e. there is no diagnosis.
 - The Team Manager for the Children with Disabilities team suggests the low number may be due to medical reluctance to label and/or reluctance of families to attend appointments. Often if a child is diagnosed with FASD the statistical prevalence of siblings also having the condition is approximately 70 per cent.
 - Social Workers are working with children who have FASD - or wider symptoms of the condition – though the workers themselves may not recognise that what the children/young people are presenting is alcohol related – hence the programme of training being rolled out.
31. With regard to training six Social Workers have been trained on ‘Have a Word’ – preventative work to establish the parent’s understanding of the impact and use of alcohol upon their unborn child. The intention is that the workers then train their peers so that practice is cascaded. Specific training on FASD was held on 5 April 2017 for the children with Disabilities Team and this is due to be rolled out to all Social Work practitioners. The training has been organised and funded by public health.
32. The Head of Service for Looked After Children advised that screening for children at risk of FASD needs to be embedded into the care system. Where children are identified as being potentially at risk of FASD it should be followed up with a referral to a Paediatrician. LAC are a cohort with a high probability of FASD prevalence and the panel’s consideration of this topic has raised the profile of this issue. In terms of current screening arrangements it was acknowledged that there needs to be a way of red flagging, as soon as possible, any likelihood of FASD along with what follow up action needs to be taken.
33. A robust screening tool template has recently been developed, which details whether a child has any Special Educational Needs or if there has been any risks to the child such as exposure to alcohol in utero. This issue should be picked up at the initial assessment stage but given the low numbers of children diagnosed with FASD locally, the systems need to be revisited. The question was posed as to whether it could be to a child’s detriment to be diagnosed with FASD. In response 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 in a child’s permanence report to ensure that when the child reaches 8, 9 and 12 evidence is contained in their case file to assist in any diagnosis. The Specialist Nurse for Looked After Children will be able to flag FASD / FAS on the system as a possible issue from 1 April 2017.

The Gateshead and Peterborough Studies

34. In Gateshead the Looked After Children’s (LAC) Paediatrician has re-examined the LAC case files and identified as part of the study 200 children with FASD. In Peterborough two audits of children were conducted in a community Paediatric clinic setting. The first audit counted the number of children seen during a two-and-a-half year period between April 2010 and August 2013, with 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%).

35. The Head of Service for Looked After Children advised that any similar work undertaken in Middlesbrough would need to focus specifically on FAS and not cover the full FASD spectrum, as this alone will be a significant piece of work.
36. Reference was also made to Public Health England (PHE) proposing to undertake some work in the North East on establishing prevalence rates for FASD. 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 faces is that the service had been on a downward spiral since 2010. The service is only now starting to be rebuilt and as of September 2017 the priority will be to rebuild relationships with schools and undertake more work directly with young people.
37. It was also noted that as part of the Peterborough's Safeguarding Children's Board training programme a new course on Foetal Alcohol Syndrome Disorders (FASD) is included. One of the key aims and learning outcomes of the course is to enable participants to recognise FASD and secure the earliest possible intervention. The sessions are delivered by a Consultant Community Paediatrician, who holds a lead Clinical role for Children in Care and is Medical Advisor to the Adoption Panel in Peterborough.

Pathways to care - commissioning support services for FASD

38. The Director of Strategic Planning and Performance at South Tees CCG confirmed that at present there is no formal care pathway for FASD. Community Paediatricians tend to focus on a broader range of attention and attachment disorders. The Commissioning Manager at South Tees CCG gave a presentation on the information the panel requested as follows:-
39. What CAMHS / LD support is currently being commissioned for children and young people in Middlesbrough?

South Tees CCG commission multi-disciplinary community teams to support children with both mental health and learning disabilities. Some staff specialise in children and young people who have a learning disability. The Team consists of a good mix of staff including Consultant Psychiatrists, Consultant Psychologists, Occupational Therapists and Mental Health Nurses. A separate Crisis Team is also in place to support young people in any crisis situation. In such a scenario the young person is seen within 1 to 2 hours. The multidisciplinary team respond to referrals, invite young people in for triage and undertake comprehensive assessments. The CAMHS Manager advised that FASD is not diagnosed or treated by CAMHS in the truest sense. However, co-morbid mental health conditions, for example, anxiety and depression are treated by CAMHS.

40. How much is being spent in Middlesbrough on CAMHS/LD support?

It was explained that no breakdown is available at a Middlesbrough level. However, in 2016/17 at a South Tees level, the agreed contract values are:

- £2,642,306 on community CAMHS
- £16,533 on Learning Disability specific CAMHS community support*
- £238,937 on Learning Disability respite services
- £95,086 on CAMHS eating disorder services. Figures from latest Contract Management Board papers

It was noted that the figure of £16,553 on Learning Disability specific CAMHS community support will be queried, as there is a Consultant Child and Adolescent Learning Disability Psychiatrist and other specific LD clinicians for Middlesbrough.

What proportion of support is accessed by children and young people who are looked after?

- Looked after Children's (LAC) CAMHS is commissioned by Middlesbrough Local Authority with a separate contract and reporting structure.
- Looked after Children from other local authorities are seen by the general teams and there is no breakdown of activity available by LAC/non-LAC.

41. Are generic treatments available to children and families experiencing challenging behaviours?

- Yes, some support is given all along the pathway. Staff within the Middlesbrough Team specialise in Positive Behaviour Support and parenting support.
- Input is assessed and based on need.
- Input ranges from parent support training days, individual packages, groups, consultation to special schools.

42. Members were keen to understand whether individual clinical pathways are commissioned for any of the following conditions: - Autism, ADHD, Attachment Disorders, FASD, Sensory Processing Disorder, Conduct Disorders, other neurodevelopmental conditions?

43. It was advised that of that list, pathways are only commissioned for:

- Assessment of Autism Spectrum Disorders
- Assessment and treatment of ADHD
- Positive Behaviour Support for Behaviours that Challenge.

44. Are any comparative figures available on the number of children diagnosed with FASD in the last 3 years in Middlesbrough, Stockton, Darlington, Redcar & Cleveland and Hartlepool?

- The CCG does not hold this information.
- **Data has been requested from Tees, Esk and Wear Valleys FT to determine**

numbers of children and young people who have a FASD diagnosis code in services.

Diagnosis and the challenge facing Paediatricians

45. Consultant Paediatricians at James Cook University Hospital (JCUH) are aware of FASD and have attended training days and departmental days on the condition. All general Paediatricians and LAC Paediatricians regularly work with children who have neurodevelopmental issues and this is already the pathway these children are taking. The Consultant Paediatrician advised that in her view the lack of a formal care pathway is from the CCG's perspective not such an issue.
46. Any child referred to a Paediatrician for neurodevelopmental delays, learning disabilities or specific problems with attention / memory and significant behavioural disturbances is assessed in clinic. A normal part of a Paediatrician's role involves taking background information, family history and assessing whether there have been any nutritional deficiencies prior to or following birth. Multi-disciplinary and multi-agency assessments by other agencies are also undertaken including assessments by Speech and Language Therapists, Physiotherapists and Neuropsychologists and this process holds true for all children seen in clinic. Anecdotally it is recognised that there are waiting lists for assessment by Children and Adult Mental Health Specialists (CAMHS) for autism, attachment disorders and ADHD. The point was also made that one of the difficulties families face with children waiting for assessments is being told following a long wait that it is not autism or ADHD. The question was posed as to where were families supposed to access support next?
47. The Consultant Paediatrician advised that FASD is not a straightforward diagnosis but a diagnosis of exclusion and several factors need to be considered including behavioural problems, cognitive problems, poor maternal health, parental drug and alcohol misuse and many other issues that affect a baby's development. In addition, neglect, attachment disorder, genetic background and learning disabilities all need to be considered. There are no definitive biological markers for this condition. FASD and FAS are also an umbrella term for a spectrum of disorders and often it cannot be qualified that a child's problems are due to the mother's consumption of alcohol during pregnancy. It was emphasised that very rarely is there only one issue and children coming through the looked after system have often experienced early neglect and childhood trauma. There are also two versions of FASD AR and D. The Commissioning Manager (South Tees CCG) confirmed that at present there are also issues with the coding for the condition and no register where the information is stored. Data on numbers of people with FASD is taken from those who have been through hospital with a diagnosis of FASD.
48. The Consultant Paediatrician made the point that it is important to look at the difficulties faced by these children, find out what those difficulties are and how the children can be best supported. These children need good access not just to Paediatricians but to appropriate Educational Psychologists. Having supporting documentation including assessments by an Educational Psychologist, CAMHS, education colleagues and the interface between professionals is needed to obtain the right information. The panel expressed the view that at present it appears we are not getting to that point quickly enough and there is a real need to work closely with CAMHS, given that there is no

commissioned pathway to accommodate FASD. It was confirmed that efforts are being made to condense waiting times for autism and ADHD diagnosis. However, it is not necessarily the case that a specific pathway for FASD is the best solution. It is more about how the CAMHS system can be best used to provide support for children with FASD.

49. Reference was made to the fact that the LAC CAMHS contract ensures that CAMHS workers are part of the LAC team. As a result of that direct pathway LAC children can be seen very quickly. In order for a child to go through the full system and obtain a diagnosis of FASD behavioural assessments need to be undertaken, the child needs to be seen by an Educational Psychologist, an Occupational Therapist and a Speech and Language Therapist in order to build up a complete picture of the child's needs. These are children with complex needs and there is no quick fix. There is also no generic treatment for FASD and all children with the condition present with very individual needs. When undertaking a diagnosis a Paediatrician will look back over all aspects including the child's other medical conditions, which can account for the child's presentation. The Paediatrician will also take into consideration as to whether the child had been seen by a Geneticist or experienced any significant learning difficulties in school. It was confirmed that this process can easily take a year.
50. The FASD Network representative advised that an Occupational Therapist assessment for a child with FASD is an ideal first step but yet a rare service. The real benefit of this assessment is around slower processing speeds and the impact this can have on regulating a child's behaviour at home, as well as in school. In response the Consultant Paediatrician expressed the view that there is still much debate as to whether FASD as a condition is accurately quantifiable and these children need to be looked at in the whole. A lot of children assessed for ADHD or autism will not have FASD but professionals need to ensure their needs are met. Rather than focusing on diagnostic labelling the focus should be on meeting the child's needs and putting the child at the centre of the work.
51. A Healthcare Needs Assessment on Foetal Alcohol Spectrum Disorders in the North East of England, undertaken in August 2016 also highlights that anecdotally clinicians have described a silent need that is difficult to quantify - children with probable FASD are not given formal diagnoses or are cared for under the remit of a secondary diagnosis such as ADHD. This occurs for a number of reasons; perceived stigma around the diagnosis acts as a deterrent, as does uncertainty on the part of clinicians about how to confirm a diagnosis, particularly where there isn't a clear history of maternal alcohol abuse, finally there is a perception that many fail to understand how and why the needs of children with FASD differ from those with ASD, ADHD, LD or other disabilities, and there is a question over the value added by a further diagnosis, which may simply serve to label the child.¹
52. The Commissioning Manager South Tees CCG confirmed that at present there is not a lot of data available to the CCG and this needs to be revisited. It is a chicken and egg situation given the uncertainty of what a diagnosis looks like from a clinician's perspective. If a child is not deemed to be on the autism spectrum or have ADHD what

¹ Healthcare Needs Assessment: Foetal Alcohol Spectrum Disorders in the North East of England, Dr Zoe Greaves, April 2016

pathway of care is available? The child has arrived at the end of the journey as can only be diagnosed with FASD through exclusion.

53. The FASD Network representative advised that their organisation deals with families in this situation on a daily basis. The child may display some of the traits but not fulfil all of the diagnosis criteria. When no diagnosis is given the children and families are left struggling and there is a limit to the support available in the community. The question was also raised as to whether these children receive appropriate help at school, as the issue is much wider than meeting a set of diagnostic criteria for ADHD or Autism. The Healthcare Needs Assessment; Foetal Alcohol Spectrum Disorder states that it is clear that diagnosis of FASD is dependent on a number of factors, firstly abnormalities must be recognised, whether by parents or health professionals such as midwives or health visitors. Secondly there must be access to and availability of secondary care services, with a physician who is able to recognise and identify possible signs of FASD, and finally the range of professionals required to give a firm diagnosis must be accessible and available to the patient and their family. It is clear that the availability of all these factors is often variable, and in many cases limited.

Is having a diagnosis beneficial?

54. The benefit of receiving a diagnosis of FASD was queried and the point was raised as to whether there is any evidence to demonstrate better outcomes for a child diagnosed with FASD. The FASD Network representative expressed the view that a FASD diagnosis provides understanding for the family in the same way a diagnosis of autism or ADHD does. Children with FASD present very different challenges for parents compared with those recommended to undertake the prescribed parenting courses and having an explanation also makes a difference to the practitioners working with the child. Attachment therapy and art therapy can be provided and the treatment plan tweaked as appropriate. It also makes a difference to the child themselves and prior to diagnosis children often feel they are stupid, bad or a failure.

55. It was acknowledged that there are challenges in the diagnosis of FASD but obtaining a diagnosis and accessing post diagnostic support are important for children and families. Reference was made to work undertaken in Peterborough and Gateshead and the Chair expressed the view that the Council should learn from good practice. If a model is in place in Gateshead using an integrated approach the panel should be encouraging that same dialogue and Multi-Disciplinary Team (MDT) approach in Middlesbrough. The Peterborough research looked specifically at Looked After Children and given the demographics of the town a similar piece of research could be undertaken in Middlesbrough. Public Health and the South Tees Consultant Paediatrician who had expressed an interest in FASD could be approached to undertake a piece of work in this area. The view was expressed that despite the challenges it would appear Middlesbrough has some good foundations on which to build.

56. The Consultant Paediatrician emphasised that evidence of FASD remains in its infancy and in five years' time more accurate data can be presented. The evidence referenced at present is anecdotal and there is insufficient evidence to substantiate the claims. FASD is a very difficult diagnosis to reach. The Service Manager of Paediatrics advised that there are also differences in the diagnostics criteria for FASD in different countries.

The panel expressed the view that irrespective of the diagnostic criteria for FASD it appears at present post diagnostic support is commissioned from CAMHS and there is a gap in the current level of provision. A cohort of these children may have learning disabilities and behavioural issues, which also impact on schools and children's services.

57. Reference was made to the work undertaken in schools and it was questioned how aware staff are of the condition. It was confirmed that a number of training sessions on FASD has been held in schools, however, the onus for management of the condition is not on teaching staff. The Executive Member for Education and Skills advised that there are real concerns around some of the teenagers currently coming through the Pupil Referral Unit. Some had severe behavioural problems and recognition needs to be given to the fact that this is not due to naughtiness but a case of early influences driving behaviour.
58. The Executive Member for Education and Skills advised that at present a lot of work is being undertaken by Public Health to produce a toolkit for schools, which addresses a number of issues. This 'extra life offer' for schools consists of a number of short, evidential based digital animation videos to support young people on a number of preventative issues. Reference was made to a school that has a child with FASD, which has been involved in the making of a short animation video to explain to other children in the school about the condition. The Chair posed the question as to the so what effect. Did having a diagnosis have any positive implications for families who are caring for a child with FASD? The point was made that as a result of the recognition of the condition health and education services are better able to target support.

Involving Educational and Clinical Psychologists

59. Unfortunately there has been a much depleted Educational Psychology Service in Middlesbrough for a couple of years. Therefore, it is not possible to comment on the training and skill set of an existing team, as such. The Principal Educational Psychologist was appointed in August 2016 with the task of re-building a service and additional staff will be joining the team after Easter, with further staff joining in September 2017. It was advised that advice would need to be sought from local and national training providers to get a fully accurate response as to the nature of the training programme content for EPs in training. However, many (if not most) EPs are 'aware' of FASD, if not trained. In addition, some experienced EPs have received and delivered training on this subject (for example to foster carers and specialist provision (special schools) often when this has fallen under their Specialist Senior EP roles (e.g. specialist senior complex needs roles).
60. The Principal Clinical Psychologist advised that experience has yielded 2 areas worthy of consideration: Firstly, it is extremely difficult to broach the subject/trace the history without "blaming" the mother, which is why it might be that diagnosis tends only to be sought/given when children are looked after. A second reflection is that many of these effected children when older are perhaps receiving Autism Spectrum Disorder, or other, diagnoses instead.
61. In terms of the support provided to children diagnosed with FASD or probable FASD educational provision tends to be 'needs led' and not 'labels led'. In other words,

support is provided following an assessment of need (either at a pre-statutory level or statutory level). This means that provision is mapped and determined on an individual basis, rather than a one size fits all based on diagnosis alone. It is highly likely that staff in early years are working with children with FASD, but whether the child has a diagnosis, and whether staff are FASD aware, are separate questions. The Principal Educational Psychologist raised the following queries: - How many children have our Paediatricians / CAMHS colleagues diagnosed with FASD in the last year? Does their routine screening / assessments ask explicit questions around alcohol consumption during pregnancy?

62. The question was posed as to what improvements can be made to current provision to ensure children with difficult to diagnose conditions receive the right support at the right time?

- Children currently seem to go down 'pathways', one at a time often. There is an ASD pathway (which when staffing permits is multiagency), and an ADHD Pathway (CAMHS), but it is unclear which service would claim that FASD is 'theirs'. This should be open to a wider discussion about joint commissioning of approaches to assessment.
- Multi-disciplinary case discussion would be helpful (FASD as a condition of medical origin) and knowledgeable educational psychologists, through involvement with multidisciplinary case discussions, can support with the educational, social, emotional implications of FASD.
- Middlesbrough's Educational Psychology Team does have access to an Educational Psychologist in the region with considerable complex needs experience, as well as FASD experience if further support is required.

63. From an Educational Psychologist's perspective it is always helpful to have the causal factors. The point was made that FASD has a very spikey profile and a child will require a Psychologist's support during the transition phases including moving to secondary school and college. The FASD Network representative advised that families who have a child with FASD would be delighted to have that support but there are issues with capacity. The Principal Educational Psychologist confirmed that capacity is an issue and although by September 2017 the service will have a full complement of staff consideration needs to be given to the use of Clinical Psychologists in the undertaking of these assessments along with Educational Psychologists.

A high degree of uncertainty in data estimates

64. In terms of estimating the prevalence of FASD in England there is 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) is unknown. Estimates can be made using research gathered elsewhere and applying it to Middlesbrough's population. However, such estimation is subject to certain assumptions and prone to error, which lead to uncertainty in the estimates.

Assumptions include:

- 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 does not vary much with time

65. The evidence highlights 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 is the latest statistical data available there are 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. This suggests that rates of alcohol misuse in women of childbearing age in Middlesbrough are likely to be higher than the England average.

66. 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 is as follows (based on research included in a 2016 report by the British Medical Association):-

- FAS – representing the more severe end of the spectrum. 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 denominator of 1,925 live births per annum.
- FASD – including the broader spectrum of conditions. 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.

67. Further research from Italy on 6 year old children shows a prevalence of FAS between 4 and 12 per 1000 live births. This figure equates 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 equates to between 469 and 1,272 children in Middlesbrough. In summary, these combined studies provide 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 (FASD)

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

68. It was emphasised that these are estimates and it needs to be recognised that:

- Foetal alcohol syndrome (FAS) represents a fraction of all foetal alcohol spectrum disorders (FASD)
- There is a high degree of uncertainty in these estimates
- There may be differences between the study populations and Middlesbrough

- There is little understanding of the number of adults living with FAS and FASD
69. Reference was made to the admissions data for Foetal Alcohol Syndrome (dysmorphic) and it was explained that Hospital Episode Statistics (HES) record reasons for admission to hospital in England. In the ten years for which data is available routinely, the maximum number of admissions in a year is 30 and for each of the most recent five years there are between 10 and 13 admissions annually. Middlesbrough data is not available due to such small numbers.
70. Routine reporting for all diagnostic codes is only available for the last three years and there has been a considerable increase in the number of admissions compared to primary diagnosis only. In 2013/14 there are 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.
71. It is worth recognising that the HES data refers only to hospital admissions, rather than outpatients, where it is expected the majority of individuals with FASD would be encountered. Therefore whilst this data can show that FASD is at times a recognised condition coded during admission it cannot substantively contribute to an incidence or prevalence, and rather serves to highlight the need for more robust data collection with regards to the occurrence of FASD in healthcare settings.²
72. In terms of securing funding for a specific piece of research on FASD in Middlesbrough reference was made to the following possibilities:-
- The FUSE partnership - an alliance with the University may have research interest opportunities that are worth exploring.
 - The Royal College of Public Health has various grant funding opportunities that could potentially be accessed.
 - External grant funding including the DCLG Communities Fund, which provides funding to Local Authorities working with community groups to deliver solutions to entrenched social issues could be considered.

CONCLUSIONS

1. Based on the evidence, given throughout the investigation, the scrutiny panel concluded that:

RECOMMENDATIONS

2. The Health Scrutiny Panel recommends to the Executive:

ACKNOWLEDGEMENTS

3. The Health Scrutiny Panel would like to thank the following individuals for their assistance with its work:

² Healthcare Needs Assessment: Foetal Alcohol Spectrum Disorders in the North East of England, Dr Zoe Greaves, April 2016

Fiona Alexander – Principal Educational Psychologist
Phil Archman – Service Manager Paediatrics – South Tees Hospitals NHS Foundation Trust
Craig Blair – Director of Strategic Planning and Performance - South Tees CCG
Councillor J Brunton - Executive Member for Education and Skills
Mark Burdon - Commissioning Manager (Mental Health) - South Tees CCG
Maria Catterick - FASD Network
Michelle Conley - Commissioning Manager (Health Inequalities) - South Tees CCG
Heather Corlett – Commissioning Manager - South Tees CCG
Leon Green – Public Health Intelligent Specialist
Graeme Nicholson - Health Improvement Specialist (Best Start and Families) Public Health
Middlesbrough
Dr Maeve O’Sullivan – Consultant Paediatrician – South Tees Hospitals NHS Foundation Trust
Rob Morris – Service Manager Children Adolescent & Mental Health Service – CAMHS
Jane Wilson – Head of Service – Looked After Children, Placements, Children with Disabilities

BACKGROUND PAPERS

The following sources were consulted or referred to in preparing this report:

- Reports to, and minutes of, the Community Safety & Leisure Scrutiny Panel meetings held on 20 December 2016, 31 January, 28 February, 28 March and 28 April 2017.
- All Party Parliamentary Group on FASD, Initial report of the inquiry into the current picture of FASD in the UK today, December 2015.
- Foetal Alcohol Spectrum Disorders: A North East Healthcare Needs Assessment, Public Health England, Dr Zoe Greaves, 2016.
- Stockton Borough Council’s People Select Committee, Scrutiny Review of Foetal Alcohol Syndrome Disorder, April 2016.
- How foetal alcohol spectrum disorder affects the care system, The Guardian, 9 February 2016.

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