People Select Committee

A meeting of People Select Committee was held on Monday, 18th January, 2016.

Present: Cllr Mrs Jean O'Donnell(Chairman), Cllr Eileen Johnson(Vice-Chairman), Cllr Kevin Faulks, Cllr Lisa Grainge, Cllr Di Hewitt, Cllr Stefan Houghton, Cllr Barbara Inman, Cllr Mrs Sylvia Walmsley

Officers: Peter Acheson (Consultant in Public Health), Peter Mennear (Scrutiny Officer), Jenna McDonald (Governance Officer)

Also in attendance: Janet Mackie (Head of Midwifery and Children's Services), Maria Catterick (FASD

Network UK)

Apologies:

PEO Evacuation Procedure

45/15

The evacuation procedure was noted.

PEO Declarations of Interest

46/15

There were no declarations of interest.

PEO Minutes for signature - 16 November 2015 47/15

The minutes of the meeting held on 16 November 2015 were signed by the Chairman as a correct record.

AGREED that the minutes were signed by the Chairman as a correct record.

PEO Draft Minutes - 14 December 2015 48/15

Consideration was given to the draft minutes of the meeting held on 14 December 2015. There was a query relating to the clarity of one of the paragraphs. This was to be addressed.

AGREED that the minutes be approved subject to amendments outlined above.

PEO Scrutiny Review of Foetal Alcohol Spectrum Disorder (FASD) 49/15

The Committee received a presentation on Foetal Alcohol Spectrum Disorder (FASD) from the founder of FASD Network UK, a social enterprise which provided support to caregivers of children and families affected by FASD. FASD Network UK also provided training for professionals and practitioners and advocated for services and support. And from the Head of Midwifery at North Tees and Hartlepool NHS Foundation Trust. FASD Network was not a commissioned service and used events to fund its activities.

Members heard that the founder in attendance of the meeting, experienced many cases of FASD whilst foster caring and had ran the Network since 2011. Members heard that an add was placed in the local newspaper by the foster carer in order to encourage other people to share their stories and experiences of FASD and as a result of this and further work, 800 families were now linked in with the Network on Facebook.

Key points were highlighted as follows:

- Children with FASD often presented facial characteristics at birth however, many cases of FASD could only be detected through behavioural issues. Children usually had higher functioning than someone with learning disabilities and symptoms were more similar to autism spectrum conditions.
- Challenges existed around diagnosis of FASD, it was noted that the cost of one diagnostic clinic based in Surrey was £3500 and the nearest centre to provide diagnosis on NHS was in Liverpool.
- With regard to training, Members heard that there were currently three paediatricians training in the Royal Victoria Infirmary and one in North Tees University Hospital that were agreeing to specialise in this area
- During the meeting, the Committee was presented with a doll which displayed likely facial characteristics of the more extreme Foetal Alcohol Syndrome. The doll displayed the following characteristics; wide set eyes, a thinner top lip, lower set ears and thinner legs/arms. It was highlighted that facial characteristics of FASD were only visible in around 10% of children born with the disorder
- Public information leaflets and postcards were produced and distributed in order to highlight key messages about FASD

The Committee raised the following points/questions:

- It was asked whether FASD was often miss-diagnosed, in response, it was noted that FASD was often miss-diagnosed with other disorders such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD)
- Members were keen to understand how long FASD had been in the public domain, it was noted that FASD had been known for nearly 400 years in the UK
- The Committee highlighted that while it was important for women to understand that they should not consume alcohol during pregnancy, it was equally important to understand the damage which alcohol could cause to the unborn child.

As late as the 1980s, the danger of alcohol in pregnancy was not covered in maternity training. Members heard that in recent years, the North East Maternity Network had taken a lead to prevent and increase awareness of FASD, The Committee was reassured that the message throughout the North East was 'No drinking during pregnancy. It was noted that until they had been recently reviewed, the national guidelines state that small amounts of alcohol may be okay.

- It was noted that any alcohol exposure small or large was recorded in the red book provided by the midwife after the birth of a child. This would allow clinicians to work back and identify possible causes for conditions. The Red Book noted any issues relating to a child's health.

- Members asked whether it was possible for a child born with FASD not to display any facial characteristics of the disorder. In response, it was heard that many children with FASD were born without any of the facial characteristics. It was asked how a child could be diagnosed with the disorder without displaying facial characteristics, it was noted that FASD could often be diagnosed through behavioural issues.
- It was asked whether scans were carried out to identify organic brain damage. It was heard that scans were not often carried out however reports of a child from school and home were helpful.
- It was noted that it was possible for children without FASD to present similar facial characteristics to a child with FASD. Although FASD was not easily diagnosed, genetic screening ruled out genetic conditions which narrowed down diagnosis.
- Members asked whether services required by children with FASD were similar to services required by children with Autism. Members were informed that whilst the services required were similar, it was difficult for those with FASD to access autism services, for example as the criteria appeared to be too restrictive. It would be a case of using existing resources more effectively and looking at the gateway process. It was noted that the status of the care provider/foster carer was an issue when accessing services as many were not entitled to particular carer support services whereas previously these were more openly accessible.
- It was noted there was some incidence of Child on Parent violence and challenging behaviour, and so parents and carers needed support too.
- In terms of barriers to service, there was a perceived barrier within CAMHS for example the length of time taken to get a diagnosis that may never come. It was important to have a 'back story' to enable diagnosis.

The role of maternity and health services was outlined and discussed as follows:

- It was noted that maternity services were involved in pregnant womens' care from eight weeks. Therefore they could not influence the early stages of pregnancy.
- It was noted that if a pregnant person was drug taking a safeguarding referral would be made, followed by a pre-birth assessment and potential subsequent interventions. If significant levels of drinking were identified or suspected, a referral would also be made.
- The new national alcohol guidelines were welcomed by health professionals and replaced the previous more ambiguous advice.
- It was noted that in relation to smoking there was very direct advice provided to people; it was important to be specific about the advice on alcohol in a supportive fashion.

- It was highlighted that prevention was key. It was important target schools, colleges, universities, nightclubs, youth clubs etc in order to educate on FASD, and family planning services.
- The number of unplanned pregnancies was around 50% of the total. These were reducing in the younger population.
- The Red Book did not indicate the level of drinking, just that it had occurred. Therefore alcohol was flagged up in the majority of Red Books. Significant levels of drinking would be flagged up via the safeguarding referrals.
- The Audit C system flagged up alcohol issues amongst other patient groups. In the South Tees area health visitors were undertaking Audit C with every parent, in order to prevent future incidence of FASD should they have more children.
- Addictive Behaviour Midwives had yearly awareness sessions.
- Diagnosis did not normally occur in post natal wards as it took longer to diagnose, and North Tees and Hartlepool Trust did not record incidence as there was no national code for it.
- In relation to research and intelligence on FASD, it was noted that other countries such as Canada were further ahead than the UK. It was highlighted that any opportunity to learn from other countries should be taken.
- Members heard that many local bars and pubs were in support of posters and information leaflets on FASD being advertised on their premise when contacted by FASD Network. It was noted that feedback from the public was positive and supportive.
- It was highlighted that it was equally important to educate men on FASD as it was to educate women recognising their supporting role, and all generations. It was noted that self censorship would be more effective in the longer term. The message was more effective when alcohol was described as a toxin. It was noted that despite the messages on danger of smoking being very clear for decades, there were still people who took up smoking and who smoked during pregnancy.
- Members requested statistics relating to FASD from countries such as New Zealand and South Africa. There were case studies from some First Nation Communities where FASD was much more prevalent. Dedicated services were provided in some of these areas, within the UK services would need to be more embedded.
- It was noted that a regional study was taking place on book-in bloods taken by midwives which would test whether people were being honest about their levels of drinking. Northumberland has committed funds to the study and all local authority areas were invited to join the study making a contribution of £5,000 each.

The Committee commended the work carried out by volunteers and partners, noted that consideration be given to the £5,000 contribution to join the regional

study, and consideration be given to how barriers to accessing services can be removed and the role of family planning services.

AGREED that the information and suggested recommendations be noted.

PEO Work Programme 50/15

Members gave consideration to the work programme 2015-16.

AGREED that the work programme be noted.

PEO Chair's Update 51/15

The Chair provided no update.