

Greater Huddersfield CCG, North Kirklees CCG and Kirklees Council

Health and Adult Social Care Scrutiny Panel - 15th October 2019

Foetal Alcohol Syndrome

1. Background

Foetal Alcohol Syndrome (sometimes known as FAS) is a rare condition which occurs when the developing baby is exposed to alcohol in the womb. Alcohol can cross the placenta into an unborn baby's blood stream. The exposure of an unborn baby to alcohol can then affect the development of the brain, leading to challenges in learning and development. Alcohol can also affect the development of other parts of the unborn baby's body, particularly the face. The exact amount of alcohol that causes FAS is unknown but FAS can be completely prevented by avoiding the use of alcohol in pregnancy.

In the UK and Ireland we currently know little about the exact numbers of babies and children affected by FAS and the services they require to support them throughout their childhood. The lack of national data is also reflected locally, the local hospital admission codes for Kirklees Q86.0 (Foetal alcohol syndrome (dysmorphic), P04.3 (Foetus and new born affected by maternal use of alcohol), O35.4 (Maternal care for (suspected) damage to foetus from alcohol) were examined over a 5 year period. The results have shown 5 cases, an average of 1 per year. National data and research has also suggested small numbers of effected cases:

<https://patient.info/doctor/fetal-alcohol-syndrome-pro>

In the epidemiology section of the report they say there were only 272 admissions across the whole of England in 2013-14 (which is consistent with the very small numbers in the Kirklees data) and suggests there is significant under-reporting.

The Royal College of Paediatrics and Child Health acknowledge there is a gap in knowledge, and the British Paediatric Surveillance Unit has recently launched a yearlong study to gain additional information on FAS:

<https://www.rcpch.ac.uk/bpsu-study-fetal-alcohol-syndrome>

2. Symptoms of foetal alcohol syndrome

A baby exposed to alcohol in the womb may have:

- a head that's smaller than average
- poor growth – they may be smaller than average at birth, grow slowly as they get older, and be shorter than average as an adult
- distinctive facial features – such as small eyes, a thin upper lip, and a smooth area between the nose and upper lip, though these may become less noticeable with age
- movement and co-ordination problems, known as cerebral palsy

- learning difficulties – such as problems with thinking, speech, social skills, timekeeping, maths or memory
- mood, attention or behavioural problems – such as autism-like behaviour or attention deficit hyperactivity disorder (ADHD)
- problems with the liver, kidneys, heart or other organs
- hearing and vision problems

These problems are permanent, though early treatment and support can help limit their impact on an affected child's life.

3. Current position and Services in Kirklees.

In Kirklees we do not currently have any discrete services for children affected by FAS, instead mainstream provision aims to identify and meet children, young people and family's needs.

3.1 Paediatric Provision

At both Mid-Yorkshire NHS Trust and Calderdale and Huddersfield Foundation Trust if there are neonatal concerns then children and young people are reviewed by Neonatal consultants. Then this is followed by transfer of care to consultants in Paediatric Neurodisability. All children and young people are also referred to clinical genetics following which a diagnosis is established. Patients then receive a follow up and an Education Health and Social Care Plan is developed.

If a GP refers a child to a paediatrician for developmental concerns, and after taking the relevant history, detailed examination and plotting growth, patients might undergo blood tests and then are referred to clinical genetics for their opinion. Following a joint diagnosis patients get Child Development Centre follow-up and an Education Health and Social Care Plan. There is no treatment for foetal alcohol syndrome, and the damage to the child's brain and organs can't be reversed but an early diagnosis and support can ensure that support is available early.

3.2 SEND Provision

There are statutory processes in place for a child with Special Educational Needs and Disabilities (SEND). This can result in the request for a statutory assessment towards an Education Health and Care Plan (EHCP), and the request has to show the level of presenting need alongside current strategies and provision in place in order to demonstrate why additional resources are required.

FAS is not a category in its own right, and is not detailed as such in the EHCP glossary.

However, it can impact on any of the four areas of need – Cognition and Learning, Physical and Sensory, Communication and Interaction and, Social Emotional and Mental Health Difficulties. As such, an EHCP will reflect the needs presented by that child rather than the condition itself. This also applies to the level and type of support that a child may receive.

There are far greater numbers of children and young people in our mainstream schools with identified Special Educational Needs and Disability at a SEN Support level. These may also have FAS but again their presenting needs would be addressed.

3.3 CAMHS provision

Our local Child and Adolescent Mental Health Services (CAMHS) Learning Disability Service and Core CAMHS provider introduced a new Neurodevelopmental pathway which provides a single, multi-disciplinary assessment pathway for a range of conditions, including Autism Spectrum Conditions (ASC) and ADHD. If a child appears to display the features of FASD at the assessment they will be referred to a paediatrician for diagnosis.

Conversations are taking place with paediatricians to explore better links between paediatrics and the Neurodevelopmental pathway.

There is currently no specific support based on the diagnosis of FASD alone. However, if the child had associated Learning Disability, they may be referred to the disabled children's team or CAMHS LD team. If there were behavioural issues it may be appropriate to provide support via family support services or a parenting group

There doesn't currently appear to be any children and young people with FAS in our local CAMHS provision. Although it should be noted that some symptoms of FAS can present as similar to Autism Spectrum Conditions so those children may well be represented within this cohort.

The National Institute for Health and Care Excellence (NICE) is developing new guidance for FASD.

<https://www.nice.org.uk/guidance/indevelopment/gid-qs10139>

The guidance is currently open for consultation, with the guidance expected to be published in July 2020. It would be prudent to wait for this evidence based guidance to be published before making significant changes to pathways and services.

3.4 Substance Misuse Provision Children and Young Peoples Services

Change Grow Live (the Base) deliver Hidden Harm Provision in Kirklees. CGL understand that young people affected by parental/familial substance misuse are at far greater risk of increased and significant harm, and are more likely to develop substance misuse problems themselves in adulthood.

They have embedded hidden harm provision as a key aspect of the service model in order to safeguard young people, support parents and prevent the inter-generational transmission of substance misuse.

They have a dedicated worker focussed on Hidden Harm and they are supported by a Designated Safeguarding Lead who ensures integration with other services, and provide training and support to staff

The service provided supports the prevention of harm to young people. CGL provide the following support:-

- Developing good relationships with the new adult services provider (a separate contract with CGL). If needed, they support them to develop comprehensive initial assessments, which will include identifying young people who have regular contact with their adult service users.
- A system ensures rapid referral of at risk young people identified through the adult service, to our young people's service;
- CGL work in partnership with Kirklees Safeguarding Children Board, Stronger Families and early help services to deter inter-generational transmission of substance misuse to young people;
- Attend relevant meetings locally, such as MARAC (Multiagency Risk Assessment Conference) , Integrated Safeguarding Meetings, etc.:
- Assessments include a question that looks at parental and familial substance misuse to help identify additional risks young people may be at;

CGL have access to a wide range of agencies including the police and social services, ensuring they are aware of young people at risk i.e. CSE, gang involvement, early sexualisation, low self-esteem and the development of risky behaviours etc. which can be related to parental substance misuse.

CGL help those affected to better understand and develop effective coping strategies, in relation to their parents' substance misuse. Many of these young people develop curiosity around experimentation themselves. As a result, a pathway has been developed between Children's Emotional Wellbeing Service and CGL to jointly provide this support effectively where required. CGL provide time-limited, structured interventions for young people and parents on substance use and related practical/emotional support (if the young person requires it, they will be referred into treatment services).

The hidden harm support programme is personalised to meet the individual needs of services users and typically includes:

- Direct Work with the Child:
- 1:1 therapeutic support interventions;
- Group work programmes
- Work to improve understanding of dependency, why people use alcohol/drugs,
- assist child to understand where parent is up to in terms of their recovery;
- Basic drug and alcohol awareness;
- Work to delay/deter/prevent child's own use of drugs;
- What to do in an emergency;
- Work to safely explore thoughts, wishes and feelings;
- Work to develop resilience;
- Explore family relationships/support network;

3.5 Substance Misuse Provision - Adult Services.

CGL ask every client coming into service regardless of their substance, about their alcohol use. The audit and if necessary SADQ (Severity of Alcohol Dependence Questionnaire) is completed with everyone and where need is identified by the assessment tools, the client is either seen by one of the nurses for an alcohol assessment or a health care assistant for a health assessment. This is regardless of pregnancy but provides information to utilise as a baseline if a client then becomes pregnant.

CGL work closely with SWANS (support for women and antenatal service), which provides services for women with complex social needs. The provision is predominantly in South Kirklees, there is no equivalent provision in North Kirklees at present. In North Kirklees the vulnerable women's midwife is contacted directly. CGL would complete the supporting families' pathway (with consent) and relevant social care and midwife involvement would be as part of a Multi-Disciplinary Team.

The midwifery team would usually lead on FAS discussions, however, in a recent Serious Case Review in North Kirklees it showed good evidence that colleagues were raising the issue of FAS. They were also discussing all risks in relation to birth defects caused by drug or alcohol misuse in pregnancy. This included FAS as well as brain defects in relation to cocaine use in pregnancy.

4. Preventing foetal alcohol syndrome

According to professional advice Foetal alcohol syndrome is completely avoidable if alcohol is not consumed during pregnancy. The risk is higher the more alcohol that is consumed. There is no proven "safe" level of alcohol in pregnancy. Not drinking at all is the safest approach.

A discussion occurs at the antenatal contact with Thriving Kirklees' 0-19 Practitioners regarding alcohol, drugs and smoking. If required a referral or signposting to other services would be made at that time. The advice provided is really simple, and would be in line with current evidence and best practice regarding alcohol intake during pregnancy, and prior to conceiving.

The guidance is: The Chief Medical Officers for the UK recommend that if you're pregnant or planning to become pregnant, the safest approach is not to drink alcohol at all to keep risks to your baby to a minimum

Alcohol in Pregnancy is a priority within the Public Health and Prevention work of the West Yorkshire & Harrogate (WY&H) Local Maternity System (LMS). Initial scoping has taken place across local Maternity Services across WY&H.

At the time of women booking into the maternity service, midwives ask women about their alcohol consumption and their partners. The questions asked include 'did you drink before you were pregnant and are you drinking alcohol now?' They are also shown an alcohol consumption visual aid to help work out what they drink pre-pregnancy and now. This is used as an opportunity to start the discussion around risks of alcohol consumption during pregnancy. This is consistent across CHFT and MYHT.

At MYHT maternity notes are now electronic/online so paper notes are minimal. The women and partners are signposted towards leaflets, including those around alcohol, which are available online.

As part of the CHFT provision women get a leaflet “Alcohol in Pregnancy” with their notes and booking pack.

If the woman answered yes to the question about continuing to consume alcohol at booking then this is followed up at future appointments at both Trusts with targeted support regardless of volume of alcohol consumed as any alcohol is considered to be a risk.

At MYHT the Vulnerable Women’s Specialist Midwife will support the women’s Community Midwife, who may do joint visits if needed. A referral will be offered to CGL (Change Grow Live – substance misuse service in Kirklees) and there is also the option for women to access SWANs (although this is in Huddersfield).

At CHFT the Substance Misuse Specialist Midwife can see the woman or carry out a joint appointment with the woman’s Community Midwife (depending on need the Specialist Midwife can caseload), a referral will be offered to CGL (Change Grow Live – substance misuse service in Kirklees). There is also an option for the woman to access SWANs provision.

Both trusts offer a 20 week scan where any anomalies tend to be identified and the woman would be counselled dependent on findings at that stage.

Midwives report that the number of women saying that they do continue to consume alcohol is very low, beyond those that are already engaged with specialist services.

West Yorkshire & Harrogate Local Maternity System (WY&H LMS) have recently established an Expert Group around substance misuse – both Specialist Midwives locally are fully engaged. These groups are tasked with reviewing the most up to date evidence, intelligence and practice, and making recommendations to Place around action to take as well as identifying what should happen at scale across the LMS footprint.

5 Increasing the knowledge of professionals

It is recognised that there is a need to raise the awareness and knowledge of professionals of FASD. To support this we are preparing a bid for funding which has been made available from the Department of Health and Social Care with the aim of ‘developing tools to help improve training and education of professionals to raise the awareness of FASD’.

6 Summary of Actions

- Clarified advice and information regarding alcohol provided by ante-natal and midwifery services (see above)
- Contacted Dr Kathryn Johnson about regional FASD working group. It was confirmed that the working group is progressing well and although currently there is not a Kirklees paediatrician involved it does not diminish the regional

progress made. Dr Johnson expects that the NICE guidance will reflect the approach taken by the regional working group and in the Scottish and Canadian papers but agrees that service re-design should await publication of the guidance to ensure best practice is followed.

- Confirmed NICE guidance to be published July 2020. The lead clinician for the Neuro developmental pathway will review and take part in the NICE FASD consultation.
- Clarified Neuro developmental pathway. Currently there is no specific support based on the diagnosis of FASD alone, however, if the child had associated LD then they may be referred to the disabled children's team or CAMHS LD team. If there were behavioural issues it may be family support services or a parenting group or through educational provision. As a result of this report conversations are taking place between the lead clinician and local paediatricians to improve the pathway and diagnosis rate.
- A funding bid is being prepared by the Thriving Kirklees Partnership to support raising awareness of and increasing the knowledge of professionals around FASD.

Tom Brailsford - Head of Children's Joint Commissioning

North Kirklees CCG, Greater Huddersfield CCG and Kirklees Council.