

Greater Huddersfield CCG, North Kirklees CCG and Kirklees Council

Health and Adult Social Care Scrutiny Panel - 15th January 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 (Fetal alcohol syndrome (dysmorphic), P04.3 (Foetus and newborn affected by maternal use of alcohol), O35.4 (Maternal care for (suspected) damage to foetus from alcohol) were examined over a 5 year period. This results have shown 5 overall 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 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 year-long 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 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 provision would accept referrals for FAS if there is Learning Disability alongside the FAS diagnosis and there are additional mental health concerns.

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.

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 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.

The advice Thriving Kirklees' 0-19 Practitioners provide 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 with in the Public Health and Prevention work of the West Yorkshire & Harrogate (WY&H) Local Maternity System (LMS). This work stream is underdevelopment and will be launched in January 2019. Initial scoping has taken place across local Maternity Services across WY&H.

Across the LMS provision for alcohol in pregnancy and FAS varies. Every maternity services provider routinely asks all Women about their alcohol consumption at booking and a risk assessment is undertaken. Women are then sign posted/referred to appropriate support. Some providers also provide leaflets and information for women at booking.

Guidelines are variable across west Yorkshire with some maternity services not having a guideline in place; others only have neonatal abstinence guidelines (which often predominantly focus on drug withdrawal rather than alcohol).

Mid Yorkshire Trust have a care pathway in place for drug and alcohol use in pregnancy and Calderdale Trust have a Substance Misuse Midwife. All 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.

The Substance Misuse specialist Midwife works with other midwives, ensuring the question in relation to alcohol use pre pregnancy are asked, and encouraging the midwives to take the opportunity to ask the woman about her alcohol use and attitude towards her drinking.

This includes making pregnancy the window of opportunity to be alcohol free and to think about how they will manage postnatally and in the future. Women needing support who are struggling with their Alcohol use are referred to myself and the drug and alcohol team in Huddersfield. The midwives are able to give information around FAS and FASD, the risks of alcohol in pregnancy.

**Tom Brailsford - Head of Children's Joint Commissioning
North Kirklees CCG, Greater Huddersfield CCG and Kirklees Council.**