



Understanding the Fetal Alcohol Spectrum Disorder (FASD): what support for young adults in Hertfordshire?

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June 2023

Introduction – About the Fetal Alcohol Spectrum Disorder (FASD)

Effects of pre-natal alcohol are known to have lifelong consequences, though the impact this has on adolescents and adults is less well understood. The cognitive deficits, behavioural problems, psychopathology and other secondary disabilities associated with FASD affect an individual's ability to navigate their daily life and become independent adults.

The Effects of FASD

According to the Government guideline on FASD, in the US, the life span prevalence was 61% for disrupted school experiences, 60% for trouble with the law, 50% for confinement (in detention, jail, prison, or a psychiatric or alcohol or drug inpatient setting), 49% for inappropriate sexual behaviours on repeated occasions, and 35% for alcohol or drug problems.

Symptoms include but are not limited to:

- Learning difficulties
- Problems in memory, attention and judgement
- Problems receiving and processing language
- Brain damage
- Heart defects
- Facial distinctions – low set ears, small and wide-set eyes, thin upper lip
- Below average height and weight¹

In Germany, a 20 year study followed 37 patients who showed very poor outcomes following a psychosocial and career interview. Among those, 18 people (49%) had received special education, 14 (38%) had passed primary school, and only 5 (13%) had a secondary school education. In terms of occupational status, only 5 people (13%) had ever held job.

Although the study participants were among those most severely affected, the study clearly highlights the extent of life-long social challenges that FASD can cause.²

FASD in the UK

In the UK, approximately 41% of pregnant women are estimated to consume alcohol during pregnancy. In fact, advice around drinking alcohol during pregnancy is usually passed along generations so there are many misunderstandings about whether or not it's safe.

¹ drymester.org

² Gov.uk, 2021 publication on FASD

A recent prevalence study carried out in Greater Manchester found that FASD may affect up to 3.6% of children. Other estimates consider this number to be around 2% of children in the UK, which would be slightly more than the amount of people on the autism spectrum, a condition that is much better understood by both doctors and the general public.³

Adults with FASD

Needs and Challenges Identified

Currently, most of the discussion about pathways concern only children and young people. Although all public health bodies have recognised FASD as lifelong, the adult pathway is along the lines of the Autism diagnosis.⁴

Based on Freedom of Information, the vast majority of Clinical Commissioning Groups are not commissioning services for FASD prevention, diagnosis or post-diagnostic care for those with FASD. Nearly 80% said they do not provide diagnosis for children with FASD, while 92% said they do not provide diagnosis for adults. Only 19% of Trusts and Health Boards said that they provide post-diagnostic services for those with FASD⁵, and 31% of the GPs said they had in-depth education regarding FASD.

Nevertheless, the first step toward accessing proper support is a diagnosis. As many professionals lack proper training in recognising the wide spectrum represented by those with FASD, a diagnosis would improve the understanding on how people are affected by FASD and would improve support delivery.⁶

Families affected by FASD across the UK also report challenges in accessing support and/or benefits for health, education, social care, housing, and other financial support. Additional barriers relate to access Education and Health Care Plans (EHCP), therapies like Occupational Therapy or Speech and Language, assisted employment or internship schemes, financial support like the Adoption Support Fund or benefits and housing, etc.⁷

Improving the screening and diagnosis of FASD would have numerous benefits. Earlier access to programs or resources may prevent or reduce secondary outcomes that can occur among those with

³ McCarthy et al, 2021

⁴ GOV.uk, 2021 publication on FASD

⁵ National Organisation for FASD

⁶ National Organisation for FASD

⁷ National Organisation for FASD

FASD, such as problems with relationships, schooling, employment, mental health and addictions, or with the law.⁸

Progress and Support

Following decades of inaction, there have recently been several important developments. Among these:

- 1. The Department of Health and Social Care** released its first FASD Health Needs Assessment for England on International FASD Day, 9 September 2021. The Needs Assessment highlights⁹
¹⁰:
 - a lack of robust prevalence estimates in England;
 - the importance of multi-sector working to support individuals through the life course;
 - better training and awareness for health professionals;
 - better organisation of services to improve accessibility;
 - a need to develop innovative approaches to support those living with the condition.
- 2. The NICE Quality Standard** includes care management plans. Transitioning to adulthood is a key point as is ensuring that education, social services, housing, criminal justice and all sectors understand that an FASD diagnosis is lifelong and that quality of life depends on the timely provision of the support that people with FASD deserve. Repeat assessments and a mental capacity assessment, where needed, will help to ensure the vital types of support that people with FASD are entitled to is available. A special focus is needed to help individuals with FASD understand their diagnosis in ways they can access¹¹.
- 3. Integrated Care Systems (ICSs) and NHS trusts can now start to build a case for developing local pathways for prevention, diagnosis and support.** - could not find additional information.
- 4. The Green Paper on FASD** explores how Government can maximise the impact of the recent recommendations¹². Comments on the draft quality standard for FASD from 2020 identified a need to promote awareness of the risks of alcohol in pregnancy.

FASD in Hertfordshire

Based on recent birth statistics, an equivalent of 1,202 babies are born with FASD in Hertfordshire and Essex each year.¹³ According to FASD Network UK, the current NICE guidance makes no mention of

⁸ Centre for Addiction and Mental Health, 2016

⁹ National Organisation for FASD

¹⁰ GOV.uk, 2021 publication on FASD

¹¹ National Organisation for FASD

¹² GOV.uk, 2021 publication on FASD

¹³ drymester.org.uk



adult provision, therefore only the British Medical Association is used for guidance regarding the needs of adults with FASD.

As a result, there is no existing action plan anywhere in the UK for supporting adult service delivery. However, if diagnosed, they are entitled to receive support from all generalised services for adults with complex needs and/or learning disabilities.

Many adults require interdependence rather than independence as some levels of support may be required across the lifespan. People should not be transferring to adult services until there are services ready, as there are currently no commissioned and funded services for adults with FASD so they fall through all systems offers. Moreover, the adult workforce has not had training on FASD on their professional academic courses so they have a poor understanding of how to work with people with FASD effectively.

Support and advocacy in the area is delivered by Hertfordshire FASD Support Network through virtual meetings, dedicated helpline online resources, email support and regular newsletter.

They also run FASD Club for children and young people with FASD to meet and learn about their condition and coping strategies, and for parents and carers.

The network is actively engaged in the prevention and raising awareness of FASD among the population by organising meetings in schools, gathering resources and information on how to access further support for young people and contacts for therapists and practitioners that could diagnose the disorder¹⁴.

Additionally, Hertfordshire have begun the process with the new ICS to develop an appropriate action plan to ensure it has the required services for children and young adults with FASD (0-25 yrs), including supported living services¹⁵; along with clear prevention messages and awareness raising where necessary¹⁶, such as the #DRYMESTER campaign to ensure those who could be pregnant or planning a pregnancy not to drink alcohol at all, funding is also provided by the East Hertfordshire District Council to the Hertfordshire FASD Support Network.

It is possible that advocacy around FASD and increased support delivered by local organisations and the council have seen the number of referrals in need of treatment, diagnosis and support for children and young adults increasing over the past year.

¹⁴ <https://hertsfasd.org.uk/>

¹⁵ Hertforshire.gov.uk

¹⁶ National Organisation for FASD

Resources

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