BACCHNEWS
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British Association for Community Child Health
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Fetal Alcohol Spectrum Disorder

"The time is now"

p10-15

Fetal Alcohol Spectrum Disorder (FASD)

As someone with an interest in improving awareness and diagnosis of FASD in the UK, it is a delight to see an active focus on FASD, in this BACCH News Edition with articles from my colleagues Roisin Reynolds, Dr Ges Gregory and Dr Alex Forsyth. It was a real privilege to have been involved with them and others in the recent UK wide Round Table discussions hosted by National FASD-UK. Participants shared their insights and views on a range of topics that are key to joined-up thinking from a national perspective about how to ramp up FASD prevention, diagnosis and support services. This culminated in the publication of *'The Time is Now'* document, full of information on research, training, educational resources and practical ways of developing a service in your area, which keeps the voices of those with lived experience and what they need, at its core. The release of *The Time is Now* fortuitously coincided with the publication of the NICE Quality Standard on Fetal Alcohol Spectrum Disorder with 5 standards of expected care for those with FASD.

So many things developing across the UK, I commend *The Time is Now* report as a way of catching up with whatever area of FASD interests or challenges you.

'The Time is Now' - The National Perspective on Ramping up FASD Prevention, Diagnosis and Support Services, National Organisation for FASD

'Healthier Pregnancies, Better Lives' Queen's Nursing Institute Scotland, QNIS, in partnership with Cattanach and the National Lottery Community Fund. This programme will identify and build upon the earliest opportunities to improve the life chances of women, their partners and their children.
Watch the livestream for the unveiling of "The Time is Now" report from March 2022:
https://youtu.be/Pwbd0Ibyyh8?t=1291

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A Very Positive & Rapid Influence on Change

Reflecting on work to reduce alcohol exposed pregnancies in Greater Manchester

Each year, a large number of pregnancies in the UK are exposed to alcohol. Estimates put the prevalence of alcohol exposed pregnancy (AEP) at 41·3% (CI 32·9%- 49·9%).[1] In some of these cases, the baby can go on to develop fetal alcohol spectrum disorder (FASD), the largest preventable cause of learning difficulty. While precise figures are not available, estimates put the prevalence of FASD in children in the UK at around 3%.[2, 3] Those with FASD can have difficulties with cognition, executive function, social communication skills, hyperactivity and impulsivity[4] and, if unsupported, are at high risk of future secondary outcomes, such as school exclusion, breaking the law (or being accused of doing so), mental ill-health and alcohol abuse.[5] Despite this high prevalence, FASD remains largely hidden and under-recognised. In part this is because it can be difficult to diagnose, especially if records of alcohol consumption during the pregnancy are missing by the time the difficulties become apparent (typically when the child is in primary school) and if certain facial features (which are present in a minority of those with FASD) are absent.[6] Because of this lack of recognition, diagnostic services, support services and prevention has been slow to develop.

This is about to change. Following decades of inaction, in what has been described as a 'tipping point', [7] there have recently been several important developments. Among these have been the publication of a Department of Health and Social Care health needs assessment;[8] a maternity high impact area document on reducing the incidence of harms caused by alcohol in pregnancy, produced by Public Health England;[9] and the publication of the UK's first ever study to directly ascertain the prevalence of FASD.[2] This culminated in the publication of the first ever quality standards for FASD.[10] The aim of this article is to describe a nation-leading programme of activities that preceded and informed these national developments. The programme, starting in 2018, was designed and delivered in the Greater Manchester city-region.[11]

The Greater Manchester Reducing Alcohol Exposed Pregnancies Programme was a system-wide programme that aimed to reduce the number of alcohol-exposed pregnancies (AEP) and prevent new cases of FASD. Although precise levels of alcohol exposure during pregnancy and rates of FASD were unknown, it was recognised that in Greater Manchester, with its high levels of alcohol consumption and related harm, alcohol exposure during pregnancy would be higher than the national average. From the outset it was important to provide an academic rationale for the programme, and as part of this, the first study to directly assess the prevalence of FASD in a sample of primary schools was commissioned,[2] which has been pivotal to the whole programme. Prior to this, estimates for the UK had been based on international modelling, rather than UK data.[3]

The study found that FASD may affect between 2% and 4% of children,[2] and this would equate to between 619 and 1,238 babies affected by FASD born in Greater Manchester each year, based on current population data.[12] This provided a baseline that will allow the monitoring of progress in reducing new cases of FASD. Separately, the study also confirmed that parents found taking part useful and not overly distressing.[13] However, many children were found to have undiagnosed neurocognitive disorders, and parents reported significant barriers to obtaining support for their children.

A golden thread that ran throughout the programme was the need to provide reliable and consistent information about alcohol use in pregnancy so that parents-to-be can make informed decisions. The core message, in line with guidance from the Chief Medical Officer, is that there is no safe amount and no safe time to drink alcohol during pregnancy. This was promoted by the award winning #Drymester digital campaign, with a website, downloadable resources for health professionals and social media posts.[14] The first campaign of its kind, the target audience was broad including potential new parents plus partners, families, and friends. Although locally focused, #Drymester has been adopted nationally by maternity providers and internationally by FASD campaigners. For example, #Drymester materials are now shown via 'Now Baby TV' in 132 antenatal departments in the UK. More recently, #Drymester

was extended to workplaces, encouraging them to 'spread the word' about the impacts of drinking alcohol in pregnancy and the risk of FASD.[15] Employers that have already signed up include a local authority, a housing association and a beauty salon.

Tailored training has been provided to over 900 health and social care staff – including health visitors, general practitioners (GPs), school nurses – to equip them with the right knowledge and skills to discuss the harms of alcohol use in pregnancy. Positive feedback has been received for this. It is clear that conversations about alcohol in pregnancy were happening before, but not to the same extent as they are now. The programme evaluation found that, of the over a thousand pregnancies at risk of alcohol exposure, 67% of women went on to engage with a prevention intervention. Of those who were identified as at risk, 18% reduced alcohol consumption.[16]

Parents with lived experience of AEP and FASD were involved right from the start. Through the 'Parents as Partners' group the parents shared personal insights that shaped and enhanced the programme. Their feedback highlighted the lack of support for families affected by FASD. The programme addressed this by providing grants to voluntary sector organisations to run support groups. The parents also highlighted the need to reach young people who may one day be parents themselves. 'Birthday', an interactive performance and educational workshop by young people from the Oldham Theatre Workshop, has reached around 5,000 young people in schools. Birthday was developed into a short film,[17] which has been used nationally. In the foreword of the programme's evaluation report, family support group, FASD Greater Manchester, terms the programme as ***"ground-breaking"*** and highlights its ***"very positive and rapid influence on change for the AEP and FASD agenda".***[16] A comment from a family with lived experience of FASD, says ***"[Greater] Manchester had the insight and courage to invest in and raise awareness of a condition which has been ignored for far too many years."***

The AEP programme has raised public awareness of the risks both in the region and further afield, provided new forms of support for those at risk of an alcohol exposed pregnancy and the families of people with FASD, while placing alcohol use in pregnancy firmly on the agenda for upstream intervention. The programme, in particular the prevalence study and #Drymester, has succeeded in raising the profile of AEP and FASD. Other parts of the country are now embarking on their own journeys to tackle the issue[7] and national policy is following in the form of the Department of Health and Social Care needs assessment[8] (where the Greater Manchester programme is cited as an example of good practice), and the publication of the National Institute for Health and Care Excellence (NICE) Quality Standards.[10] We now need to ensure that the NICE quality standards are implemented effectively across the country. As a leading FASD support organisation rightly says, ***'the time is now'***.[7]

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NICE Quality Standard for FASD: A Big Step Forward for Assessment of Children in the UK

The National Institute for Health and Care Excellence, NICE Quality Standard [QS204] on FASD was published on the 16 March 2022.[1] It sets out how health and care services can improve the diagnosis, assessment, and prevention of fetal alcohol spectrum disorder.

It includes five quality statements.

The first two refer to support and advice for women regarding alcohol consumption in pregnancy and the documentation of this in their health records.

The next two statements are that children and young people at risk should be referred for assessment and where indicated have a neurodevelopment assessment.

The first study in the UK to directly assess FASD in a systematically ascertained sample of children in 2021 found FASD in 1.8% (1.0%-3.4%) of the population studied, or 3.6% (2.1% - 6.3%) where possible cases were also included. The implications are that a large number of children are likely to present for assessment which should be offered according to this guidance, and Paediatric and neurodevelopmental services must now be prepared to respond to this need.[2]

Rather than replicate detailed guidance, NICE refer to the Scottish Intercollegiate Guidelines Network (SIGN) guideline, 'SIGN 156, 2019: Children and young people exposed prenatally to alcohol', as the recommended guidance, as this has been well researched and is already in use.[3]

Summary of SIGN-156 Diagnostic Guidance

A diagnosis of FASD with sentinel facial features may be made if an individual meets the following criteria:

- simultaneous presentation of the three sentinel facial features (short palpebral fissures, smooth philtrum and thin upper lip); AND
- prenatal alcohol exposure confirmed or unknown; AND
- evidence of severe impairment in three or more of the identified neurodevelopmental areas of assessment or, in infants and young children, presence of microcephaly.

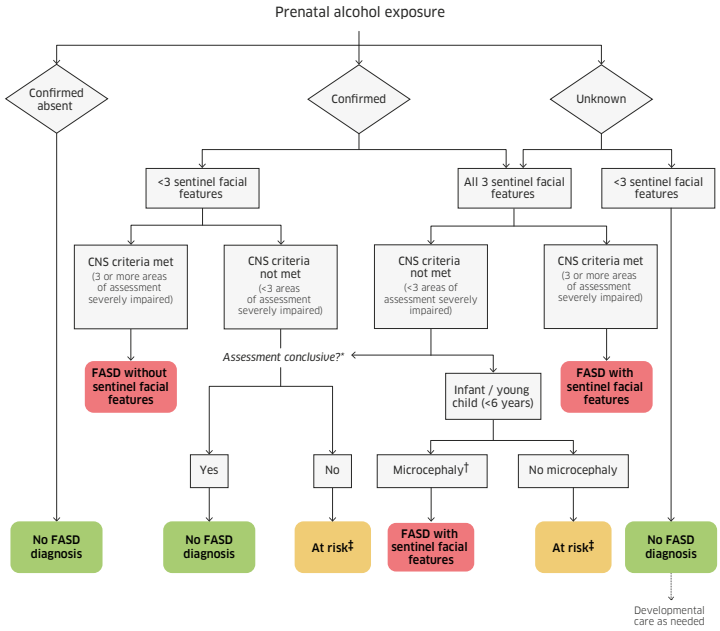
A diagnosis of FASD without sentinel facial features may be made if an individual meets the following criteria:

- confirmation of prenatal alcohol exposure; AND
- evidence of severe impairment in three or more of the identified neurodevelopmental areas of assessment.

For both diagnoses:

- Contribution of genetic factors should be considered in all cases and referral may be indicated in atypical cases or where prenatal alcohol exposure (PAE) is uncertain.
- Growth impairment and other birth defects and/or health issues should be documented if present.
- Hereditary, prenatal, and postnatal factors that may influence developmental outcome should be recorded.

The range of possible outcomes of assessments are shown in the diagnostic algorithm below. Please note, Central Nervous System (CNS) criteria is equivalent to the neurodevelopmental areas of assessment.



* Assessment conclusive = clinician conducting the neurodevelopmental assessment is satisfied that the session was a true representation of the person's ability and that any deficits reported were not due to extenuating circumstances. Assessments may be inconclusive for children under six years of age, because some areas of assessment cannot be investigated with confidence until the person is older or because of other confounding factors, such as temporary life stress or illness.

† Microcephaly is not the only pathway to diagnosis for infants and young children; these individuals may also receive other FASD diagnoses, as specified elsewhere in the algorithm, if they show three areas of substantial impairment on neurodevelopmental tests.

‡ At risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure. An at-risk designation includes situations where a full neurodevelopmental assessment is not conclusive because of age or situational factors; therefore, FASD may not be the diagnoses. Clinical judgement is recommended.

Contribution of genetic factors should be considered in all cases and referral may be indicated in a typical cases or where PAE is uncertain.

Figure 1: SIGN ***https://www.sign.ac.uk/media/1092/sign156.pdf***

For children with and without sentinel features, the neurodevelopmental aspect of the assessment is of key importance, both in relation to diagnostic formulation as well as developing a care management plan.
The areas of neurodevelopmental assessment are listed as:

- motor skills
- neuroanatomy/neurophysiology
- cognition
- language
- academic achievement
- memory
- attention
- executive function, including impulse control and hyperactivity
- affect regulation
- adaptive behaviour, social skills, or social communication

A diagnosis or descriptor of FASD is made only when there is evidence of pervasive and long-standing brain dysfunction, which is defined by severe impairment (i.e., a global score or a major subdomain score on a standardised neurodevelopmental measure that is ≥2 SDs below the mean, with appropriate allowance for test error) in three or more of the neurodevelopmental areas of assessment. High levels of variance between major subdomain scores can emerge when assessing neurodevelopmental areas. If the size of the discrepancy is found to be uncommon (i.e., it occurs in ≤3% of the base rate of the population), and the lower of the two discrepant scores is at least one standard deviation below the mean, then this may be regarded as indicative of evidence of severe impairment or atypical development within that particular area of assessment *(Figure 2).*

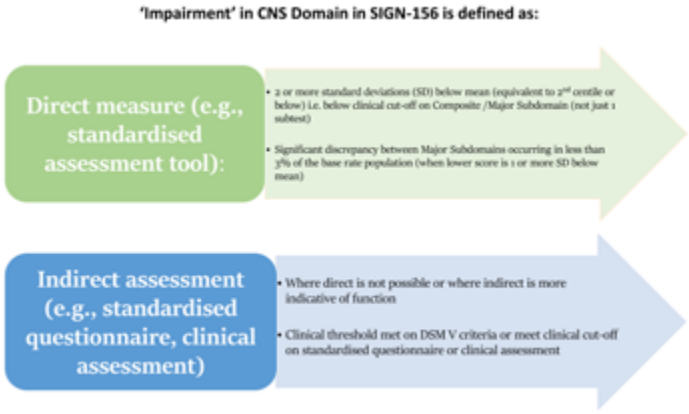


Figure 2: Definition of neurodevelopmental impairment according to SIGN-156

Neurodevelopmental areas of assessment

For many paediatricians, the neurodevelopmental part of the assessment will be the most challenging as there is no single neuropsychological measure, nor pattern of neuropsychological profiles, that is specific to all individuals with FASD. It is presumed that differences in the dose and timing of exposure to alcohol prenatally, as well as interacting genetic and environmental influences on brain development account for the variability in presentations. However, according to the SIGN-156 guidance, the most common neurodevelopmental disabilities include attention, executive function, spatial working memory, mathematics, communication, and adaptive behaviour.

The SIGN-156 guidance on neurodevelopmental areas of assessment guidance outlines a range of direct and indirect assessment tools and methods that can determine evidence of neurodevelopmental impairment, and many will need to be administered by experienced practitioners with knowledge of which are appropriate for the age of the child at the time of assessment (***https://www.sign.ac.uk/assets/neurodevelopmental_areas_of_assessment_criteria.pdf).***

If the only objective of an FASD assessment is to establish that diagnostic criteria are met (i.e., there is severe impairment in at least 3 neurodevelopmental areas), there is a risk that children who are offered the bare minimum at assessment could have vital information missing in relation to their overall difficulties and needs. Any assessment should therefore be as comprehensive as possible, with the voice of the child in respect to their pattern of difficulties also being incorporated, and further assessment should be signposted as needed. This is especially important if we are to offer advice on long term management plans for affected children.

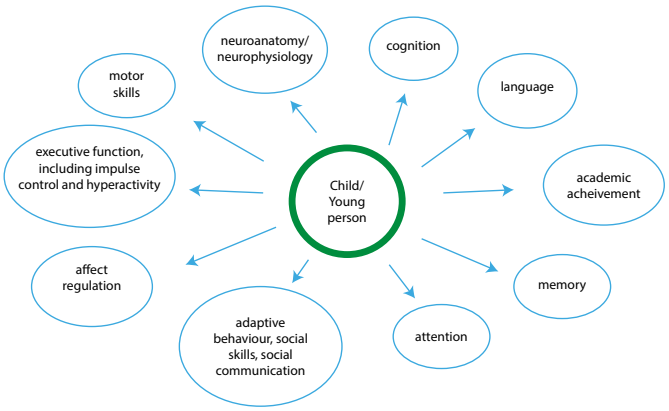


Figure 3: Neurodevelopmental areas of assessment

Neuroanatomy, neurophysiology, and motor skills.
Impairments are described in the SIGN-156 guidance and are largely self-explanatory. It is important that the clinician can rule out any other cause before this can be attributed to the prenatal alcohol exposure.

Cognition
Evidencing impairment in cognitive functioning requires direct standardised assessment.

Many individuals with FASD will not fall in the intellectual disability IQ range (below 70); nevertheless, there could be significant variability between major subdomain (index) scores, which may be indicative of impairment according to the SIGN-156 guidelines.

Assessments should ideally be carried out by experienced psychologists, and different tools applied in accordance with the individual's age. For example, the Wechsler Preschool and Primary Scale of Intelligence, WPPSI, for ages 2-7 years; the Wechsler Intelligence Scale for Children, WISC-V, for ages 6-16 years; and the Wechsler Adult Intelligence Scale, WAIS-IV, for anyone over 16 years of age.

If children are not presenting as being within the impaired range at a young age, but cognitive difficulties are later suspected, reassessment should be considered - especially prior to transitioning to adult services as criteria for intellectual disability may be met.

Academic achievement
This can be difficult to determine unless there has been a standardised test such as the Wechsler Individual Achievement Test (WIAT), as many school tests are not standardised. In addition, the clinical team must determine that the individual has had consistent exposure to academic instruction before a deficit can be recorded.

Language
Children with FASD may appear superficially to have good language skills, possibly being described as chatty. Impairment may not be apparent unless a speech and language assessment is carried out, which can include assessment of language fundamentals as well as higher level language abilities. Impairment may also be present if there is sufficient discrepancy between subdomain scores. Assessment tools such as the Clinical Evaluation of Language Fundamentals, or Children's Communication Checklist can be useful.

Memory
Impairment is present when a score below the clinical cut-off is obtained on a composite measure of overall memory, verbal memory, or visual memory, or when there is a large discrepancy between verbal and non-verbal memory, with a base rate of less than 3% and the lower of the two discrepant scores is at least one standard deviation below the mean.

A deficit in working memory should be considered under executive function rather than memory. An example of memory assessment is the Wechsler Children's Memory Scale.

Attention
In many definitions and theories of brain function, attention overlaps with some of the executive functions. In order to distinguish these areas of assessment for diagnostic purposes, attention is here defined as sustained or selective attention and resistance to distractions. Deficits in inhibition, impulse control or hyperactivity should be considered under executive function rather than attention. Impairment in attention by indirect assessment is present when a clinical assessment provides converging evidence of impairment from multiple sources, including clinical interview,

Continues overleaf

questionnaire, file review and direct clinical observation during neurodevelopmental testing.

Executive function, including impulse control and hyperactivity
Executive function refers to a set of higher-level skills involved in organising and controlling one's own thoughts and behaviours to meet long-term goals. Although there is some overlap between attention and executive function in many conceptualisations, in the SIGN-156 guidance it is defined as impairment in working memory, inhibition/impulse control, hyperactivity, planning and problem solving, or shifting and cognitive flexibility.

Impairment in executive function can be measured by direct means using subtests of tools such as the NEPSY, used to assess neuropsychological development for children ages 3-16 years, or the Delis Kaplan Executive Function System (D-KEFS) for ages 8 onwards.

Whilst direct assessment may be useful, due to the 'frontal lobe paradox'[4], structured clinic-based assessment may not always be indicative of an individual's day-to day executive functioning ability. Also, a clinic environment may not reproduce 'hot' executive functioning conditions (see Figure 4). Compared to controls, those with FASD tend to exhibit more executive functioning difficulties when there is emotional arousal (such as in a high-stake situation)[5].

As such, consideration should be given to measuring executive function using indirect assessment methods such as the BRIEF questionnaires (Behaviour Rating Inventory of Executive Functioning – Parent and Teacher versions) which can be considered alongside supporting evidence from clinical interview, file review, and direct clinical observation.

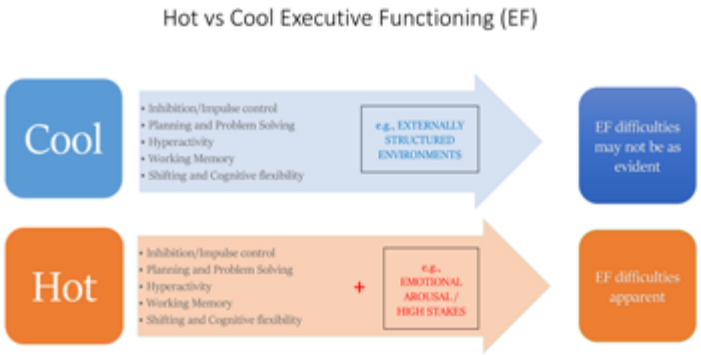


Figure 4: Illustration of possible difference between 'hot' and 'cool' executive functioning

Adaptive behaviour, social skills, or social communication.
For children and adolescents who have not had a consistent caregiver within the last two years, clinicians may need to consider how and when is best to assess adaptive behaviours. Observations and ratings should be across environments where appropriate. The Adaptive Behaviour Assessment System, ABAS, or Vinelands Adaptive Behaviour Scales can be considered as measures of adaptive function. Assessment of social skills and social communication may include diagnostic interview (such as for Autism), in combination with observation and background information.

Affect regulation
Disturbances of affect regulation should only be attributed to prenatal alcohol exposure if they are longstanding and not thought to be in response to unfavourable life events or environmental conditions such as adverse childhood experiences, multiple placements, or are situationally specific, for example, specific phobias.

Report writing

The findings of a clinical and neurodevelopmental assessment need to be formulated in a comprehensive report that will also include recommendations and future implications for the child or young person.

NICE quality standard 5 states that there should be a management plan to address the child's needs and the report will be fundamental to any plan. There are resources available on the SIGN-156 website such as assessment summary templates.

Implications for the role of the paediatrician

The NICE Quality Standards and the SIGN-156 guidance will be invaluable in the consideration of how to assess children at risk of FASD as it offers a clear description of what an assessment must include, and as such will standardise the quality of assessments throughout the country.

A multidisciplinary approach is likely to be necessary for certain standardised direct assessments to be carried out (e.g. by psychologists, speech and language therapists, and occupational therapists etc.). Nevertheless, the paediatrician can have a key role to play. The SIGN-156 guidelines give allowance for, and examples of, methods of indirect assessment where direct standardised assessment is not possible. Depending on the availability of background information, including standardised assessments previously carried out, it may be possible for a single experienced paediatrician to determine if an individual meets criterion for FASD and to provide feedback and recommendations accordingly. Alternatively, the paediatrician may only be able to carry out part of the assessment whilst being the co-ordinator of referrals to a wider team in relation to various aspects of the assessment. In this case, it may be that the formulation and feedback of any diagnosis reached does not have to sit solely with a paediatrician but could be facilitated through team working, and this may be advantageous if considering ongoing management plans which are indicated in NICE standard statement.[5]

Key Points:

- The newly published NICE quality standard QS 204 covers assessing and diagnosing fetal alcohol spectrum disorder (FASD)
- Details of the neurodevelopmental assessment are clearly outlined in SIGN-156 Guidance
- Paediatricians have a key role to play but comprehensive assessment should be carried out through a multidisciplinary approach where possible
- Clinicians should be aware of the potential difficulties of assessing executive functioning in a structured clinic setting
- Clinicians need to consider how cognition may appear to be more impaired over time and reassessment should be considered
- Formulation of diagnosis and management plans can be coordinated by experienced practitioners e.g. psychologists

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