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RESEARCH ARTICLE

# Assessing and supporting children and young people with probable or diagnosed fetal alcohol spectrum disorder: The experience of clinicians working within child and adolescent mental health services

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[Correction added on 22 August 2024, after first online publication: The spelling of the 3rd author's last name and the spelling of 'Single' in the 3rd affiliation has been corrected.]

## Abstract

**Background:** Fetal alcohol spectrum disorders (FASD) are a group of conditions that occur due to prenatal alcohol exposure (PAE), which impacts physical, behavioral, and cognitive ability. The literature demonstrates that healthcare professionals lack knowledge and understanding of FASD, resulting in children and young people (CYP) often getting misdiagnosed with neurodevelopmental disorders or the diagnosis of FASD missed, increasing their risk of experiencing secondary mental health difficulties. Child and Adolescent Mental Health Services (CAMHS) are the commissioned service to diagnose neurodevelopmental conditions and support CYP with mental health difficulties, therefore, it is likely that CYP with probable or diagnosed FASD will present in CAMHS. There is currently no research exploring the awareness and understanding of FASD within these services.

**Methods:** Constructivist grounded theory was utilized to explore the barriers and facilitators clinicians experience when assessing and supporting CYP with probable or diagnosed FASD within CAMHS. A sample of 12 CAMHS clinicians from an NHS Mental Health Trust situated in the Northeast of England were interviewed. Interviews were transcribed and analyzed and grounded theory techniques were utilized to generate an end model.

**Results:** The end model was developed on a box analogy with four categories. 'Unable to Open the Box' captures barriers CAMHS clinicians experience when exploring FASD, 'Things that Help Open the Box' captures facilitators CAMHS clinicians experience when exploring FASD, 'Asking Others About the Box' captures systemic influences CAMHS clinicians may experience when exploring FASD, and 'Making the Box Easier to Open in Future' captures how we can support CAMHS clinicians moving forward to explore FASD.

**Conclusions:** This model provides new insights into the barriers and facilitators CAMHS clinicians experience when assessing and supporting CYP with probable or

diagnosed FASD, highlighting key clinical implications. Recommendations for future research are outlined to expand the knowledge base for this area.

**KEYWORDS**
assessment, Child and Adolescent Mental Health Service, fetal alcohol spectrum disorder, prenatal alcohol exposure, qualitative, support

## INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is an umbrella term used to describe a set of life-long disorders due to prenatal alcohol exposure (PAE) (Mukherjee et al., 2006). PAE can cause harm to the fetus, where physical, behavioral, and cognitive difficulties may occur as a result (Mukherjee et al., 2006; Vorgias & Bernstein, 2022). The prevalence of FASD in the United Kingdom (UK) is estimated to be around 3%–6% of the population (McCarthy et al., 2021; McQuire et al., 2019). Despite high prevalence rates, barriers associated with FASD are identified within the literature that make exploring and diagnosing individuals with FASD complex.

Firstly, some professionals perceive FASD as a stigmatizing diagnosis. Howlett et al. (2019) found that 37% of pediatricians worried about stigma associated with the FASD diagnosis. Similarly, Mukherjee et al. (2015) found that 60% of respondents, including general practitioners (GPs), pediatricians, and midwives see FASD as a stigmatizing diagnosis. Moreover, professionals express insufficient knowledge and awareness of FASD. McCormack et al. (2022) conducted a systematic literature review, with main themes highlighting the lack of knowledge and awareness healthcare professionals have of FASD, the poor attitudes and beliefs they hold of FASD, including stigma and absence of training and specific guidelines to diagnosing FASD. This review concluded that there is a need for healthcare professionals to access training to improve their knowledge around FASD and to identify resources that are needed to support individuals with probable or diagnosed FASD. The scarcity of knowledge and FASD diagnostic pathways in the UK perpetuates low diagnostic rates.

Symptomology and characteristics of FASD closely overlap with many other conditions (Popova et al., 2016), particularly neurodevelopmental disorders. Lange et al. (2018) performed a systematic literature review and found that Attention Deficit Hyperactivity Disorder (ADHD) is the most common comorbid neurodevelopmental disorder among children with FASD at 52.9%. Autism Spectrum Disorder (ASD) was 2.6% comorbid. Unsurprisingly, Chasnoff et al. (2015) found that 86.5% of children with FASD are misdiagnosed with a neurodevelopmental condition, or the appropriate diagnosis of FASD is not given. This is likely due to similarities between the conditions, an adequate knowledge and awareness of neurodevelopmental disorders, and the presence of diagnostic pathways.

Research has also shown the relationship between FASD and secondary mental health difficulties. Streissguth et al. (1996) found that 94% of individuals with FASD have experienced at least one mental health problem during their life, with the most common being depression, low mood, and anxiety disorders (Pei et al., 2011). It is important to consider that the research is only capturing mental health difficulties of individuals diagnosed with FASD and does not capture those who have been misdiagnosed or an FASD diagnosis not considered. Regardless of a diagnosis of FASD, individuals will need access to mental health services if they require support for their idiosyncratic needs.

Due to the prevalence of comorbid neurodevelopmental disorders and secondary mental health difficulties among children who have probable or diagnosed FASD (Mukherjee et al., 2019; Pei et al., 2011), it is very likely that children with probable or diagnosed FASD will access assessment and support for comorbid neurodevelopmental conditions, and secondary mental health needs. Currently for CYP in the UK, CAMHS or Children and Young People's Services (CYPS) are commissioned to diagnose neurodevelopmental disorders and support CYP with mental health needs. However, they are not currently commissioned to diagnose FASD. Nevertheless, the evidence base exploring the prevalence of FASD and based on comorbidities and secondary difficulties this population experience, CAMHS will very likely encounter children with probable or diagnosed FASD.

The knowledge and awareness of healthcare professionals generally has been explored within the literature, however, the knowledge and awareness that CAMHS clinicians have of FASD, and their role in identifying and assessing CYP to explore this diagnosis further if identified is not understood within the literature. Moreover, their role in supporting CYP with secondary mental health difficulties who have a diagnosis of FASD is also not understood.

This study aims to create an explanatory model to understand the barriers and facilitators clinicians face when exploring, assessing, and supporting children with probable or diagnosed FASD within CAMHS. Situating the research within CAMHS aims to improve clinical practice around FASD in CYP, as it is crucial to identify FASD at the earliest opportunity so that appropriate and meaningful diagnoses are given so early intervention can be initiated (Streissguth et al., 1996). The two research questions outlined below look to address the study's aims and objectives:

1. What are the barriers and facilitators clinicians face when assessing children and young people with probable or diagnosed FASD within CAMHS?
2. What is the knowledge and experience of CAMHS clinicians when supporting children with probable or diagnosed FASD and their families?

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## MATERIALS AND METHODS

### Participants

Clinicians working in CAMHS within an NHS Mental Health Trust situated within the North East of England were eligible for inclusion in this study. The clinicians could be of any professional background, however, they had to conduct assessments, inclusive of initial mental health assessments, differential assessments, and developmental history assessments within their respective services. Participants were required to read the participant information sheet informing them of the study (Appendix S2) and sign the consent form if they wished to participate (Appendix S4).

In total, 12 participants took part in the study. All participants appointed themselves pseudonyms to retain anonymity. Demographic information obtained through a questionnaire (Appendix S3) can be found in Table 1 below.

The age ranged from 18–24 to 50–54 years, with age ranges being used to retain anonymity The sample included three applied psychologists, three assistant psychologists, three nurses, two psychiatrists, and one psychological wellbeing practitioner, who had varying experiences of working within CAMHS, ranging from 0–2 years to 10+ years. All participants had experience of conducting assessments within CAMHS, this fulfilled the inclusion criteria. Difference in participant demographics regarding age and job roles was achieved through theoretical sampling, which allowed for theoretical sufficiency to be reached after interviewing 12 participants.

### Semi-structured interviews

Semi-structured interviews were used to collect the data. An interview schedule was developed by the researcher (see Appendix S1), the research team and an expert by experience in FASD. Items were established in line with grounded theory guidance (Charmaz, 2014) and designed to gather an understanding of barriers and facilitatory factors clinicians experience in three main areas:

1. Exploring prenatal alcohol exposure as part of the assessment
2. Identifying and understanding FASD
3. Supporting a child with probable or diagnosed FASD

The interview schedule included nine initial items and was not amended throughout the interviews, as the iterative process did not warrant this change. Interviews were conducted individually with the participant and the lead researcher over Microsoft Teams. Interviews lasted on average around 30 min, with the shortest interview lasting 21 min, and the longest 57 min. Participants were reminded that interviews could be stopped at any time to terminate the interview or take a break, however, no participant requested this.

At the end of the interview, the recording was stopped, and the participant was verbally debriefed and sent an electronic debrief sheet (Appendix S5). All participants consented to receive a draft copy of the results to enable reflexivity in the research process. Finally, participants were reminded that they could withdraw their data up to 7 days after the interview, but no participants withdrew from the research.

### Analysis

Analysis and interpretation of the data were informed by the methodological approaches within the constructivist grounded theory (Charmaz, 2014), as the study explored the process of assessing and supporting CYP with probable or diagnosed FASD and the barriers and facilitators clinicians experience. The development of an explanatory framework is important to inform clinical practice.

Each interview was audio recorded and transcribed verbatim by the researcher. The first method of analysis was initial coding.

**TABLE 1** Participant demographics.

| Pseudonym | Age range | Gender | Time worked in CAMHS | Job title |
|---|---|---|---|---|
| Frankie | 30–34 | Female | 0–2 years | Psychological Wellbeing Practitioner |
| Samantha | 40–44 | Female | 10+ years | Psychiatrist |
| Louise | 50–54 | Female | 10+ years | Nurse |
| Tom | 45–49 | Male | 0–2 years | Applied Psychologist |
| June | 25–29 | Female | 0–2 years | Assistant Psychologist |
| Bart | 45–49 | Male | 10+ years | Psychiatrist |
| Ruby | 25–29 | Female | 0–2 years | Applied Psychologist |
| Daisy | 25–29 | Female | 0–2 years | Assistant Psychologist |
| Beth | 18–24 | Female | 0–2 years | Assistant Psychologist |
| Violet | 40–44 | Female | 0–2 years | Nurse |
| Jack | 30–34 | Male | 5–7 years | Applied Psychologist |
| Una | 40–44 | Female | 10+ years | Nurse |

Coding is the pivotal link between collecting data and developing an emergent theory (Charmaz, 2014).

The researcher adopted line–by-line coding by naming each line of the written data (Glaser & Strauss, 1967), capturing participants' views and feelings. 'In-vivo' codes were also used to represent the words and language of participants, supporting the researcher to remain grounded in the data. The second phase of focussed coding was utilized. This process involves focusing on the most significant or frequent codes from the initial coding phase, to sharpen or condense codes that are important within the emerging data (Charmaz, 2014). Focussed coding is more conceptual and provides greater theoretical insight than initial coding (see Appendix S6). A further level of development involves theoretical coding; taking focussed coding to a higher sophisticated level (Charmaz, 2014). Theoretical codes are thought to be integrative, helping the researcher move focused codes in a theoretical direction making the analysis coherent and comprehensible (Charmaz, 2014). Memo-writing was conducted by the researcher throughout to achieve reflexivity. Triangulation of the analysis was also completed with two researchers from the research team.

A constant comparative method was used throughout the data analysis process. This method is designed to aid generation of a theory which is integrated, consistent, and close to the data (Glaser, 1965). In addition, memo-writing was conducted by the researcher throughout to achieve reflexivity and triangulation of the analysis was also completed with two researchers from the research team.

## RESULTS

### Respondent validation

To ensure rigor, the researcher invited participants to provide feedback on and validate the emerging theory. Five participants gave feedback about the end model (Figure 1; see below), sharing that it resonated with their views and experiences (see Appendix S7).

The end model is situated around a box, which resembles the CYP and whether they have FASD or not. This model developed from a participants' quote "Opening a box you can't contain or put the lid on", which appeared to resonate in other participants' experiences. Therefore, this metaphor informed the model and category names. There were 4 categories and 11 subcategories in the end model. All categories, subcategories and corresponding quotes can be found in Appendix S8.

### Unable to open the box

'Unable to Open the Box' explores the barriers clinicians experience when assessing CYP with probable or diagnosed FASD. This includes four subcategories: feelings, exploring, similarities, and what's inside.

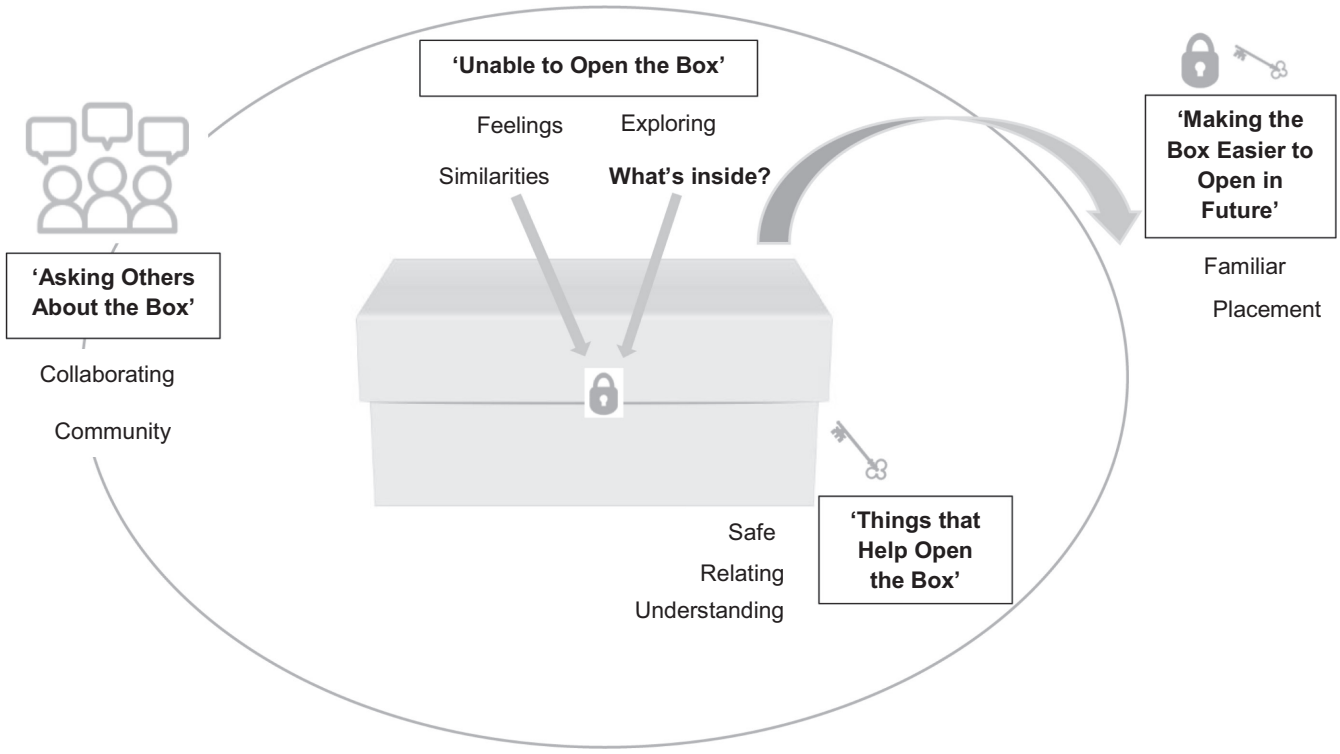


FIGURE 1 End model.

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## Feelings

When asking families about PAE or having conversations around FASD, clinicians spoke about how parents, particularly biological mothers, may experience emotions of self-blame and shame:

> ...I think the negativity attached to it as a whole is a really massive barrier to it because its automatically presumed as just a detrimental thing...
>
> – P9 Daisy

Clinicians voiced that perceived parental self-blame and shame may prevent parents from sharing their experience of PAE. Several clinicians conveyed experiences of negative emotional reactions to the question being asked:

> ...parents might feel that they don't want to share this or don't feel comfortable saying this because of that potential feeling of judgement.
>
> – P1 Frankie

Clinicians also spoke honestly about difficult and uncomfortable emotions, they experience when asking parents about PAE within the clinical assessment process:

> ...I find it awkward.
>
> – P5 Tom

> There's something about the question, about erm, alcohol and substances during pregnancy that's really emotive I think for me and for them.
>
> – P12 Jack

## Exploring

Clinicians spoke about how a lack of information is a barrier they experience when gathering information around PAE. They recognized that parents may minimize their reported alcohol consumption, or may have forgotten if they drank and if so, how much, as it may have been a long time ago:

> ...it's really hard because I think everyone lies about their alcohol intake... there's lots of research that everyone minimises it to some extent.
>
> – P2 Samantha

Experiences or perceptions of working with children in alternative care arrangements were also discussed in relation to gathering information. Clinicians spoke about how often caregivers may not have the correct or full information, resulting in not knowing if the child was prenatally exposed to alcohol:

> With looked after children it can be difficult, because they don't always know the full history...
>
> – P6 June

## Similarities

Clinicians were somewhat aware of the overlap and similarities in presentation between FASD and neurodevelopmental conditions such as ADHD and ASD. Based on the uncertainty clinicians feel when assessing and supporting children with FASD, most felt that they would explore these other conditions first before thinking about FASD:

> ...I wouldn't be sure whether I would mis, mis-label it as something else... think that I would probably go down those routes before I go 'hang on, is it FASD'.
>
> – P1 Frankie

## What's inside?

Uncertainty was a common theme that transpired in all clinicians' experiences. They spoke about their experiences in assessment, diagnosis, and support. Most clinicians spoke about how they would not feel confident in assessing or recognizing characteristics of FASD in CYP:

> Not confident at all... I'd have to get a lot of advice basically and learn how to do it, yeah
>
> – P5 Tom

Several clinicians also raised concerns over the diagnosis of FASD, where their experience has been uncertainty whether the child will get a diagnosis or not. This is primarily due to clinicians not knowing the diagnostic route, and if services are commissioned to diagnose. This may lead to clinicians not exploring the diagnosis of FASD with families as they feel that no one is going to act, leaving them in a dilemma as to whether they should broach it in the first place:

> I think my clinical dilemma there is I'm not sure if the local paediatricians would diagnose...so, the dilemma is, is it worth mentioning because is anyone going to diagnose it and do anything about it?
>
> – P2 Samantha

Uncertainty also filtered through to support, where most clinicians voiced feeling uncertain about how to best support a child with probable or diagnosed FASD:

> I also don't know what you do with it. So, with autism I know what sort of the interventions and ADHD I know what kind of stuff you do, LD I've got a rough

idea…Fetal alcohol symptom disorder…I don't really know what to do with it.

– P5 Tom

## Things that help open the box

'Things that Help Open the Box' depicts factors that facilitate assessing and supporting CYP with probable or diagnosed FASD. This category contains three subcategories, safe place, relating, and understanding.

### Safe place

Clinicians spoke about factors that assist them in having conversations around PAE with families. Clinicians' views varied around the best mode of contact to enable them to ask about PAE. Some voiced that face to face was most helpful whereas others preferred telephone contact:

> I prefer doing it face to face because I think you get more information and you get a better read of the person…
>
> – P8 Ruby

> So, on the telephone [pause]…the person doesn't have to make eye contact, they don't have to be aware of my body language and feel judged, I am just a blank person with a voice, so I think it's a little bit easier for them to open up more about the sensitive stuff on the phone.
>
> – P13 Una

Clinicians spoke of the helpfulness of including PAE as a prompt within the assessment proforma, as it helped to reduce personal uncomfortable feelings when asking about PAE:

> …we have a differential erm assessment template, which does make it easier because I do sort of set it up to say I am just going to go through these questions…some of them can be quite uncomfortable and you don't have to answer if you don't want, but I'm just going to go through them anyway.
>
> – P5 Tom

Moreover, clinicians recognized that from experience, it is easier to have the conversation with a caregiver as they were not responsible for PAE and the impact this may have on the child:

> …having that conversation with adoptive parents because they aren't blaming themselves might be a bit easier… because you're not blaming them are you really…
>
> – P11 Violet

### Relating

Most clinicians spoke about the strength of developing a positive relationship with families when exploring PAE. From their experience, they felt this led to parents and clinicians feeling safer to ask and respond:

> I think that…definitely having a good sort of safe therapeutic relationship with a family to be able to think about this and ask those questions in the context of that safety is really helpful…
>
> – P12 Jack

Normalizing these conversations was also spoken about with clinicians noticing it helps to reduce judgment as parents are aware it is a routine question, rather than it just being asked to them:

> …setting the context, normalisation…these are the questions we ask to everyone, sometimes that's just a relief for people because they don't think are you asking me this because you think I have or are you asking me this because I look like somebody who would drink during pregnancy.
>
> – P8 Ruby

### Understanding

Clinicians spoke about their previous experience, either clinically or training they have attended, which has helped them to ask more about PAE and have open conversations about FASD, as they have more knowledge:

> I would be confident because in my previous role… there was a lot of FASD and you had to have a lot of those difficult conversations with parents…
>
> – P6 June

Facial features emerged as a necessity, with several clinicians expressing that the presence of these features provided them more certainty and confidence of FASD. Nonetheless, some clinicians understood that individuals do not need to display facial features to meet the diagnostic criteria for FASD:

> I believe there's a look to it. They've got kind of smaller heads usually and kind of a sort of kind of distance between the nose and the mouth… you can always see it

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> can you not? You're almost going to think – that's fetal alcohol syndrome.
>
> – P5 Tom

## Asking others about the box

This category explores factors that may facilitate or act as barriers to assessing and supporting CYP with probable or diagnosed FASD from a systemic lens. This category contains two subcategories, collaborating and community.

### Collaborating

Several clinicians spoke about how they would seek clinical supervision from people within their team to help them gather more information to explore FASD or to support a child with probable or diagnosed FASD. Or alternatively, professionals outside their team who are knowledgeable on FASD:

> ...I would not feel confident... I'd be going to my multidisciplinary huddle and be like, erm, like, excuse me I need assistance [laughter]...err I don't know what I am doing...
>
> – P1 Frankie

> ...paediatrics are a really helpful thing that you've found in terms of them kind of getting that child the potential diagnosis or exploring the diagnosis.
>
> – P4 Louise

However, some clinicians stated that even though they would ask their team and other professionals about FASD, professionals do not always know about FASD. This overall lack of awareness and knowledge within teams may result in clinicians not receiving support from others to assist them exploring FASD:

> ...it is that awareness within me but also within the wider team [pause] because, that's where you can get the support coming through. If I wasn't confident and they don't know who do I go to?... I don't know if anyone else would know what it is
>
> – P1 Frankie

### Community

Clinicians spoke about poor awareness of FASD from society collectively, making it difficult for the clinician to have these conversations about FASD or for systemic support to be provided:

> ... one of the other barriers is the family's awareness or recognition of it....
>
> – P1 Frankie

> I think it's just...just society...I don't think it's talked about very much... If you were to ask the average person what's autism, they'd have a rough idea, what's ADHD, they'd have a rough idea, what's a learning problem they'd have a rough idea, what's fetal alcohol syndrome and I don't think they'd have a clue.
>
> – P5 Tom

## Making the box easier to open in future

This final category explores clinicians' views on how to progress; how are they able to find the key that fits a small lock more easily. This category contains two sub-categories, including familiar and placement.

### Familiar

Clinicians spoke about how there needs to be more awareness of FASD to assist their clinical work:

> ...so, I think just more a widespread awareness of it, so not just healthcare professionals but kind of [pause] the wider community
>
> – P9 Daisy

One factor that clinicians spoke about was that they cannot be expected to have a lot of awareness and knowledge of FASD as they have had no training on it:

> ... I've had lots of training on ASD, learning disabilities, different types of erm LD presentation and neurodevelopmental disorders, but I don't think I've had any on fetal alcohol syndrome.
>
> – P5 Tom

However, several clinicians have learned through experience, and stressed the importance of gaining experience of working with CYP with probable or diagnosed FASD:

> ...I think the more experience you get of people saying yes and then kind of moving on from that or exploring it in more detail, whatever is relevant I think that can then increase your confidence in asking the next person, because you think, I know that if this parent says yes, I know how to contain that.
>
> – P8 Ruby

### Placement

Most clinicians voiced that they and their teams need more training on FASD to increase knowledge and awareness, which in turn will have a positive impact on their clinical work:

> I'd probably feel a lot more confident if I had a recognised kind of training…
>
> – P10 Beth

Clinicians also spoke about the need for clearer diagnostic pathways and services to provide assessment and diagnosis for those children who have probable FASD.

> …having some more specialist services that look at this, because I can imagine it is a real lottery isn't it, in terms of you know does the right kid get in front of the right professional at the right time, who happens to be thinking about this…so having a service that can really consider it, I think would be great for benefitting peoples understanding…
>
> – P12 Jack

> So, it is not seen as the bread-and-butter work within CAMHS, but many of these children will come to our attention but there is a need within CAMHS for awareness raising and for it to be incorporated into pathways as a differential diagnosis as part of the neurodevelopmental pathways.
>
> – P7 Bart

## DISCUSSION

The findings aimed to answer the two research questions: (1) What are the barriers and facilitators clinicians face when assessing children and young people with probable or diagnosed FASD within CAMHS? and, (2) What is the knowledge and experience of CAMHS clinicians when supporting children with probable or diagnosed FASD and their families?

The results demonstrated that clinicians working in CAMHS experience many challenges and barriers when exploring probable FASD in CYP, along with facilitators, and how clinicians can be supported in the future with regard to FASD. There was an absence of evidence to answer the second research question; supporting CYP with FASD, due to most participants having no or insufficient experience.

Feelings and stigma arose as a barrier to CAMHS clinicians exploring FASD, which is similar to other health professionals, including pediatricians, midwives, and GP's (Howlett et al., 2019; Mukherjee et al., 2015), as they do not want to elicit blame and shame on parents. Despite clinician's views, Sanders and Buck (2010) found that families feel relieved when their child is diagnosed with FASD as they have an understanding of why their child presents with difficulties. Clinicians spoke about difficulties accessing information about PAE, due to either the child being looked after, which is a challenge as children with FASD being over-represented in the looked-after population (Gregory et al., 2015), or parents underestimating and/or minimizing their alcohol consumption when asked (Denvir, 2012; Stockwell et al., 2004).

Within the current study, clinicians spoke about comorbid conditions, such as ADHD and ASD, and how they will often not consider FASD as a possible diagnosis to understand the child's presentation. They attributed this to their lack of confidence, knowledge, and absence of NICE guidelines around FASD. NICE quality standards were published in March 2022 (National Institute of Health and Care Excellence, 2022), however, clinicians did not mention these standards within the research. CAMHS clinicians within this study felt uncertain of FASD within all stages of the assessment, diagnostic, and intervention process, which is also a common theme with wider professionals (McCormack et al., 2022). The absence of multidisciplinary and wider support from society due to lack of knowledge and awareness was also discussed and corroborates previous literature (Coons et al., 2018), highlighting the systemic barrier of uncertainty around FASD, which perpetuates the complexities of exploring FASD.

On the other hand, clinicians expressed factors that facilitate the assessment and support of CYP with probable or diagnosed FASD. They spoke about creating a safe place, with some preferring face to face, and others telephone contact when asking about PAE. The importance of developing a therapeutic relationship and normalizing PAE was discussed as a facilitator, which corroborates previous research (Chang et al., 2011; Muggli et al., 2015) as it helps enhance feelings of safety and trust. Previous experience of assessing or supporting a child with probable or diagnosed FASD was also a facilitator. Current research demonstrates the need for experience to enhance knowledge and awareness of FASD to assist clinical practice (McCormack et al., 2022). The presence of facial features facilitates clinicians assessing FASD, with some clinicians requiring the presence of facial features and referring to them as part of the diagnostic criteria to increase certainty. However, most clinicians were unaware that only 10% of children display sentinel facial features (Brown et al., 2018), and can still be diagnosed with FASD without them (Bashista, 2022). Therefore, the presence of facial features can act as a facilitator, however, the absence may lead to clinicians not thinking about FASD as a possible explanation for the child's presentation.

Clinicians expressed hopes for the future, including the vital need to increase knowledge and awareness through more exposure to FASD clinically and within training. Reid and Moritz (2019) found that professionals who attended specific FASD training reported positive changes in their clinical work, including asking about PAE, providing FASD assessments and consultation with other professionals regarding FASD. Specialist services or a pathway to diagnose FASD was also discussed, where research has shown that assessment and diagnostic services support individuals

and families to better understand FASD and their needs (Flannigan et al., 2021).

## Implications for clinical practice

There is a significant need for the development of training to increase knowledge and awareness of clinicians working in CAMHS. Training should also be available to other professionals and society, to reduce the high rates of misdiagnosis and support the early identification of FASD, which is crucial to reduce secondary difficulties (Streissguth et al., 1996). The implementation and commissioning of diagnostic service specifically for FASD within the NHS or incorporating FASD as a diagnostic outcome in current neurodevelopmental pathways, will also help enhance identification of CYP with FASD. The National Organisation for FASD (2022) also highlights the need to act on FASD now, displaying how NHS Trusts are currently working on establishing FASD services.

The model highlights that there are many barriers and facilitators in relation to exploring FASD. Addressing these holistically is required to continue unpicking the complexity of FASD and to assist in thinking about how to improve early identification of FASD.

## Limitations of the study

There was limited evidence gathered around the second research question, exploring the knowledge and experience of CAMHS clinicians when supporting children with probable or diagnosed FASD and their families. However, this is likely to be representative due to low diagnostic rates. In addition, the generalizability of the research is limited, as recruitment was only bound to one NHS trust and not clinicians from other services working with CYP where FASD is likely to be prevalent. Limited generalizability is also a critique of the constructivist grounded theory approach as even though respondent validation took place, the findings cannot be applied to other clinicians' experiences in different contexts. However, when situating the findings in the context of the evidence base, the findings from the current study support previous literature, particularly around lack of knowledge, lack of FASD services, and stigma.

Researcher bias also needs to be recognized due to the alignment the researcher has with the social constructivist approach. The researcher acknowledged their experiences of working in CAMHS and CYP with probable or diagnosed with FASD and how this may have influenced decisions which could have impacted the interview process and interpretation. Nonetheless, the researcher employed multiple techniques including constant comparative method, memo-writing, and triangulation to reduce the influence of bias on the findings. In addition, constructivist grounded theory acknowledges that the end theory is one understanding of the data rather than a universal truth, and that different researchers may arrive at a different model with different categories and sub-categories.

## Strengths of the study

This study is the first to explore the barriers and facilitatory factors CAMHS clinicians experience when assessing and supporting CYP with probable or diagnosed FASD. Previous research has studied the perspectives of other healthcare professionals including pediatricians, GPs, and midwives (Howlett et al., 2019) and the perspectives of parents and caregivers. CAMHS staff play an important role in ensuring FASD is considered when assessing CYP so the appropriate diagnosis is given. Clinicians who participated in this research also had a range of different job titles, roles, and years of experience, which is a strength as barriers and facilitators were explored from different staff group perspectives who constitute the multidisciplinary team. Results showed consistencies across all professions, where all sit in the 'not knowing' position when it comes to assessing and supporting CYP with probable or diagnosed FASD within CAMHS.

The development of the end theory provides a useful insight into these barriers and facilitators CAMHS clinicians experience when assessing and supporting CYP with probable or diagnosed FASD in CAMHS. Future considerations around assessment and support for CYP with probable or diagnosed FASD were also captured within the model, identifying needs of clinicians so they are best able to care and support CYP.

## Recommendations for future research

As participants were only recruited from one NHS Trust, future research should look to explore the barriers and facilitators clinicians experience in other NHS Trusts or private assessment services. Replication of the study across the UK with different population groups working in CAMHS could strengthen the understanding of assessing CYP with probable or diagnosed FASD and the applicability of the end model.

Future research could also look at the perspective of the child, and what their experiences are of the barriers and facilitators when accessing assessment for probable FASD, and to explore the meaning of the diagnosis to them. Alternatively, research could also explore the experiences of adults who were diagnosed with FASD in their childhood, who could provide a retrospective view of their experience of receiving a diagnosis. Exploring experiences of those who have probable FASD but not diagnosed or diagnosed with an alternate condition could also be captured within the research. This would increase understanding around CYP and their families understanding of why a diagnosis of FASD was not received, to support the research captured by clinical services around reasons for high rates of missed diagnoses or misdiagnosis.

Future research should further explore CAMHS clinicians' experiences of supporting CYP with probable or diagnosed FASD, making it an inclusion criterion for participant recruitment. This is pivotal in order to increase the evidence base of how we can best support the

needs of CYP with probable or diagnosed FASD, as research exploring this is scarce.

The impact of training on improving awareness and knowledge of FASD on professionals and society, and the impact it has on clinical practice needs to be explored. From the evidence base, it is imperative that FASD-specific training is delivered to healthcare staff alongside an evaluation capturing the usefulness of the training and the impact it has on clinicians' clinical practice.

Finally, NICE quality standards outline that commissioners need to commission services for neurodevelopmental assessment that consider FASD as a diagnosis. Future research should continue to monitor and evaluate the development of these services, and the barriers and facilitators clinicians and families experience when accessing these services. The development of an FASD diagnostic service can also help future research explore and add to the current evidence base around the prevalence of FASD within the UK, and comorbidities these children experience.

## CONCLUSION

Clinicians working in CAMHS describe many barriers they face in relation to identifying, assessing, and supporting CYP with probable or diagnosed FASD within their services, particularly emotional responses and stigma, information about PAE being unavailable, lack of knowledge and awareness, and comorbidities with other disorders. They also spoke about the systemic lack of awareness around FASD which acts as a barrier to clinicians exploring a diagnosis further. All of these barriers result in higher rates of misdiagnosis of FASD with a comorbid condition, or a missed diagnosis of FASD. Nevertheless, facilitatory factors including creating a safe space, normalizing and having previous experience assist clinicians to be able to explore and ask about PAE. Moving forwards, clinicians spoke about the need for training and specialist services or for FASD to be a diagnostic outcome in current neurodevelopmental pathways in the NHS to be commissioned so the needs of the child can be appropriately understood and supported.

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### CONFLICT OF INTEREST STATEMENT

The author(s) have declared that they have no competing or potential conflicts of interest. All authors share responsibility for the final version of the work submitted and published.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

### ETHICS STATEMENT

Ethical approval was granted from the Teesside University School of Health and Social Care Ethics Board on 1st March 2022. Following this, the study also received ethical approval from the Health Research Authority (HRA) on 21st April 2022. The NHS Trust Research and Development department confirmed its capacity and capability to deliver the study on 28th June 2022.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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