



University of  
**Salford**  
MANCHESTER

# Exploring the experiences of social workers in working with children suspected of having fetal alcohol spectrum disorders

Gilbert, DJ, Mukherjee, RSA, Kassam, N and Cook, PA

<b>Title</b>	Exploring the experiences of social workers in working with children suspected of having fetal alcohol spectrum disorders
<b>Authors</b>	Gilbert, DJ, Mukherjee, RSA, Kassam, N and Cook, PA
<b>Type</b>	Article
<b>URL</b>	This version is available at: <a href="http://usir.salford.ac.uk/id/eprint/59762/">http://usir.salford.ac.uk/id/eprint/59762/</a>
<b>Published Date</b>	2020

USIR is a digital collection of the research output of the University of Salford. Where copyright permits, full text material held in the repository is made freely available online and can be read, downloaded and copied for non-commercial private study or research purposes. Please check the manuscript for any further copyright restrictions.

For more information, including our policy and submission procedure, please contact the Repository Team at: [usir@salford.ac.uk](mailto:usir@salford.ac.uk).

Submitted: 8/6/2020

Accepted: 7/12/2020

[Article]

[Title]

**Exploring the experiences of social workers in working with children suspected of having fetal alcohol spectrum disorders.**

**David J Gilbert**

University of Salford, UK

**Raja AS Mukherjee** [Raja.Mukherjee@sabp.nhs.uk]

University of Salford, UK

**Nisha Kassam** [nishakassam@hotmail.com]

University of Salford, UK

**Penny A Cook** [p.a.cook@salford.ac.uk]

University of Salford, UK

[Abstract]

Fetal alcohol spectrum disorder (FASD) is one outcome from prenatal alcohol exposure. Social workers are likely to encounter children with the condition, due to the greater likelihood of prenatal alcohol exposure among children in social services settings. This study explores the experiences of social workers in working with children suspected of having FASD and the support offered to social workers, the children and their families. Semi-structured interviews followed by qualitative framework analysis were conducted with seven child and family social workers along with one child protection solicitor who had experience of handling FASD cases. The two main themes that emerged from the data were a lack of knowledge about FASD and the paucity of diagnosis. Lack of knowledge among the social workers was linked to difficulty in managing children suspected to have the condition, feelings of frustration and normalisation of challenging behaviours. The paucity of diagnosis led to an under-emphasis of FASD in

assessments, a dearth of specialist services and confusion about its specific effects in contexts of multiple substance misuse and harmful socio-environmental factors. The need for increased FASD awareness within social services and the development of FASD-targeted support for children and families is highlighted. Social workers would benefit from the inclusion of FASD-focused training in their curricula and professional development plans. Improving the diagnostic capacities of health institutions would address the paucity of diagnosis and raise the profile of FASD, especially in the social services setting.

### Keywords

FASD, social workers, FASD services, children with FASD

Corresponding author:

David Gilbert, Postgraduate Research Student, School of Health and Society, Allerton Building, University of Salford, Salford M6 6PU

Email: D.J.Gilbert@edu.salford.ac.uk

### [H1] Introduction

Globally, the alcohol consumption rate during pregnancy is difficult to establish due to a lack of accurate records of drinking patterns, the inaccuracies in self-reports and the stigmatisation of what could be deemed as irresponsible behaviour (Derauf, Katz, and Easa, 2003; Wurst, et al., 2008). An estimate from a systematic review and meta-analysis by Popova and colleagues (2017) suggests that, globally, 10% of women consume alcohol when pregnant, while a recent survey put the prevalence at over 40% in the UK (O’Keeffe, et al., 2016). Prenatal alcohol consumption can result in fatal or adverse consequences for the unborn baby. Fetal alcohol spectrum disorder (FASD) is one such consequence, comprising a continuum of related disorders described in the Institute of Medicine guidelines as fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) (Hoyme, et al., 2016). This list was subsequently simplified in the Canadian and Scottish guidance to just two categories: ‘FASD with sentinel facial features’ and ‘FASD without sentinel facial features’ (NHS Scotland, 2019).

**Commented [PC1]:** Dear Editor: thank you for editing this to make clear what we meant by stigmatisation. However, we were concerned that this wording made it look as if we labelled the behaviour as irresponsible.

Therefore, we have modified this a bit to say ‘what could be deemed as irresponsible behaviour’

This is to emphasise that we are not saying the behaviour is irresponsible. In fact, we believe the opposite: a woman rarely sets out to recklessly harm her baby. Rather, she might be suffering from untreated addiction, be subject to violence or abuse, or simply be unaware of the pregnancy.

However, the view that it is ‘irresponsible behaviour’ is certainly what leads to the stigmatisation.

We hope you agree that this wording makes it clear that we (and the journal) do not believe that FASD is simply caused by irresponsible behaviour.

Estimating the burden of FASD in terms of prevalence and economic and societal costs is confounded by diagnostic difficulties, lack of simplified and universal guidelines and the presence of co-morbidities, often resulting in mis/missed diagnosis (Mukherjee, et al., 2017). Nevertheless, a few studies have published prevalence and cost estimates in different settings. For instance, employing a systematic review, Lange and colleagues (2017) cited the FASD prevalence as seven per 1000 children and young people globally. The same study provided modelled estimates for countries that did not have prevalence data and put the UK rate at over 3% in children and young people. In a separate study that used a screening algorithm in a UK birth cohort, FASD screening prevalence was estimated to range between 6% and 17% (McQuire, et al., 2018). Cost estimates are equally varied; in Canada they range from between \$1 billion and \$3 billion annually while in the US, the range is between \$150 million and \$9 billion (Popova, et al., 2011; Popova, et al., 2016a). In the UK, evidence on the economic cost of FASD remains scarce, but it is reported to cost £3000 per week to support a child with FASD (All Party Parliamentary Group (APPG), 2015). Consequently, FASD should be recognised as a significant public health issue (Mukherjee, et al., 2017; Popova and Chambers, 2014).

FASD is associated with lifelong disabilities which, if unsupported, can lead to wider secondary consequences. Its management requires concerted effort by multi-disciplinary teams that include health professionals and allied health professionals as well as social services personnel who are involved in referring, managing and implementing interventions (British Medical Association (BMA), 2016). Gibbs and colleagues (2020) pointed out that social services are well positioned to work with children who have FASD because it is likely to be more common among the children of families known to social services due to their greater substance and alcohol misuse. This argument is supported by findings from a meta-analysis which demonstrated an overall global pooled FASD prevalence of nearly 17% for children in childcare settings (Lange, et al., 2013). Furthermore, in an audit of looked after children attending a community paediatric clinic in Peterborough, UK, 34% had a history of prenatal alcohol exposure (Gregory, Reddy and Young, 2015).

Systematic review evidence demonstrates that early and appropriate interventions result in improved outcomes for children with FASD (Carmichael-Olson, 2009; Fuchs, et al., 2010; Reid, et al., 2015). Other studies have indicated the potential for successful interventions that employ a multiple system approach, with the inclusion of social services alongside other health professionals (Pelech, Badry and Daoust, 2013; Petrenko, 2015). This suggests that social

workers should be part of the multi-disciplinary team responsible for FASD management and need to be equipped to develop and provide requisite services. Possible interventions by social services include the provision of support, social care and advocacy (Bagley, 2019; Pei, et al., 2015). However, a growing body of literature has identified individual and systemic barriers to their development and implementation (Chamberlain, et al., 2017; Mukherjee, et al., 2015; Petrenko, et al., 2014; Ryan, Bonnett, and Gass, 2006).

A recent Scottish study of social workers with prior knowledge of FASD and working in an adoption team evidenced a lack of FASD awareness and uncertainty about the condition and that this limited the extent and variety of possible interventions (Gordon, 2019). In Scotland, there is a concerted national action on FASD using various approaches, including the national FAS surveillance programme covering diagnosis of fetal alcohol syndrome rather than the wider spectrum, the development of an FASD awareness toolkit, the development of guidance and the provision of continuous training and development for health professionals (Watts, 2015). Moreover, the body responsible for the development of national clinical guidelines (Scottish Intercollegiate Guidelines Network - SIGN) has issued FASD guidance that health service providers must follow (SIGN, 2019). At the time of writing, the equivalent body in England, the National Institute for Health and Care Excellence (NICE), is yet to issue any guidance, although it is expected shortly. Consequently, in England, there is no concerted national action and no published research that explores the experiences of social workers in working with children suspected to have FASD. This study therefore seeks to fill this void by conducting research in England that explores social workers' familiarity with FASD, including those with or without prior FASD knowledge or experience, and reviews the support offered to them and the families of children suspected of having the condition. The findings contribute to the body of knowledge around FASD and expand the evidence base within the English setting which, in comparison to Scotland, is less well established.

## **[H1] Methods**

### [H2] Research design

The research questions were:

- What are the experiences of social workers working with children suspected or diagnosed with FASD?
- What is the support available to social workers and families with respect to FASD?

Due to the exploratory nature of the investigation, a qualitative research approach was employed as this is sensitive to context and facilitates the analysis of complex data (Pope and Mays, 1999).

[H2] Sample description

Purposeful sampling where participants are selected based on their relevance to the research (Bowling, 2014) was used. A snowball approach was employed whereby two participants in the organisation acted as gatekeepers in that they helped the researchers gain access to others in different parts of the country (De Laine, 2000). They gave information sheets to potential participants who, if willing, gave permission for their details to be passed on to the research team.

**Table 1.** Characteristics of participants.

<b>Participant</b>	<b>Gender</b>	<b>Social services team/description</b>	<b>Level of FASD experience /knowledge and evidence for this</b>
SW1	Male	Children social worker in child protection team	Experience and good knowledge:  Gave detailed description about the features of FASD and characteristics of children with FASD. Confirmed experience working with children suspected to have FASD and made referrals for diagnosis. During member-checking, confirmed that knowledge was through personal study.
SW2	Male	Children social worker in child protection team	Experience and good knowledge:  Self-reported good knowledge of FASD and this was confirmed during the interview. Detailed characteristics of children with FASD and was aware of misdiagnosis of FASD.
SW3	Female	Social worker in child removal team	Experience and good knowledge:  Knowledge of FASD came from personal study, because of need to go to court with evidence to support child removal. Cases included infants with FASD. Identified a physical feature ('thin lips') as a characteristic of FASD. Did not evidence experience in working with older children.
SW4	Female	Social worker in court locality team	No direct experience and superficial knowledge:  Personal study of FASD. No direct experience working with the children, but awareness of neglect of children by parents who abuse substances.

SW5	Male	Social worker in the looked after children's team	Some experience and superficial knowledge:  Some experience of working with FASD. Superficial knowledge including awareness of some characteristics including challenging behaviours. There was no confirmation of personal research.
SW6	Female	Children social worker	No direct experience and superficial knowledge:  Had worked in child protection team but had not directly worked with any diagnosed child. Had reviewed cases involving children with FASD.
SW7	Female	Children social worker in the child protection team.	No experience and lack of knowledge:  Confirmed experience in working with mothers who consumed alcohol during their pregnancies. Mentioned that she had not come in contact with FASD but did not rule out the possibility of FASD.
CPS	Male	Child protection solicitor working with social workers in the child protection team.	Good knowledge but no direct experience.  Did not work directly with children therefore no experience. Demonstrated knowledge of facts and characteristics of FASD during interview.

The sample comprised seven **child and family** social workers and one child protection solicitor, all of whom practised in various parts of England, namely Sussex, Essex, Cambridgeshire and Greater Manchester. They came from a variety of different settings including child protection, child removal, court locality and looked after children teams. They all worked with children from homes characterised by histories of substance and alcohol misuse and other environments inauspicious for healthy child rearing. Social workers who had prior knowledge of FASD and had experience of working with children suspected to have it were recruited alongside those who had no such prior knowledge or experience. The social workers varied in the number of years of professional practice. Table 1 shows participant characteristics, including an assessment of their level of knowledge and experience and an explanation of how that assessment had been determined. The level of knowledge was ascertained by self-report from the participants during the recruitment phase and was further supplemented during the interviews. The level of experience was assessed from the interview data, based on whether the participant had ever worked directly with children diagnosed or suspected to have FASD. It will be seen that this information provides a useful context for interpreting the data.

**Commented [PC2]:** Dear Editor: we have changed this to 'child' to be the same as the abstract, and so that it is less ambiguous. Otherwise it might read as if we interviewed children.

## [H2] Data collection

Data were collected using semi-structured interviews with open-ended questions; telephone and face-to-face interviews were employed. The interviews were conducted in English and audiotaped. The average duration was 30 minutes and a reflective journal and post-interview sheet were maintained. Questions initially established the participants' experience of FASD and those with experience were asked for details of their work. For all participants, the interview explored their perception of the scale of the problem among looked after children and its impact on families. There were also questions on the support needs of social workers with regard to FASD.

## [H2] Data analysis

Framework analysis was used for data analysis (Gale, et al., 2013). This seeks to 'identify commonalities and differences in qualitative information before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes' (Gale, et al., 2013:1). Recorded interviews were transcribed into transcripts and initial codes generated. The transcripts were coded independently by two researchers (DG and NK) who then met to achieve consensus on coding. Emerging themes were identified and indexed and overarching ones developed (Pope and Mays, 1999). No data analysis software was employed. The emerging results were then given to participants to check the interpretation of the data.

## [H2] Ethics

Ethical approval was obtained from the University of Salford Research Ethics Committee (reference number: HST1819-291).

## [H1] Results

The two over-arching themes that emerged from the analysis were lack of knowledge on FASD and paucity of diagnosis. Lack of knowledge was associated with three sub-themes: difficulty in managing the children, feelings of frustration and normalisation of challenging behaviours, discussed below. The paucity of diagnoses was linked to under-emphasis of FASD, absence of FASD-targeted support, confusion about the impact of combined substance misuse and the significance of socio-environmental factors (see Figure 1).

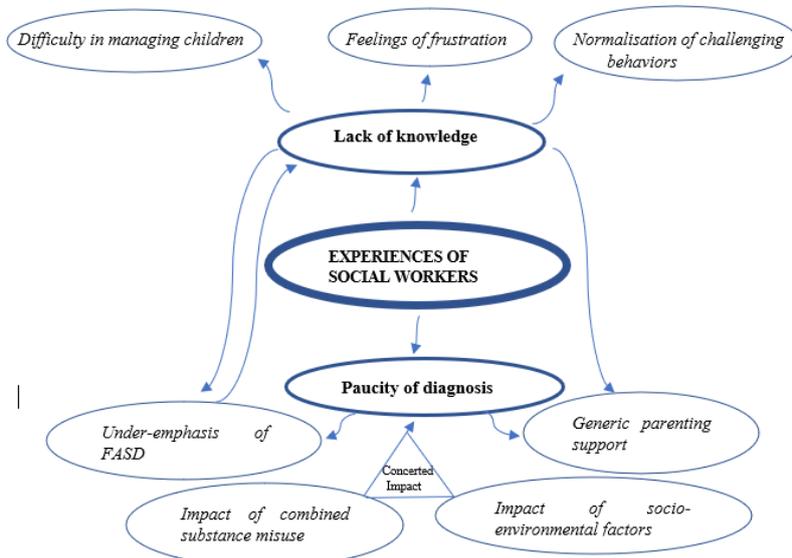


Figure 1: Spider diagram showing themes and their interconnections.

Note: Arrow head points in the direction of linked sub-theme(s).

## [H2] Lack of knowledge on FASD

Four participants – three social workers and the child protection solicitor – had a good knowledge of FASD in contrast to the other three whose understanding was minimal or at best superficial. Social workers who were well informed had made referrals for FASD diagnosis in the past and could describe the characteristics associated with the condition, suggest comorbidities, and identify resulting behavioural difficulties. Superficial knowledge was evidenced by an awareness that FASD was an outcome of alcohol consumption during pregnancy but an inability to give any more details. Those with knowledge also explained that their learning had not come from system-embedded and tailored professional training but from personal and individual research:

But, I think maybe in hospital, maybe they have support system. I wouldn't know but for me as a social worker, as in the term FASD, yeah, is a term that I have had to research myself when writing reports for the court [pause] and how that FASD impacts on a child to evidence what it is I have put into the court. (SW3)

Some participants confirmed that they had not had training specific to FASD but had attended substance misuse training where it was mentioned:

Yeah, sorry. I know it's been explored. Erm, I have trained on it where we've had training around substance and alcohol misuse. I've never actually had any kind of training that's just focused on fetal alcohol syndrome. Always seen as part of other trainings. (SW6)

I mean there's a recent training on the impact that alcohol has on children that I want to go on. I don't know if specifically, if it is focused on fetal alcohol syndrome or... I don't think there's a specific module or specifics on just fetal alcohol syndrome. I don't think there is... no. (SW7)

It was noteworthy that the participants who had good knowledge mostly came from the child protection team. This is because they have responsibility for providing evidence on the damage caused by parental substance misuse to courts considering whether to remove children from abusive parents. Despite the lack of FASD-specific training, these social workers had independently studied the effects of alcohol use by pregnant mothers and knew about FASD as a possible outcome.

Overall, three sub-themes were extracted from the overarching lack of knowledge theme: difficulty in managing the children, feelings of frustration and normalisation of challenging behaviours.

*[H3] Difficulty in managing the children.* Related to the lack of knowledge just described, social workers reported difficulty in managing and supporting children suspected to have FASD. This was exclusively raised in relation to challenging behaviour. For example, this quotation from SW5 refers to children who had not received any diagnosis but were suspected of having the condition and displayed impulsive behaviours:

I can't say either way, whether the behaviour is linked to the fetal alcohol syndrome, but that their behaviour is quite ... very impulsive. It can be quite aggressive and, erm, quite erratic that they, erm, the children I'm thinking of who have gone to ... are suspected of having fetal alcohol syndrome are quite challenging. Their behaviours are challenging in school and at home as well. (SW5)

Another participant mentioned that several strategies had been attempted by schoolteachers to manage the child's difficult behaviour but to no avail. But there was a noticeable lack of clarity about the interventions described and the behavioural problems in school tended to include a plethora of difficulties, such as aggression and difficulty in making friends:

So, some behavioural problems in schools, and the teachers trying to put interventions in place but also finding it very difficult to support them. (SW2)

The social workers acknowledged that their own lack of knowledge was a source of stress. For example, one who demonstrated good knowledge of FASD reported feelings of insufficient empowerment to manage children suspected of having the condition. There was an absence of support on how to cope in difficult situations that resulted in feelings of incapability:

You feel, to the professionals, you feel ill-equipped to deal with this, and you also feel dis-empowered because you are dealing with something you may not know how to deal with and where else to go to have proper support. In a nutshell, that's all I could say. (SW2)

[H3] *Feelings of frustration.* Participants relayed widespread feelings of frustration among the children, their families and professionals. They also explained that children were badly affected by this due to the inability of parents and professionals to understand their needs:

And there has been a lot of confusion and misunderstanding by teachers, by parents...so the adoptive parents will then have to struggle, in the challenges they face day to day without understanding why the child is behaving in a certain way, which also results in a lot of frustration on the side of the child. Because they are trying to communicate something that nobody really knows why they are behaving the way they are really behaving. (SW2)

... I could say, it is frustrating for a person, to the families, and it is also depressing and frustrating to the child. (SW2)

Previous literature shows that after 'fighting hard' to get a diagnosis for their children, parents face the further challenge to identify and obtain the right support and/or services (Salmon, 2008). This is undoubtedly a major source of frustration for families and compounds other difficulties such as children's poor behaviour, as described below:

So, behaviours, they can have some erratic behaviours, yeah, you know, and they can be very abusive and at times aggressive. They can do some self-harming, you know, once they are [pause] ... that's why I say managing their emotion can be difficult that they can start using sharp objects to self-harm. (SW1)

[H3] *Normalisation of challenging behaviours.* In general, social workers attributed children's challenging behaviours to being 'the norm' for looked after children rather than being specific to FASD. For example, one social worker, when being asked if she found it difficult working with children suspected to have FASD, described how social workers have learned to accommodate children's challenging behaviour because it is 'normal' for that population:

Erm, I think it is [pause] that was the majority of the cases when I was in child protection. Yeah. That I think that's the norm isn't it? There are those kinds of issues which are the norm that you deal with. Yeah. Okay. So, you learn... it's not... if that makes sense because it becomes the norm of the behaviours that you kind of... those experiences that you have to try and understand. (SW6)

Another participant highlighted the children's behaviour as 'the same' across the caseload:

However, these other characteristics, which is very amazing like I have said, they are the same. They like telling stories, they erm, erm, have difficulty in managing their emotions. So, and they are insecure. You know, they, they [pause]... it takes a long time for, for you to develop trust with them. So, and they sometimes have memory loss, one way or the other and they can be aggressive, either verbally or physically. (SW1)

It was noteworthy that in all interviews, none of the participants identified organic brain damage as a potential reason for the behaviour difficulties they witnessed in the children, in contrast to frequent references to other possible causes such as exposure to harmful environments. This finding further buttresses the general lack of knowledge about FASD among the social workers, since an aware practitioner would be more likely to probe the cause of a child's difficulties and, if found to be due to FASD, provide suitable management strategies.

#### [H2] Paucity of diagnosis

All participants reiterated the difficulty in accessing diagnosis for children suspected to have FASD. While some mentioned delays, others mentioned virtual impossibility. The general theme of paucity of diagnosis generated four subthemes: under-emphasis of FASD, absence of FASD-targeted support, the impact of combined substance misuse and the impact of socio-environmental factors.

When children do receive a diagnosis, it is usually only after delays:

But from my experience, the first problem that I've come across is erm, is sometimes, it does take time for diagnosis to come through. Erm, it is difficult to, for mental health professionals to properly come up with the diagnosis for some of the children I have come across who received the diagnosis eventually. (SW2)

Another participant who demonstrated a good knowledge of FASD affirmed that he had never received a diagnosis for the children with whom he worked but was able, in conjunction with other professionals, to conclude that the characteristics displayed by the child indicated FASD:

But one thing I must assure you is, as I said, I have never quite come across a child that has been diagnosed with that. But the symptoms, from what I have read and what we have agreed with the other professionals, we seem to share the same idea that it is this type of condition. (SW1)

Globally and in the UK, the dearth of diagnoses is a result of missed and incorrect diagnosis, sketchy histories of maternal alcohol consumption and the presence of comorbidities (Mukherjee, et al., 2017; Chasnoff, Wells and King, 2015), compounded by a lack of awareness of the condition among professional groups (Mukherjee, et al., 2015). The co-occurrence of other neurodevelopmental conditions often masks the presence of FASD (Popova, et al., 2016b), as in this study where participants were aware of cases where a child was suspected to have it, but other diagnoses such as attention deficit hyperactivity disorder (ADHD) took precedence.

So, some of them will end up having diagnosis of things like social anxiety and some other disorders, some other neurodevelopmental disorders that tend to be, if I may use the word co-morbidity, which comes along with many combinations of disorders in giving that diagnosis at the same time. So, we have FASD, we have diagnosis of ADHD, and some of them may also be in the spectrum, have diagnosis of ASD, and then they could be medicated for a different sample. (SW2)

It was noteworthy that participants with prior knowledge of FASD mentioned that on suspicion of it, they had made referrals for diagnosis and finally had managed to get one:

And we've made referrals to erm, general practitioners and other professionals to undertake some assessments to check whether this is the condition. (SW1)

... and then, after we have tried to do that internally, we then outsource, which will involve things like you know, making referrals to specialist services. (SW2)

[H3] *Under-emphasis of FASD.* Participants consistently reported that both during social work training, and when probing children's challenging behaviour, attention is routinely diverted to other neuro-developmental disorders. One participant mentioned that FASD is 'neglected' within social services even though it is commonly encountered:

It's a condition or a disorder, erm, that seems to erm, that seems to [pause], if I can use the word neglected, might be an understatement. But it is a disorder that has not had a lot attention especially the social services. It is a disorder that is common, but it has not had special, proper attention. (SW2)

This lack of attention is further reflected in lack of knowledge about FASD in contrast to, for example, ADHD. Two participants mentioned that throughout their careers, FASD had never been a subject of focus:

Because I mean... I have been with the [unclear] for three years now and we usually have what we call e-learning where they advertise, all the trainings that are for [unclear]. They are free training. I haven't seen any training on you know, fetal alcohol syndrome. (SW4)

In all the three places, I have not really come across a special attention. I mean I could tell what it is for a child with ADHD, two years old, I could say from the top of my head [pause] you know, all the services, all the interventions but not for, with this disorder. (SW2)

One social worker gave an example where the lack of diagnosis:

Erm, I know, erm, professionals seem quite willing to blame any behaviour or any actions on all levels because of, uh, fetal alcohol, despite the fact that there is no, there's been no [pause] diagnosis. He's just been suspected. (SW5)

The above quotation illustrates that even when FASD is suspected, unless there is a formal diagnosis there can be reluctance by professionals to air the suspicion. The phrase 'seems quite willing to...' implies a criticism of those attributing problems to undiagnosed FASD.

[H3] *Absence of FASD-targeted support.* The participants consistently confirmed that the support offered to families with children suspected to have FASD was generic and not targeted to the condition. The generic support ranged from parenting skills and effectiveness training and drug awareness support without any specific intervention for FASD:

Majority of the support to start with, is generic, erm, parenthood support. It is a generic parenthood support, is a kind of routine structure, boundaries, and ... (SW2)

The child protection solicitor said that no additional or targeted support is routinely offered to children who are diagnosed with FASD; instead, they are likely to be classified under different special needs categories which inadvertently sidelines any consideration of FASD:

No, no specific targeted support because like I said they will come under any umbrella of specific needs. There is no additional support that is given to a child that is suffering from that syndrome. (CPS)

However, one participant did describe a generic intervention that involved strengthening the families' support networks and was routinely offered to families affected by FASD in order to provide respite:

And part of our intervention is what we call family conferences. Using this approach, we are trying to bring along some support network. A stronger support network is possible which includes family and friends and providing respite first of all. Because some of the parents will be struggling on their own, so we strengthen the support network. When we strengthen the support networks, then that helps; you know, these parents have [pause] you know, respite. You know the children are supported by different people, yeah. (SW2)

[H3] *Impact of combined substance misuse.* It was common for participants to mention the use of other drugs, whether stimulants and/or depressants, in combination with alcohol by parents of children suspected to have FASD. They often found that the fetus had been exposed to a variety of harmful substances:

Erm, the case is, I probably would have come across, but I can't specifically remember if it is specific alcohol misuse. It's always a combination of drugs and alcohol. (CPS)

This boy, erm, from the historical background, before he went into care, his mum was abusing alcohol and other drugs. (SW1)

In some cases, social workers pinpointed a specific drug misused by the pregnant mother in conjunction with alcohol. Social worker SW3 mentioned heroin:

So, she had, they were issues around the [pause] between her and the partner, the father of the baby, and then issues to do with alcohol and substance misuse. She was using heroin throughout her pregnancy. (SW3)

These observations confirm findings that demonstrate the frequent combination of alcohol and other drugs during pregnancy (Sherwood, et al., 1999) and how this leads to under-emphasis of the role of alcohol while at the same time complicating the chances of obtaining a diagnosis. This becomes more complicated when mothers' misuse of alcohol and other substances continues producing other reasons for social services to get involved. For example:

... But I have worked with children who come from homes where the parents, due to their problematic use of alcohol and substances, they are not able to care for these children resulting in their needs not met. And the local authority getting involved to make sure that these children's need are met. (SW4)

*[H3] Impact of socio-environmental factors.* The social workers catalogued neglect, physical abuse and violence as typical features of the environments in which many children suspected of having FASD have been exposed. This can be seen in the quotation of a social worker who tries to describe the circumstance around the first time she had to remove a child from the biological parent:

The first parent [pause], the issue was abusing alcohol and drugs, and a lot of domestic abuse and violence. (SW3)

SW6 also mentions that the background of a child suspected of having FASD was characterised by a nexus of issues, ranging from domestic abuse to poor mental health, which affected the child's behaviour. The social worker thought that behavioural problems may have been due to the interplay of these factors:

The behaviours that you saw were kind of a mix of issues because it may not have always been an issue. There may have been domestic abuse as well, and mental health. (SW6)

It is noteworthy that this participant had a self-declared lack of knowledge about FASD, despite reviewing cases of a child likely to be affected. Another participant relayed that neglect was rife in a case she handled because both parents spent all of their income on their drug habit:

The parents, both parents, they were addicts of crack cocaine and heroin and that, [the children] were six and ten years old. But the impact on that one, on those children was neglect. The parents neglected their children's need because all they were doing with their money was, you know, funding their misuse – substance misuse – and neglecting the children. (SW3)

The complex nature of the children's backgrounds and the dearth of authoritative research make it difficult to disentangle the specific effects of FASD and develop effective services.

### **[H1] Discussion**

This is the first study to explore the experiences of social workers working with children suspected of having FASD in England. Our findings show a lack of knowledge about FASD among social workers and a paucity of FASD diagnoses. The only other UK study was based in Scotland (Gordon, 2019), a country that is more developed in terms of diagnosis and support for FASD (NHS Scotland, 2019). Here, social workers were working with a significant number of diagnosed children but while they had more knowledge than their English counterparts, Scottish social workers still reported limited knowledge and uncertainty in working with affected children. This finding is consistent with studies undertaken throughout the world (Gahagan, et al., 2006; Gardner, 2000; Mukherjee, et al., 2015; Mukherjee, 2019). For instance, in New Zealand, mothers of children with FASD explained that it was they who provided professionals with information because the professionals knew so little about it (Salmon, 2008). May and colleagues (2018) in the US also express concern about this situation as FASD has a higher prevalence there than other neurodevelopmental conditions such as autism.

The social workers in this study who had good knowledge of FASD had independently researched the subject, reflecting proactivity despite the absence of system-embedded training. However, others, including one who had reviewed cases of children with FASD, only had a poor understanding. What is important here is that while this lack of knowledge could be excused in those who do not work directly with children, it does mean that FASD is unlikely to be a consideration when supporting parents, which is a serious deficiency. This lack of FASD-tailored training for professionals is common other countries (Elliott, et al., 2006; Gibbs and Sherwood, 2017) and may be due to several reasons: insufficient evidence to prove the burden of FASD, diagnostic difficulties and the absence of universally agreed evidence-based interventions (Mukherjee, et al., 2015). The inclusion of FASD in social work training schedules, therefore, could prove useful in reducing the risk of ongoing harm to the children, lowering some of the costs associated with FASD through providing appropriate support and

informing practices that dissuade drinking in pregnancy, especially if substance misuse specialists were assigned to mothers with a risk of alcohol misuse.

As was found in this research, several studies report that children with FASD present challenging behaviour and are difficult to manage (Salmon, 2008; Streissguth, et al., 2004). The difficulties these create and the feelings of frustration among the social workers could be reduced by developing guidelines for the management of FASD. These could not only inform practitioners about best practices, but also alert them to possible brain damage as a cause of behavioural and social problems and challenge the view that difficult behaviour is normal (Streissguth, et al., 2004).

Several studies evidence that parents of children with FASD require and want support regarding their children with FASD (Chamberlain, et al., 2017; Hall and Graff, 2011; Ospina, 2013). However, the present study found that the only parenting support offered was generic, which is inadequate for children with FASD as they require different parenting strategies to typically developing children (Paley and O'Connor, 2009; Rutman and van Bibber, 2010). As family support networks and non-pharmacological treatments are recommended for families of children with neurodevelopmental disorders (Hall and Graff, 2011; Young, et al., 2016), it would be beneficial if individuals within these networks were FASD aware as it would improve the efficacy of the support the children receive.

The association between parental substance abuse and removal of children from the care of biological parents is well recognised (Besinger, et al., 1999; Burd, et al., 2011; Gregory, et al., 2015; Selwyn and Wijedesa, 2011) and this relationship was found in this study. Given the high prevalence of FASD among looked after children, it might have been expected that social workers would have encountered a significant volume of FASD diagnoses. This study dashes this expectation; it revealed a strong consensus that children with FASD diagnosis are rarely encountered and that diagnostic difficulties contribute to the paucity of diagnoses which, in turn, leads to an under-emphasis of FASD and lack of targeted services. It is also the case that medical practitioners are reluctant to diagnose the condition due to the absence of targeted services (Mukherjee, et al., 2015). Thus, to break this circle, improvements in diagnosis should be accompanied by the development and implementation of focused interventions.

Finally, this study also found many cases of combined substance misuse among parents of children suspected with FASD, similar to the research by Bagley and Badry (2019). The combined impact of substance misuse and adverse socio-environment act in concert to complicate the chances of obtaining a FASD diagnosis. In prenatally exposed children, the behavioural outcome from the effects of the additional drugs is difficult to categorise as the challenging behaviours reported by social workers are likely to result from a mélange of prenatal substance exposure and other adverse childhood conditions. Existing literature stresses that alcohol is the greatest influential factor on brain damage in children prenatally exposed to multiple substance misuse (Behnke, et al., 2013; Nutt, King and Phillips, 2010). So, future research is needed to tease out the extent to which other addictive drugs abused in pregnancy are responsible for the behavioural difficulties of the children and, similarly, how much of this is due to wider conditions known to have harmful effects, such as neglect and maltreatment. This is important because children with FASD often develop secondary morbidities such as involvement with drugs, the criminal justice system and domestic violence (Allely and Gebbia, 2016). Recent research by Mukherjee and colleagues (2019) has begun to unravel these forces producing evidence that when both prenatal alcohol exposure and neglect are present, prenatal alcohol exposure appears to be the more significant factor in the developmental deficits in the children.

#### **[H1] Strengths and limitations**

The strengths of this study are that participants were purposively recruited from four different locations across England and from different social services teams. Secondly, the sample of social workers included participants with prior knowledge of FASD and/or experience of working with children suspected of having the condition and those who had neither. They also had different roles. Other strengths included the independent coding of the transcripts by two researchers and the member-checking of the interpretation of the data by the participants.

As with many qualitative studies, the small sample size does not permit generalisation or provide a complete picture of social workers' knowledge and experience of this area of work.

#### **[H1] Conclusion**

Despite the fact that FASD may be implicated in more than a quarter of looked after children in the UK, social workers had surprisingly little knowledge of the condition, even for those with suspected cases in their workloads. In the social workers' accounts, this was linked to a lack of attention paid to FASD by the services who employed them. This lack of recognition

led to difficulty in managing the children, feelings of frustration and the normalisation of challenging behaviours. The complexity of the children's backgrounds, including the impact of combined substance misuse and damaging environments, meant that FASD was not recognised or diagnosed, and its role in causing the observed difficulties tended to be under-emphasised. Social workers who had prior knowledge of FASD often made referrals for diagnosis, but these rarely resulted in identification. Consequently, the support offered both families and children with FASD was mostly generic, even though FASD-tailored support would be more beneficial. There is a need for increased awareness of the condition within social services and the development of FASD-targeted support for children and their families. Social workers would benefit from the inclusion of FASD-focused training in their curricula and professional development; improved diagnostic capacities in health institutions would address the paucity of diagnosis and raise awareness of FASD across all welfare services.

### **Acknowledgements**

The authors are grateful to the professionals who took part in this study, and for their participation in member-checking the final analysis.

### **Funding**

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### **Declaration of conflicting interests**

The authors declare that there is no conflict of interests in the publication of this work.

### **References**

All Party Parliamentary Group (APPG) (2015) Initial report of the inquiry into the current picture of FASD in the UK today. London: APPG. Available at: [www.basw.co.uk/system/files/resources/basw\\_104720-4\\_0.pdf](http://www.basw.co.uk/system/files/resources/basw_104720-4_0.pdf)

Allely CS and Gebbia P (2016) Studies investigating Fetal Alcohol Spectrum Disorders in the criminal justice system: A systematic PRISMA review. *SOJ Psychology* 3(1): 1–11.

Bagley K (2019) Responding to FASD: What social and community service professionals do in the absence of diagnostic services and practice standards. *Advances in Dual Diagnosis*. 12(1/2): 14–26.

- Bagley K and Badry D (2019) How personal perspectives shape health professionals' perceptions of Fetal Alcohol Spectrum Disorder and risk. *International Journal of Environmental Research and Public Health* 16(11): 1936.
- Behnke M, Smith VC and Committee on Substance Abuse, et al. (2013) Prenatal substance abuse: short- and long-term effects on the exposed fetus. *Pediatrics* 131(3): e1009–e1024.
- Besinger BA, Garland AF, Litrownik AJ, et al. (1999) Caregiver substance abuse among maltreated children placed in out-of-home care. *Child Welfare* 78(2): 221–239.
- Bowling A (2014) *Research Methods in Health: Investigating health and health services*. Maidenhead, Berkshire: McGraw-Hill Education.
- British Medical Association (BMA) (2016) *Alcohol and Pregnancy: Preventing and managing fetal alcohol spectrum disorders*. Available at: [www.bma.org.uk/media/2082/fetal-alcohol-spectrum-disorders-report-feb2016.pdf](http://www.bma.org.uk/media/2082/fetal-alcohol-spectrum-disorders-report-feb2016.pdf)
- Burd L, Cohen C, Shah R, et al. (2011) A court team model for young children in care: The role of prenatal alcohol exposure and Fetal Alcohol Spectrum Disorders. *The Journal of Psychiatry & Law* 39(1): 179–191.
- Carmichael-Olson H (2009) *A Call to Action: Advancing essential services and research on fetal alcohol spectrum disorders: a report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect*. US Department of Health and Human Services. Available at: [www.cdc.gov/ncbddd/fasd/documents/calltoaction-P.pdf](http://www.cdc.gov/ncbddd/fasd/documents/calltoaction-P.pdf)
- Chamberlain K, Reid N, Warner J, et al. (2017) A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. *Research in Developmental Disabilities* 63: 99–106.
- Chasnoff IJ, Wells AM and King L (2015) Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics* 135(2): 264–270.
- De Laine M (2000) *Fieldwork, Participation and Practice: Ethics and dilemmas in qualitative research*. Thousand Oaks, CA: Sage Publications
- Derauf C, Katz A and Easa D (2003) Agreement between maternal self-reported ethanol intake and tobacco use during pregnancy and meconium assays for fatty acid ethyl esters and cotinine. *American Journal of Epidemiology* 158(7): 705–709.
- Elliott EJ, Payne J, Haan E, et al. (2006) Diagnosis of foetal alcohol syndrome and alcohol use in pregnancy: A survey of paediatricians' knowledge, attitudes and practice. *Journal of Paediatrics and Child Health* 42(11): 698–703.
- Fuchs D, Burnside L, Marchenski S, et al. (2010) Children with FASD-related disabilities receiving services from child welfare agencies in Manitoba. *International Journal of Mental Health and Addiction* 8(2): 232–244.

Gahagan S, Sharpe TT, Brimacombe M, et al. (2006) Pediatricians' knowledge, training, and experience in the care of children with Fetal Alcohol Syndrome. *Pediatrics* 118(3): e657–e668.

Gale NK, Heath G, Cameron E, et al. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology* 13(1): 117. Available at <https://bmcmmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-13-117>

Gardner J (2000) Living with a child with Fetal alcohol syndrome. *MCN: The American Journal of Maternal/Child Nursing* 25(5): 252–257.

Gibbs, A., Bagley, K., Badry, D., & Gollner, V. (2020). Foetal alcohol spectrum disorder: Effective helping responses from social workers. *International Social Work*, 63 (4), 496–509. <https://doi.org/10.1177/002087281880403>

Gibbs A and Sherwood K (2017) Putting Fetal alcohol spectrum disorder (FASD) on the map in New Zealand: A review of health, social, political, justice and cultural developments. *Psychiatry, Psychology and Law* 24(6): 825-842.

Gordon L (2019) Social workers' experiences of supporting children exposed to alcohol in Utero: An interpretive phenomenological analysis. D Clin Psy thesis, University of Glasgow. Available at: <http://theses.gla.ac.uk/73047/1/2019GordonDClinPsy.pdf>

Gregory G, Reddy V and Young C. (2015) Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis. *Adoption & Fostering* 39(3): 225–234.

Hall HR and Graff JC (2011) The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing* 34(1): 4–25.

Hoyme HE, Kalberg WO, Elliott AJ, et al. (2016) Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics* 138(2): e20154256.

Lange S, Probst C, Gmel G, et al. (2017) Global prevalence of fetal alcohol spectrum disorder among children and youth: a systematic review and meta-analysis. *JAMA Pediatrics* 171(10): 948–956.

Lange S, Shield K, Rehm J, et al. (2013) Prevalence of fetal alcohol spectrum disorders in childcare settings: a meta-analysis. *Pediatrics* 132(4): e980–e995.

May PA, Chambers CD, Kalberg WO, et al. (2018) Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA* 319(5): 474–482.

McQuire C, Mukherjee R, Hurt L, et al. (2018) Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: A population-based birth-cohort study. *Preventive Medicine* 118: 344–351.

- Mukherjee R (2019) FASD: The current situation in the UK. *Advances in Dual Diagnosis* 12(1/2): 1–5.
- Mukherjee R, Cook PA, Fleming KM, et al. (2017) What can be done to lessen morbidity associated with Fetal alcohol spectrum disorders? *Archives of disease in childhood* 102(5): 463–467.
- Mukherjee RAS, Cook PA, Norgate SH, et al. (2019) Neurodevelopmental outcomes in individuals with fetal alcohol spectrum disorder (FASD) with and without exposure to neglect: Clinical cohort data from a national FASD diagnostic clinic. *Alcohol* 76: 23–28.
- Mukherjee R, Wray E, Curfs L, et al. (2015) Knowledge and opinions of professional groups concerning FASD in the UK. *Adoption & Fostering* 39(3): 212–224.
- NHS Scotland (2019) SIGN 156: Children and young people exposed prenatally to alcohol. Available at: [www.sign.ac.uk/assets/sign156.pdf](http://www.sign.ac.uk/assets/sign156.pdf)
- Nutt DJ, King LA and Phillips LD (2010) Drug harms in the UK: A multicriteria decision analysis. *The Lancet* 376(9752): 1558–1565.
- O’Keeffe LM, Kearney PM, Greene RA and Kenny LC (2016) Alcohol use during pregnancy. *Obstetrics, Gynaecology & Reproductive Medicine* 26(6): 188–189.
- Ospina, M. and Dennett, L., (2013) Systematic review on the prevalence of fetal alcohol spectrum disorders. *IHE Institute of Health Economics, Alberta, Canada*.
- Paley B and O’Connor MJ (2009) Intervention for individuals with fetal alcohol spectrum disorders: treatment approaches and case management. *Developmental Disabilities Research Reviews* 15(3): 258–267.
- Pei J, Tremblay M, Pawlowski A and Poth C. (2015) *Best Practices for FASD Service Delivery: Guide and Evaluation Toolkit*. Alberta, Canada: Alberta Clinical and Community-Based Evaluation and Research Team.
- Pelech W, Badry D and Daoust G (2013) It takes a team: Improving placement stability among children and youth with Fetal Alcohol Spectrum Disorder in care in Canada. *Children and Youth Services Review* 35(1): 120–127.
- Petrenko CL (2015) Positive behavioral interventions and family support for fetal alcohol spectrum disorders. *Current Developmental Disorders Reports* 2(3): 199–209.
- Petrenko CLM, Tahir N, Mahoney EC, et al. (2014) Prevention of secondary conditions in Fetal alcohol spectrum disorders: identification of systems-level barriers. *Maternal and Child Health Journal* 18(6): 1496–1505.
- Pope C and Mays N (1999) *Qualitative Research in Health Care*. London: BMJ Books.

Popova S and Chambers C (2014) Fetal alcohol spectrum disorders must be recognized globally as a large public health problem. *The International Journal of Alcohol and Drug Research* 3(1): 1–3.

Popova S, Lange S, Burd L and Rehm J (2016a) The economic burden of Fetal Alcohol Spectrum Disorder in Canada in 2013. *Alcohol and Alcoholism* 51(3): 367–375.

Popova S, Stade B, Bekmuradov D, et al. (2011) What do we know about the economic impact of Fetal Alcohol Spectrum Disorder? A systematic literature review. *Alcohol and Alcoholism* 46(4): 490–497.

Popova S, Lange S, Probst C, et al. (2017) Estimation of national, regional and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: A systematic review and meta-analysis.

Popova S, Lange S, Shield K, et al. (2016b) Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis. *The Lancet* 387(10022): 978–987.

Reid N, Dawe S, Shelton D, et al. (2015) Systematic review of fetal alcohol spectrum disorder interventions across the lifespan. *Alcoholism: Clinical and Experimental Research* 39(12): 2283–2295.

Rutman D and Van Bibber M (2010) Parenting with fetal alcohol spectrum disorder. *International Journal of Mental Health and Addiction* 8(2): 351–361.

Ryan DM, Bonnett DM and Gass CB (2006) Sobering thoughts: Town hall meetings on Fetal alcohol spectrum disorders. *American Journal of Public Health* 96(12): 2098–2101.

Salmon J (2008) Fetal Alcohol Spectrum Disorder: New Zealand birth mothers' experiences. *Journal of Population Therapeutics and Clinical Pharmacology* 5(2): e191–213.

Sherwood RA, Keating J, Kavvadia V, et al. (1999) Substance misuse in early pregnancy and relationship to fetal outcome. *European Journal of Pediatrics* 158(6): 488–492.

SIGN (2019) Children and young people exposed prenatally to alcohol: A national clinical guideline. *SIGN* 156. Available at: [www.sign.ac.uk/our-guidelines/children-and-young-people-exposed-prenatally-to-alcohol/](http://www.sign.ac.uk/our-guidelines/children-and-young-people-exposed-prenatally-to-alcohol/)

Selwyn J and Wijedesa D (2011) Pathways to adoption for minority ethnic children in England: Reasons for entry to care. *Child & Family Social Work* 16(3): 276–286.

Streissguth AP, Bookstein FL, Barr HM, et al. (2004) Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics* 25(4): 228–238.

Watts M (2015) Progress in addressing FASD in Scotland. *Adoption & Fostering* 39(3): 256–262.

Wurst FM, Kelso E, Weinmann W, et al. (2008) Measurement of direct ethanol metabolites suggests higher rate of alcohol among pregnant women than found with the AUDIT: A pilot study in a population-based sample of Swedish women. *American Journal of Obstetrics and Gynecology* 198(4): 407e1–407.e5.

Young S, Absoud M, Blackburn C, et al. (2016) Guidelines for identification and treatment of individuals with attention deficit/hyperactivity disorder and associated fetal alcohol spectrum disorders based upon expert consensus. *BMC Psychiatry* 16(1): 324.

**David Gilbert** is current Postgraduate Research Student, School of Health and Society, University of Salford, UK.

**Raja Mukherjee**, School of Health and Society, University of Salford, UK, and FASD Specialist Behaviour Clinic, Surrey and Borders Partnership NHS Foundation Trust, UK.

**Nisha Kassam** is former MSc Public Health student, School of Health and Society, University of Salford, UK.

**Penny A Cook** is Professor of Public Health, School of Health and Society, University of Salford, UK.

