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**Social Workers experiences of supporting with children exposed to alcohol in  
utero; an Interpretative Phenomenological Analysis**

and

Clinical Research Portfolio

**Louise Gordon**

MA (Honours) in Psychology

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

May 2019



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## **CHAPTER 1: SYSTEMATIC REVIEW**

**The experiences of non-biological carers of children with**

**Fetal Alcohol Spectrum Disorder**

Word Count: 8308

*Prepared in accordance with guidelines for submission to the Journal of Research in Developmental Disabilities (Appendix A)*

## **1.1 ABSTRACT**

### **Background**

Pre-natal exposure to alcohol can lead to life-long developmental and cognitive complications. A disproportionate number of children with a diagnosis of Fetal Alcohol Spectrum Disorder end up in Social Services, particularly foster care. The cognitive and behavioural difficulties associated with the condition have been shown to increase the risk of crisis situations and eventual placement breakdown in foster care. Persistent experiences of placement disruptions are considered a serious problem for children with Fetal Alcohol Spectrum Disorder and linked to negative emotional outcomes. A stable home and social environment helps to buffer against the neurological difficulties associated with the condition. It is therefore imperative that non-biological carers feel prepared and supported when raising a child with Fetal Alcohol Spectrum Disorder.

### **Purpose**

This review aimed to systematically examine and synthesise qualitative studies which have sought to explore the experiences of non-biological carers of children with Fetal Alcohol Spectrum Disorder. The review sheds light onto commonly experienced challenges that may lead to multiple placement breakdowns which is known to be detrimental to the child's development.

### **Method**

Studies for this review were identified through a systematic search of the literature carried out in March 2018. No time period was specified for the search. Eight electronic databases were searched – Medline, EMBASE, PsychInfo, Psychology & Behavioural Sciences, CINAHL,

Sociological Abstracts, Social Service Abstracts and socINDEX. References and citations were searched within each of the selected studies. A total of 3302 papers were identified from the search terms for potential consideration in the review. Seven papers were selected for inclusion in the synthesis. The papers were rated using Walsh & Downe's (2006) Quality Assessment Criteria for qualitative studies.

## **Results**

Through the process of meta-ethnography, four key super-ordinate themes were developed; 1) Developing knowledge and understanding on FASD; 2) Support from professionals and others; 3) Child's presenting difficulties and 4) Personal parental impact.

## **Conclusion**

The results suggested that the carers felt unprepared in providing specialist support for children with Fetal Alcohol Spectrum Disorder, and developed their knowledge of the condition through their experiences. With a lack of specialist professional knowledge, carers reported finding the presenting cognitive and behavioural difficulties too challenging to manage, leading to placement breakdowns and stress in the family unit.

## 1.2 INTRODUCTION

The term 'Fetal Alcohol Spectrum Disorder' (FASD) was first coined by Jones and Smith (1973) to refer to a cluster of congenital birth defects arising from the teratogenic effects of alcohol exposure in utero. FASD is not a diagnosis in itself, but a term used to describe the anomalies along the spectrum. Since its classification in 1973, it is now considered to be the most common non-genetic, preventable cause of developmental disability and birth defects (May & Gossage, 2001), with an estimated prevalence rate of up to 5 in every 100 births worldwide (Popova *et al*, 2016).

Research into FASD has shown neurocognitive and behavioural disturbances, resulting in life-long challenges and disrupted adaptive functioning (Fast & Conry, 2004). The main cognitive deficits found are sensory-motor abnormalities (Connor *et al*. 2006), attention, cognition and executive function problems (Kodituwakku *et al*. 2001), and impairment in understanding the concept of cause and effect (Fast & Conry, 2004). Individuals with FASD may have poor academic achievement (Mattson *et al*. 1997), including difficulties with reading, maths and comprehension. Social skills can be affected (Greenbaum *et al*. 2009), as well as memory (Uecker & Nadel 1996), for example recalling and retrieving memories, resulting in the child confusing reality and fictional events (Fast & Conry, 2004). In addition to cognitive deficits, children and adults with FASD often have maladaptive behaviour, causing difficulties in social relationships and problems within education settings. Due to symptoms of hyperactivity and attention difficulties, children with FASD are commonly misdiagnosed with Attention Deficit Hyperactivity Disorder (O'Malley, 2011). Children with FASD are often very impulsive and have difficulty in monitoring and managing their own behaviour (O'Malley, 2011). They are

more vulnerable to peer pressure and considered very unpredictable in their behaviour, often leading to secondary disabilities (De Vries and Waller, 2004).

Unlike the primary disabilities that are caused by organic and irreparable brain damage, secondary disabilities emerge over time, as the child attempts to function within the expectations of societal norms. Streissguth (2004) conducted a quantitative study focusing on risk factors for adverse life outcomes of 415 individuals (mean age 14 years) with a diagnosis of FASD. It was concluded that 61% of the participants had disrupted school experiences, 60% had come into contact with the law and 50% had experienced imprisonment or have been kept in a mental health facility. A further 49% of participants had problems with inappropriate sexual behaviour and 35% struggled with substance abuse problems. 80% of the participants had not been raised by their biological mother, highlighting the number of children with FASD potentially in foster, kinship or adoptive care being raised by non-biological caregivers.

Non-biological caregivers are defined as individuals who are not the biological parents of a child, but who provide the emotional, physical, and social support for children unable to live with their parents (Barker, 1995). In this review, non-biological parents including foster carers, adoptive parents and kinship carers.

Birth parents may not be able to care for their children for a number of reasons. When deemed in the best interest of the child, local authority may decide that the best option is to place the child in foster care. This is can be both a short or long-term solution to provide children with a safe home. Foster carers look after the child on behalf of the local authority (British Adoption and Fostering Association, [www.corambaaf.org.uk](http://www.corambaaf.org.uk)). The child will have an assigned Social Worker who will be in close contact with the foster family throughout the duration of the child's stay. The local authority has the ultimate responsibility to look after

the children, and act as their corporate parent until the child reaches adulthood ([www.fostering.org.uk](http://www.fostering.org.uk)). All foster carers receive an allowance to cover the cost of looking after the child, and a fee to recognise the skills and expertise they bring to the fostering role ([www.fostering.org.uk](http://www.fostering.org.uk)).

If the local authority decides the child should not return to their birth parents, the child may remain in foster care long-term or may be adopted. Individuals who adopt a child have all the parental rights and responsibility is transferred over to them. The child will stay with this family on a permanent basis and usually takes on the adoptive family name (British Adoption and Fostering Association, [www.corambaaf.org.uk](http://www.corambaaf.org.uk)). Although the local authority no longer have legal responsibility for the child, adoption legislation state that local authorities are 'legally required to provide support services for all adoptive families, either themselves, or by arrangement with specialist services'. This can be emotional, financial, therapeutic or practical support (British Adoption and Fostering Association, [www.corambaaf.org.uk](http://www.corambaaf.org.uk)).

Kinship care is defined as a non-biological carer who is known to the child or family in the capacity of either a family member or a friend. Kinship care may be a permanent arrangement. This agreement is often formalised through a legal order, or a temporary and informal one. It is common for these children not to be under the guardianship of the local authority, but this is not always the case.

Streissguth & Kanter (1997) stated that it is crucial for children with FASD to have stability and structure in their home and social life to help mediate against the neurological difficulties and the development of secondary disabilities. Unfortunately, it is known that these children often experience complex and traumatic upbringings (Pelech *et al* 2013). This risk of a turbulent home life alongside the behavioural and cognitive challenges has contributed to a

disproportionate number of children with a diagnosis of FASD in care of Social Services (Pelech *et al* 2013, Fast & Conry, 2009). Astley *et al* (2002) determined the prevalence of Fetal Alcohol Syndrome (FAS) in a foster care population using a FAS Facial Photographic Screening Tool. The study found that the rates of children with a diagnosis of FAS were 10-15 times higher in foster care than in the general population. The literature estimates that 17% of children in the care of Social Services had a diagnosis of FASD (Fuchs *et al.*, 2008, Lange *et al*, 2013), and a high percentage of foster carers may be fostering a child with FASD (Brown and Bednar, 2004). It has also been found that children with FASD entered into the care system at a younger age than children with other types of disabilities (Fuchs *et al.*, 2008)

Streissguth (2004) concluded that a positive, stable family life appeared to be a critical protective factor for helping children avoid adverse life outcomes. Research into biological and non-biological carers' experiences shed light on the challenges of establishing this supportive environment. The literature suggests that factors such as cognitive and behavioural difficulties and a lack of support impacts on the stability of family life for both the carers and the children. It is evident that children with FASD require constant monitoring due to hyperactivity, aggressiveness and destructiveness (Brown and Bednar, 2004; Morrisette, 2001; Gardner, 2000). Sanders and Buck (2010) described a theme of Living in a War Zone, reflecting the chaotic home environment dealing with severe tantrums, violence, unpredictability and the difficulties in de-escalating behaviour. In Phung's (2011) qualitative study of birth and non-biological carers, one mother reported she had her nose and arm broken by her child. This disruptive and unsociable behaviour is reported to lead to isolation for both the carer and child (Mukherjee *et al*, 2013; Brown and Bednar, 2004). Further challenges arise when the child's disabilities are considered 'invisible' (Mukherjee *et al*, 2013),

leading to unrealistic assumptions and expectations about the child's capacity (Sanders and Buck, 2010). Caregivers throughout the qualitative literature described the frustration they experience in relation to the cognitive difficulties their child experiences. For example, common impairments with learning and memory requires constant re-teaching, becoming tiresome and frustrating (Sanders and Buck, 2010; Granitas, 2004; Coons *et al.* 2016). Impairments in understanding consequences and inhibiting behaviour compels carers to control their child's environment to prevent harm, keep them safe and prevent them from being taken advantage of (Sanders and Buck, 2010; Gardner, 2000; Phung, 2011). Several studies reported a lack of knowledge among professionals and the challenges accessing appropriate support (Mukherjee *et al.* 2013; Sanders and Buck, 2010; Brown and Bednar, 2004; Brown, 2015; Whitehurst, 2011). This highlighted the stress and burden placed on caregivers, often with the strain having devastating consequences on the relationships within the family (Mukherjee *et al.*, 2013; Sanders and Buck, 2010; Phung, 2011).

Difficulties experienced by these carers may lead to a crisis situation and eventual placement breakdown. Multiple placement breakdowns are considered a serious problem for children with FASD and linked to negative emotional outcomes (Brown *et al.* 2005), for example disruption to sense of belonging, connection, control, self-esteem, and attachment (Stott & Gustavsson, 2010; Plunkett & Osmond, 2004; Webster, Barth, & Needell, 2000; Unrau, Seita, & Putney, 2008).

Domeij *et al.* (2018) systematically reviewed 18 qualitative studies about the experiences of raising a child with FASD using content analysis. The review included individuals' experiences of having FASD, and caregiver's (biological and non-biological) experiences of raising a child with FASD. The opinions and experiences of biological and non-biological carers were not

reported separately, and therefore do not account for any differences between the parenting groups. To the best of the author's knowledge, no studies have specifically looked at the differences in experiences between birth and non-biological caregivers. However, data within the research has shown that there may be possible differences in the emotional experiences in response to the child's impairments. For example, Phung (2011) and Sanders (2010) reported birth mother's expressed incredible guilt for their role in their child's disabilities. Furthermore, there is evidence within the research that non-biological parents often feel anger towards the birth mothers (Sanders, 2010; Gardner, 2000). For this reason, the current review will focus specifically on the experiences of non-biological carers, to determine implications for children in Social Care Services only.

### **Purpose**

This review aimed to systematically examine and synthesise qualitative studies which have sought to explore the experiences of non-biological caregivers of children with FASD. The review will shed light onto commonly experienced challenges that may lead to multiple placement breakdowns which is known to be detrimental to the child's development and stability.

### **1.3 METHOD**

This systematic review process was conducted following the guidance in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher *et al*, 2009).

#### **Search Strategy:**

Studies were identified through a systematic search of the literature carried out in March 2018. No time period was specified for the search. Eight electronic databases were searched

– Medline, EMBASE, PsychInfo, Psychology & Behavioural Sciences, CINAHL, Sociological Abstracts, Social Service Abstracts and socINDEX. References and citations were searched within each of the selected studies.

### **Search Terms:**

The databases and search terms were chosen with guidance and approval from an NHS librarian. A review of the existing literature on Fetal Alcohol Spectrum Disorder from Google Scholar allowed alternative synonyms of the key terms to be identified.

The following search terms were used:

1. "Alcohol Related Neurodevelopmental Disorder" OR "Alcohol Related Birth Defects" OR "FAE" OR "Fetal Alcohol Effects" OR "Fetal Alcohol Syndrome" OR "FAS" OR "FASD\*" OR "Foetal Alcohol Syndrome" OR "Partial Fetal Alcohol Syndrome" OR "Alcohol-Related Disability" OR "Fetal Alcohol\*" OR "Foetal Alcohol" OR "prenatal alcohol exposure" OR "static encephalopathy"
2. "Foster parent" OR "foster\*" OR "carer\*" OR "guardian\*" OR "caretaker" OR "adopt\* parent" OR "adoptive" OR "non-biological\*" OR "parent\*" OR "Family"
3. "Qualitative" OR "Experience\*" OR "Understand\*" OR "Journey" OR "Narrative" OR "Perspective\*"
4. 1 AND 2 AND 3

All titles and abstracts were independently screened. Papers were included or excluded according to specific criteria as detailed in Table 1.

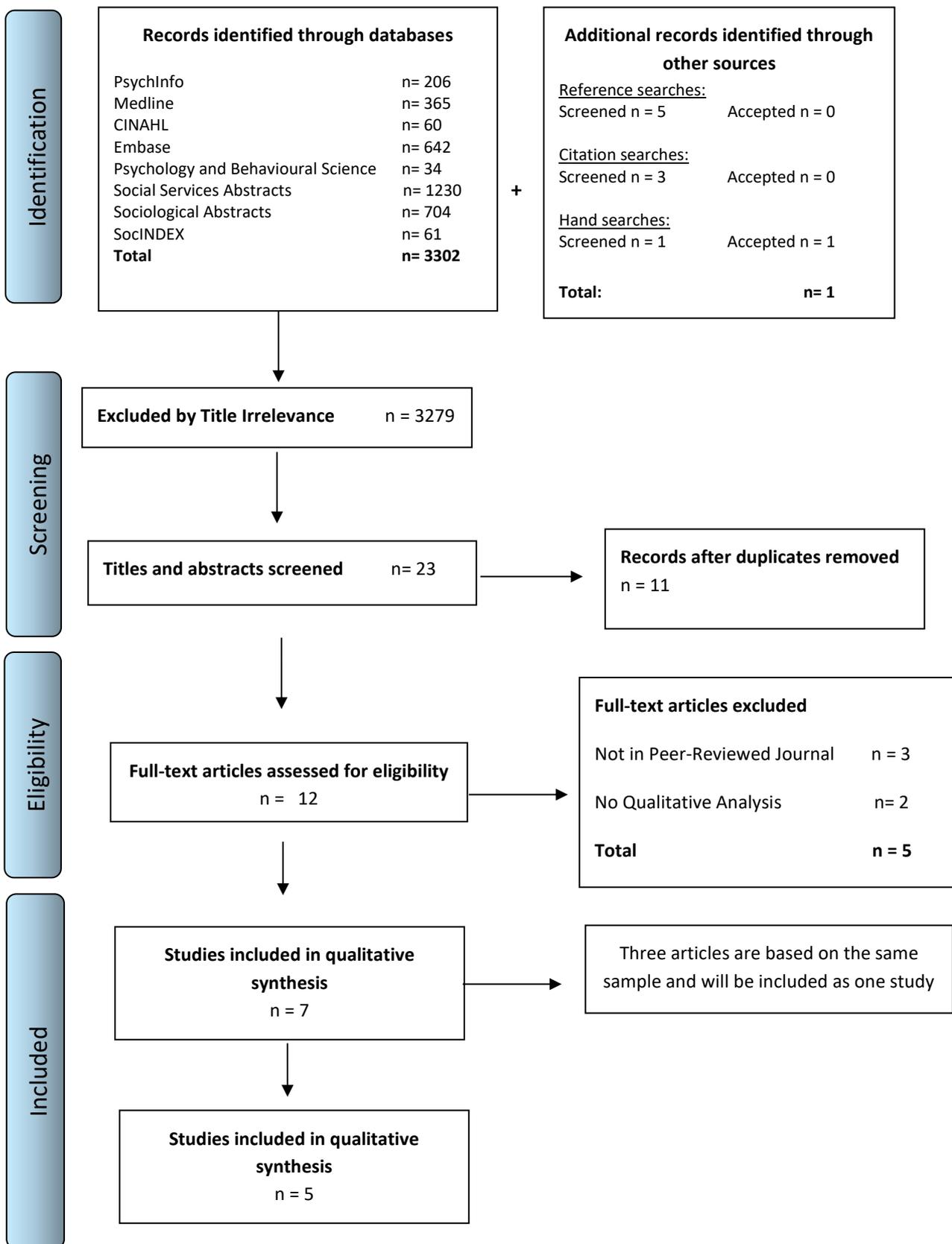
*Table 1: Inclusion and Exclusion criteria of selected studies for review.*

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>- Qualitative Studies only</li> <li>- Children with a diagnosis of FASD</li> <li>- Non-biological carers; adoptive, foster and kinship carers.</li> <li>- Current or previous experience of supporting children with FASD</li> <li>- Any direct experience included (no minimum time of caring)</li> <li>- Peer-reviewed journal</li> <li>- Published in English</li> </ul>	<ul style="list-style-type: none"> <li>- Quantitative Studies</li> <li>- Mixed method Studies</li> <li>- Case studies</li> <li>- Book Chapters</li> <li>- Unpublished including Thesis/Dissertations</li> <li>- Biological parent’s experiences included</li> <li>- Co-morbidity explicitly stated</li> <li>- Adults with FASD</li> </ul>

**Procedure:**

A total of 3302 papers were identified from the search terms for potential consideration in the review (Figure 1). Electronic searches were documented to provide a clear and transparent record of search results, detailed in Appendix B. The titles were screened by the author and all papers with irrelevant titles were excluded in the first instance. The abstracts of the remaining studies were screened and excluded if they did not fit the inclusion criteria. A hand search and an electronic citation search was also conducted. These searches resulted in a further one study to be included in the review. The remaining papers were subjected to a full text review. Seven papers were selected for inclusion in the synthesis. Three of these papers were written by the same authors and included the same pool of participants, varying only in the question being analysed. As such, a decision was made to group these papers together as one study.

Figure 1: PRISMA Flow Chart



## **Quality Approval**

The current study employed Walsh & Downe's (2006) criteria for appraising qualitative literature (Appendix C). Each study was critiqued and awarded two points if the criterion was fully met; one point if the criterion is partially fulfilled and zero points if there is no evidence that the criterion was met. This provides a total potential score of 24 points. Studies were rated as 'good' if they received a score of 18 or more (75%); 'acceptable' if they scored 12 or more (50%) or 'inadequate' if they scored 11 or less (under 50%). The quality ratings of each study can be found in Appendix D. To ensure methodological rigor and limitation of subjectivity, all of the selected studies were reviewed by an independent assessor (Clinical Psychologist), with an inter-rater reliability of 90%. Where papers were scored differently, the two assessors discussed their different appraisals to reach agreement about quality. Five of the included studies met criteria for good qualitative research, and two papers were rated as acceptable. Table 2 provides descriptions of the included studies and the quality rating awarded.

Table 2: Descriptions of studies and Quality Rating

Author & Year	Number of Participants and role	Country	Qualitative Methodology	Quality Rating
<b>Brown, Sigvaldason &amp; Bednar (2005)</b>	63 Foster Parents		Concept Mapping	14/24 Acceptable
<b>Brown, Sigvaldason &amp; Bednar (2007)</b>	63 Foster Parents	Canada	Concept Mapping	18/24 Good
<b>Brown, Sigvaldason &amp; Bednar (2007)</b>	63 Foster Parents		Concept Mapping	18/24 Good
<b>Chamberlain, Reid, Warner, Shelton &amp; Dawe (2016)</b>	10 in total: 4 Foster Parents 1 adoptive parent 5 kinship carers	Australia	Thematic Analysis	20/24 Good
<b>Gardner (2000)</b>	8 in total Foster Parents	USA	Content Analysis	12/24 Acceptable
<b>Granitsas (2004)</b>	5 in total Adoptive & Foster Parent (number unspecified)	USA	Thematic Analysis	19/24 Good
<b>Morrisette (2001)</b>	6 in total Adoptive & Foster Parent (number unspecified)	Canada	Thematic Analysis	24/24 Good

The five papers included were conducted in three countries; Canada, USA and Australia. The legalities surrounding legal guardianship and parental rights in fostering and adoption are similar across these countries. In the UK, there is a legal requirement for the local authority to provide support services for all adoptive families, however the obligations of Health and Social Care systems may differ in each country. For example, Chamberlain (2016) states that parents struggled to access post-diagnostic support, partly due to the Australian health system providing differing levels of support depending on the child’s diagnosis and whether FASD is recognised by professionals in each locality. It is therefore important to note that although the included papers all discuss the experiences of non-biological caregivers, the quality and quantity of professional support accessible to these families may vary. None of

these research papers specify or describe the type of professional support offered to the families.

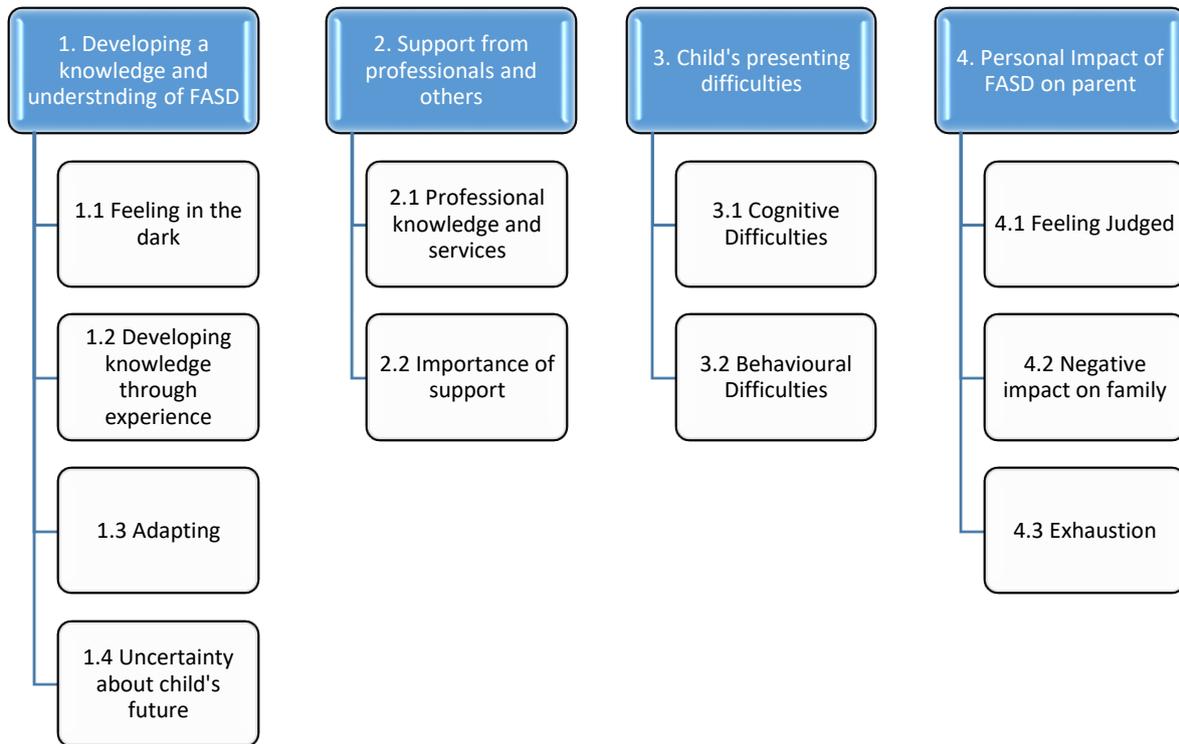
### **Method of Synthesis**

Meta-ethnography was selected to synthesise published qualitative research exploring the experiences of foster and adoptive parents of children with FASD. Meta-ethnography is a form of interpretative synthesis developed by Noblit and Hare (1988). This approach involves bringing together findings from individual interpretive accounts, resulting in conceptually rich interpretations of the phenomena in question. The process of meta-ethnography involves seven steps which can be found in Appendix E. During this process, the data can be related to one another in three ways; they may be directly comparable (reciprocal translational analysis); they may stand in opposition (refutational synthesis) or they may represent a line of argument. A list of the original themes from each of the studies included in the synthesis can be found in Appendix F. First order themes and codes were developed, noting components of the theme and illustrative direct quotes from each article. Common themes and concepts were then combined across the five studies to develop third-order themes (Major & Savin-Baden, 2010).

### **1.4 RESULTS**

The meta-ethnography process elicited four key super-ordinate themes; 1) Developing knowledge and understanding on FASD; 2) Support from professionals and others; 3) Child's presenting difficulties and 4) Personal parental impact. The four superordinate themes and subordinate themes are detailed in Figure 2.

Figure 2: Superordinate and subordinate themes



## 1. Developing a knowledge and understanding of FASD

All of the included papers discussed the development of knowledge over time. This knowledge was described along a continuum, with four emerging stages of development; 1) feeling in the dark about the condition, 2) developing an understanding through lived experience, 3) adapting their lives to accommodate the child and 4) fear about their child's future.

### 1.1 Feeling in the dark

Carers described being provided with '*no information about their child*', not having '*enough information about FASD*', leaving them to '*not know what was wrong with the child*' (Brown, 2007). Lack of information given to the parents was evident in several of the papers. A carer in Granitas (2004) described their unpreparedness;

*We were not told anything other than the fact that she had been somewhat low birthweight when she was born, small for gestational age, and they had run lots of neurological tests on her, but the paediatrician didn't draw any inferences from that for us, you know, as far as I knew, things were going to be fine.*

## 1.2 Developing knowledge through experience

All of the papers suggested a learning process that the parents went through, beginning to understand the condition as brain damage that had significant effects on their child's cognitive and behavioural development. A carer in Morrisette (2001) study stated;

*I think when I finally did read about what FAS was about, it was like a weight was just lifted off my mind and I felt like, oh, this is what I needed to know all these years.*

There is also a sense that the caregivers did much of this learning on their own, actively sourcing their own resources;

*There's a lot of things that we used [strategies] and researched different things  
(Chamberlain et al, 2016)*

## 1.3 Adapting to the child

The literature suggests this learning process is imperative when adopting or fostering a child with FASD. This learning process leads to behavioural changes in parenting styles that are more compatible and supportive for the child.

*They will never be normal children. Once I got that into my mind, no matter how frustrated I got, I lowered my expectations. I call it letting go of the perfect picture.  
(Gardner, 2000)*

#### 1.4 Concerns for the child's future

Three papers noted the concerns the caregivers had about the future of their child. This included worries from the children acquiring the skills needed to live independently, to their vulnerability in society without the protection of parental supervision.

*He's [child] going to be easily led and get in to trouble because his brain doesn't work properly (Chamberlain et al, 2016)*

*I think she will be the kid that everyone would move in, eat up all her food, steal her blind, and she would still think that they are all friends (Gardner, 2000)*

## 2. Support from professionals and others

It is clear from the research that parenting a child with FASD is challenging on many levels. Five of the papers mentioned the support from others around them to help manage these difficulties.

### 2.1 Professional knowledge and services

Four of the papers explicitly mentioned the support they received from professional services. A carer in Brown (2005) stated her need for *professionals willing to collaborate* and a *teamwork* approach was most beneficial. However, Brown (2007) noted that one carer felt *professionals (were) looking down on her*, which effected the relationship with them. The caregiver's experiences of professional services varied greatly. For example, a carer in Chamberlain et al (2016) stated;

*We had a long battle with [child] at doctors and paediatricians (...) yeah and you know all the doctors fobbed it off saying 'no it will be alright'. We went*

*Occupational Therapy for a bit and they said 'she'll be alright, she'll be alright'. But things were just not right.*

Whilst other carers experienced mixed support from professionals;

*I've had physicians that just said, well that's the way it is, you know, and not really tried to dig and ferret out information. And I have had other ones that have just bent over backwards (Morrisette, 2001)*

## 2.2 Importance of support/respice

In two of the papers, caregivers stated the importance of support from family and friends to help them cope. Brown (2005) stated the important of *extended family who help out* and having *someone to sound off to*. A parent in Gardner (2000) highlighted how vital additional support is when managing children with FASD;

*If I didn't have people to call up when I'm frustrated, or go to a friend's house for a while, I couldn't make it.*

## 3. Child's presenting difficulties

All of the included papers discussed the parenting challenges in relations to managing the cognitive and behavioural difficulties presented by the child. Caregivers in Brown (2005) and (2007) stated that often the *child is dangerous to self* by displaying *severe behavioural problems* that were *hard to manage*. This required the *supervision for children all the time* for their own, and others, protection.

### 3.1 Cognitive difficulties

Caregivers throughout three of the papers discussed their understanding and management of their child's cognitive deficits, which supports their reported constant supervision, need for respite and feelings of over-protection.

*They can't think things out (...) Since they don't understand consequences, they will never avoid being put into situations that might have a negative consequence, from tearing up a toy at home, to wandering off with a stranger that can hurt them. They don't understand. (Gardner 2000)*

*You can tell her the same thing a hundred times, and the one hundred and one time she'll do it backwards! (Granitas, 2004)*

### 3.2 Behavioural difficulties

In addition to the cognitive challenges faced, the carers also reflected on the severe behavioural difficulties and how this caused major disruption to the child's life, the parent's life and the life of their family.

*She was mauling them, wrapping her arms and legs around them (Gardner, 2000)*

*[Child] would go totally out of control. I would physically restrain him by holding him down so he wouldn't hurt himself or anyone else, because he would kick and scream and bite and everything (Morrisette, 2001)*

## 4. Personal parental impact of FASD

Given the reported challenges of managing behavioural and cognitive difficulties and poor perceived support from services, it is understandable that the carers described the personal

impact of parenting children with FASD in four of the papers. Caregivers in Brown (2007) stated that they would consider ending a foster placement if they found it was *too much work* to manage the child, when *their family was threatened* or they *feared for their own safety*.

#### 4.1 Feeling judged

Caregivers reported feeling judged about their parenting skills and their personal characteristics when advocating for their child. A carer in Chamberlain *et al* (2016) described how she felt others perceived her when trying to support her child;

*...we had a lot of GP's and I think they were just thinking I was a neurotic mother*

*I was an annoying mother I guess because I would advocate*

#### 4.2 Negative impact on the family

Within foster placements and adoption, the child is invited into the family home and therefore the family as a whole must manage any challenges the child presents with. Unfortunately, caregivers have reported family disputes and separation as a result of the additional stress in the family home.

*A lot of families have broken up over it...it's exhausting and I think it is one of the things that precipitated the divorce in the family (Morrisette, 2001)*

#### 4.3 Exhaustion

Three of the papers discussed the exhaustion felt by the carer, which may influence the reported family break downs and the explicit need for support from others and professionals. Brown *et al.* (2007) described the high needs of the children leading to *burnout*. The issue of burnout was reflected throughout the other two studies;

*She pushes and pushes until it's no longer fun... she doesn't know when to turn the limits off (Granitas, 2004)*

*Sometime I have to go for a ride because I just can't deal with it. I have to take a break. (Gardner, 2000)*

## **1.5 DISCUSSION**

To buffer against the neurological difficulties and the development of secondary disabilities associated with FASD, it is vital for these children to have stability and structure in their home and social life (Streissguth & Kanter, 1997). As there is a large proportion of children with a diagnosis of FASD in care of Social Services (Pelech *et al* 2013, Fast & Conry, 2009), it is suggested that foster and adoptive parents play a crucial role in the long-term development and outcomes for these children. This review sought to explore the experiences of non-biological caregivers of children with FASD. From the analysis of five research papers, four super-ordinate themes were identified: development of knowledge and understanding of FASD; support from professionals and others; child's presenting difficulties; personal impact of FASD on parents. Overall this review highlighted the barriers and challenges of sustaining this stable home environment, the strain on caregivers and the lack of wider knowledge to sufficiently support these families.

The current research suggests that non-biological carers feel unsupported which may have devastating consequences on both the parents and the children. Predominantly, this research suggests that there is little understanding of FASD and a varied degree of knowledge and support from professionals and specialist services. This leaves the carers in a vulnerable position of learning about this complex condition through lived experience, which may cause

a considerable amount of distress and disruption to the family unit. It is assumed that this may be the cause of multiple placement breakdowns within foster care. This research highlights that parents must be willing to make adaptations to their lives in order to accommodate and effectively support their child. However, this is not confined to the home, and carers often have to advocate for their children in other services, including educational settings. Furthermore, the challenges faced by carers suggest that they begin to feel judged by others who may not have a full understanding of FASD and the accompanying difficulties. It may feel that the parent not only has to battle at home to maintain a stable environment, but has to battle to advocate and educate society to accept the child. Caregivers must also adapt their parenting style to be able to effectively manage the cognitive and behavioural difficulties that are common in FASD. Failure to adapt, or a lack of advice and support from professionals, may lead to increased vulnerability for all those involved in the child's care, parental exhaustion and burnout. This study suggests that the stress experienced can have devastating consequences for the carers, including placement breakdowns, disrupted family life and marital separations. The breakdown of the family unit contributes to a cycle of negativity and instability in the life of the child. This may be considered the precipitating factors for the increased risk of secondary disabilities and perpetuating the continuation of negative life experiences through to adulthood.

The overall themes from these studies paint a bleak picture of the challenges non-biological carers experience living with children with FASD. However, the literature suggests that although there are specific deficits associated with FASD, the experiences of these carers may not differ significantly to non-biological carers of children with different diagnoses. Watson *et al.* (2013) investigated the stress experienced by parents, including non-biological carers,

of children with ASD or FASD. The results showed that both groups of parents experienced similar stressors, including the challenges of managing the diagnostic process and dealing with behavioural issues. However, this study did reveal distinct differences. With regards to behavioural difficulties, parents of children with FASD described difficulties in managing their children's illegal behaviours, whereas parents of children with ASD focussed more on their children's tantrums and anxieties. The children in this study had an age range between 1 year and 36 years old, which may explain the differences in the behavioural challenges. With regards to the diagnostic process, both groups described challenges, consistent with much of the literature (Caley et al. 2009; Davis & Carter, 2008). However the parents of children with FASD described specific frustrations. They reported on the difficulties of professional's lack of understanding of FASD and the challenges in obtaining a diagnosis in the absence of maternal drinking information and distinct facial features. Both groups discussed the importance of informed medical practitioners who listened to them and did not dismiss their anxieties.

Children with and without disabilities are placed in foster and adoptive care for a number of adverse reasons, often including interpersonal traumas such as physical abuse, sexual abuse, emotional abuse, neglect, and domestic violence (Kisiel et al., 2009). Those in the Welfare Systems may have experienced multiple traumatic events, often the precipitant for the child being removed from their parents (Oswald *et al*, 2010). A study by Greeson (2011) concluded that youths in foster care who had a history of trauma were more at risk of internalizing behaviour problems, posttraumatic stress, and having at least one clinical diagnosis than those without these histories. Furthermore, with the removal from their parent and the possible multiple placements, it is pertinent to consider the children attachment patterns, which is often exacerbated by the loss and separation often associated with foster care.

Children who struggle to form attachment to a caregiver in their early years may develop poor self-image, and experience feelings of shame, anger, anxiety and despair (Hughes, 2004). They may struggle to form secure relationships with others, and this may manifest in destructive tendencies which may precipitate placement breakdown (Hughes, 2004). The five studies included in this review did not include any information on the possible traumatic backgrounds of these children. The histories of the children remain unknown, and therefore the challenges the parents are experiencing may not be explained by FASD alone, but as part of a complex and potentially traumatic picture that has influenced the typical social and emotional development of the child.

In a similar respect, the literature suggests high likelihood of comorbid diagnoses in individuals with FASD. Popova *et al* (2016) conducted a systematic review of comorbidity of FASD. From data recorded in 127 studies, the results from this review revealed 428 comorbid conditions co-occurring in individuals with FASD, spanning across 18 of 22 chapters of the ICD-10. The most prevalent conditions were malformations, deformities, and chromosomal abnormalities. This review also highlighted the high prevalence of comorbid mental and behavioural disorders (between 50% and 91%) including conduct disorder, receptive language disorder, chronic serous otitis media (middle ear infection), and expressive language disorder. Again, this evidence of comorbidity in the literature questions whether the challenges faced by caregivers in this review are caused specifically by FASD as the results suggest. One paper included in this review (Chamberlain, 2016) noted 'previous diagnoses' the children in the study had received, but it is unclear if these are previous misdiagnoses or comorbid difficulties.

### **Links to previous findings**

Domeij *et al* (2018) systematically reviewed 18 qualitative studies on biological parent, non-biological parents and individuals with FASD. This review included three studies that were included in the current review (Chamberlain, *et al.* (2016), Gardner (2000) and Granitsas (2004). The analysis of Domeij *et al* review yielded some subthemes that were similar to the current study. For example, the current theme of ‘child’s presenting difficulties’ was similar to Domeij *et al* theme of ‘experiences among parents raising children with FASD’. These themes both detailed the difficulties of managing the disabilities of the child such as memory, comprehension, aggressiveness, and destructive behaviour. This theme of managing difficulties is also supported by a number of previous qualitative studies (Brown and Bednar, 2004; Morrisette, 2001; Gardner, 2000; Sanders and Buck, 2010). It suggests that the management of FASD symptoms is one of the most difficult implications of successful parenting. Domeij *et al* (2018) discusses issues of ‘stress and isolation’. They stated that living with a child with FASD burdens the whole family and parents report that they have to adapt their parenting strategies to their child’s specific needs, all of which the current study supports. Their review stated that parents often reported on the lack of knowledge among professionals in health care, social care and educational systems, causing families to feel unsupported and misunderstood by society. The current study supports this outcome, highlighting the importance of support and knowledge from professional services to help non-biological carers. They reported the dearth of specific services to support families underpins the strain on carers with children with FASD, regardless of whether the carers are biological or non-biological (Mukherjee *et al*, 2013; Sanders and Buck, 2000; Brown and Bednar, 2004; Brown, 2015; Whitehurst, 2011).

## **Limitations**

The current review focussed on the experiences of non-biological carers. However it is possible that there are distinctions in experiences and personal impact between foster, adoptive and kinship carers when considering the scope of their parental role. Future research could look at the differences between these parenting groups when raising a child with FASD, to distinguish any unique needs and support required. A further limitation of this review is that all the studies with non-biological carers were conducted within Western cultures which may restrict the generalisability of findings to other family cultural expectations. It is noted that due to the limited research in this area, a small number of studies were included in this review, with three of the studies being conducted with the same authors and the same sample of parents. Furthermore, the sample sizes within four of the papers were small, which may not be fully representative of the wider population. As all the included studies are qualitative, translations will have been influenced by the authors' own perceptions and values, and as such will be one of several possible ways of interpreting the data.

A further limitation of this review is the potential risk of bias within the five included papers. In each of the papers, participants were approached by the lead researchers, either through phone calls, support and parent groups, and parents who had participated in a previous developmental study. It is possible the parents who opted into each of these studies did so because they were having particularly difficult experiences with their children with FASD. Fetal alcohol related difficulties are on a spectrum, and it is possible that the parents in these studies represent children who are on the more severe end of spectrum, and therefore not fully representative of overall parenting experiences. Without additional information provided about the severity of alcohol related difficulties, comorbid diagnoses, and historical background of these children, there is a real risk of FASD being misrepresented in the

research. This may perpetuate the stigma attached to children with FASD and runs the risk of future non-biological carers opting not to support a child with this diagnosis.

### **Implications**

The literature shows that FASD is usually accompanied with severe cognitive and behavioural challenges that place a large and unsustainable pressure on the shoulders of carers. For the children to thrive, the literature suggests a stable family environment. For this to be achieved, prioritisation of FASD awareness at a government level should be addressed, raising awareness at a societal level and reducing the stigma attached to the disorder. For example, Canada is leading the way in their commitment and investment to the diagnosis and management of Fetal Alcohol Spectrum Disorders. The Canadian Government developed programmes (for example 'Healthy Child Manitoba') after recognising that FASD was the leading cognitive disability and the financial impact FASD has on education, health and social care (Watt, 2012). The programmes in Manitoba have included raising community awareness of FASD through a community coalition coordinator. There is a strong focus on prevention and clear messages and education for pregnant women regarding alcohol consumption. Specialist assessment and diagnostic services have been developed to provide support and reduce stigma attached to the disorder (Watt, 2012). Governments could learn from and adopt this 'top-down' approach to filter knowledge and training to professionals, specialist services and education systems. This will help carers feel supported in their efforts to raise children with FASD, with a hope in reducing placement and family breakdowns.

## **1.6 CONCLUSION**

In conclusion, this review sought to understand the experiences of non-biological caregivers raising children with FASD. There were four themes identified that outlined the journey of these carers and children through foster care or adoption, and the challenges experienced along the way. The first theme 'development of knowledge and understanding of FASD' suggested that the parents felt initially in the dark in understanding their child's condition. The literature suggests that the parents developed knowledge through their experiences and adapt their home life to accommodate their child. Having a better understanding of the condition, the carers spoke about their fears about their child's future. With a lack of professional knowledge and specialist services, carers report often finding the presenting cognitive and behavioural difficulties too difficult to manage, leading to placement breakdowns and stress in the family unit which may lead to disputes or separation.

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## **CHAPTER 2: MAJOR RESEARCH PROJECT**

### **Social Workers' experiences of supporting with children exposed to alcohol in utero; an Interpretative Phenomenological Analysis**

Word Count: 9222 (including quotes)

*Prepared in accordance with guidelines for submission to the Journal of Research in  
Developmental Disabilities (Appendix A)*

## **2.1 Plain English Summary**

### **Background**

Fetal Alcohol Spectrum Disorder (FASD) is a descriptor term for the permanent, life-long disabilities resulting from maternal consumption of alcohol during pregnancy. Children within Social Services are a particularly vulnerable and high-risk population due to adverse environmental circumstances (Lange *et al*, 2013). Research into children looked after by Social Services has found that disabled children (which may include children with FASD) were adopted after a longer period of time in comparison to non-disabled children (Baker, 2007). Cousins (2009) stated that disabled children “are hard to place” and a diagnosis of a disability would “put adopters off”. This highlights the importance of Social Workers having a sound understanding of FASD, to ensure they can provide sufficient support.

### **Aims**

The study aimed to understand and explore Social Workers’ experiences of supporting children with a diagnosis of FASD. It is hoped that the results of this study may enhance the understanding of the impact the FASD diagnoses has on the professionals supporting these children.

### **Method**

The study was conducted with five Social Workers working in Adoption Social Services who had prior experience of supporting children with FASD. Each participant was interviewed for 45 minutes about their experiences, and their interview was recorded. Audio recordings were transcribed verbatim, and the data was analysed using a technique called Interpretative Phenomenological Analysis. All data was recorded according to local ethical guidelines. Social Work Assistants were excluded.

## Results

There were four main themes identified from the analysis; lack of knowledge and awareness; dealing with uncertainty; impact of the diagnosis and vulnerability. There were several distinct smaller themes identified within each main theme.

## Conclusion

The study revealed that the adoption process for children with FASD is a complex journey, combining the attitudes and behaviours of the Social Workers and the potential adoptive parents. It is clear that the variable levels of knowledge and training, the vulnerability experienced during this process and the uncertainty they felt about the diagnosis could all influence the child's future adoption. The findings are important because they demonstrate the need to focus on the child's diagnostic journey across both Health and Social Care settings, to ensure consistency in the support offered to the child. The findings highlight the potential negative attitudes, lack of understanding and stigma attached to the FASD diagnosis, placing these vulnerable children at a further disadvantage.

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## **2.2 ABSTRACT**

### Background

Children with a diagnosis of Fetal Alcohol Spectrum Disorder are a vulnerable population, particularly within Social Services. With regards to adopting these children, there is evidence that children diagnosed with a disability can be more challenging to place due to adopter preferences.

### Aims

The study aims to understand and explore Social Workers experiences of supporting children with a (suspected) diagnosis of Fetal Alcohol Spectrum Disorder within Adoption Social Services.

### Method

Using semi-structured interviews, five Social Workers were recruited from Adoption Social Services in the West of Scotland. Each interview was transcribed verbatim and data analysed using Interpretative Phenomenological Analysis.

### Results

There were four superordinate themes identified from the analysis: lack of knowledge and awareness, dealing with uncertainty, impact of the diagnosis and vulnerability. Three separate experiences of the adoption process were identified: the Social Workers experiences and the perceived experiences of the adoptive parents and the child with Fetal Alcohol Spectrum Disorder.

### Conclusion

The attitudes, experiences and decisions of the Social Worker affect the adoptive parent's journeys, and ultimately the future of the child. The findings are important because they demonstrate the need to focus on the child's diagnostic journey across both Health and Social

Care settings to ensure consistency in the support offered to them, in line with the Scottish initiative of Health and Social Care Partnership.

What this study adds

The findings highlight the potential negative attitudes, lack of understanding and stigma attached to the Fetal Alcohol Spectrum Disorder diagnosis, placing these vulnerable children at a further disadvantage.

## 2.3 INTRODUCTION

### Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is the 'umbrella-term' given to a group of permanent, life-long disabilities resulting from maternal consumption of alcohol during pregnancy. It is estimated that, worldwide, FASD may have a prevalence rate of up to 5 in every 100 births (Popova *et al.*, 2016), making it the most common non-genetic, preventable cause of developmental disability and birth defects (May & Gossage, 2001). This estimated prevalence is five times higher than the number of estimated children and young people living with Autism Spectrum Disorder (ASD) in Scotland (The Scottish Strategy for Autism).

Children with FASD have atypical neurodevelopmental difficulties including deficits with sensory-motor abnormalities (Connor *et al.* 2006), attention, cognition and executive function (Kodituwakku *et al.* 2001), academic achievement (Mattson *et al.* 1997), social skills (Greenbaum *et al.* 2009), language (Becker *et al.* 1990) and memory (Uecker & Nadel 1996). However, the diagnostic process of FASD remains challenging as each child's presentation relies on the timing, frequency, and quantity of alcohol exposure (Astley, 2004), creating a huge variation in symptomology. The dearth of research has resulted in poor knowledge and unclear evidence-based professional practice (Chudley *et al.*, 2005, Mukherjee *et al.*, 2006). This may result in potential misdiagnosis, such as Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder (O'Malley & Nanson, 2013) and may limit opportunities for appropriate early intervention. Furthermore, misdiagnoses may lead to secondary disabilities, for example, mental health problems and inappropriate medical, psychological and social interventions (Chudley *et al.*, 2005). Long-term, misdiagnosis may cause adults to be poorly

understood and supported, leading to potential marginalisation and social maladjustment (Fagerlund *et al*, 2011).

### FASD and Social Services

There is evidence of a direct predictor between the severity of FASD and the likelihood of these children being placed into Social Services. Kvigne *et al* (2004) studied 78 children with Fetal Alcohol Syndrome (FAS) in North America. They concluded that children with a diagnosis of FAS were 64 times more likely to be removed from their mother compared to children with no diagnosis. The research also highlights the increased risk of mothers who have a diagnosis of FASD consuming alcohol during their pregnancy. Streissguth *et al* (1996) investigated a sample of 30 mother with FASD and found that 40% of these women drank alcohol during their pregnancy. Of this sample, 17% of their children had a diagnosis of FAS, 13% had a suspected diagnosis of FASD, and 57% of children had been removed from their care. Studies from Canada's Child Welfare Service have estimated that approximately 6% of children have Fetal Alcohol Syndrome (FAS), and 16.9% of children would meet FASD diagnostic criteria. (Lange *et al*, 2013).

### FASD, Parenting and Adoption Services

In the UK, children removed from their biological parents remain under the care of the Local Authority. During the initial stages of adoption, Social Services will help support the transition into a new home. After 10 weeks of the child settling in to their new home, the adoptive parents apply for an Adoption Court Order, transferring all parental rights and responsibility over to them. At this point, the child is no longer considered under the care of Social Service, and may have little to no contact with the Local Authority. Adoption is permanent, and the

child assumes all rights as if they were a birth child (British Adoption and Fostering Association, [www.corambaaf.org.uk](http://www.corambaaf.org.uk)). Unlike fostering, adoptive parents do not receive an allowance or fee, however there is limited funding to help support families in need (UK Government, [www.gov.uk/child-adoption](http://www.gov.uk/child-adoption)).

The British Association for Adoption and Fostering's (BAAF) briefing paper on 'The adoption of disabled children' refers to 'disability' as a "range of physical and sensory impairments, learning disabilities or emotional and behavioural problems" (Grant & Thomas, 2013). FASD can be considered under this definition. Research into children within Social Services has found that disabled children were adopted after a greater delay compared to non-disabled children (Baker, 2007). Furthermore, children in foster care with learning, but no other impairments, were less likely to be adopted than other children, even after age was taken into account (Baker, 2007). Baker (2007) sheds light into the complexities of parenting children with FASD, which may suggest why potential parents are hesitant to adopt these children. Potential parents will acquire the understanding that FASD is life-long brain damage, and the affected individuals may require specialist care. With this comes additional financial commitments and the extended role of 'parenting'. Brown (2015) goes further to explain the practical challenges the potential parents will consider prior to proceeding with adoption of a child with FASD. Many children with FASD have high energy levels, an inability to keep themselves safe and poor immune systems, requiring constant management and supervision. Brown (2015) explains that parenting a child with FASD is emotionally as well as physically demanding. These children are likely to meet their developmental milestones later than typically developing children, for example, walking and toilet training. Children with FASD often have well developed verbal communication, however this may mask their relatively

underdeveloped comprehension. This leads to unrealistic pressures being placed on the child and subsequent behavioural difficulties. Children exposed to alcohol in utero often have difficulties with their fine motor skills and require long-term support for tasks such as dressing. They can often be regarded as clumsy children due to difficulties with spatial awareness. Brown (2015) continues to describe the behavioural difficulties parents often report. This can cause a huge stress on the parents. They are often impulsive, hyperactive and have sensory processing difficulties which can manifest in emotional eruptions. When faced with the reality of the complexities of raising a child with FASD, adopters may realise these children do not fit with their dream of family life. Instead, the family must be prepared to learn alternative strategies for the child, be prepared to provide long-term support and advocate on behalf of their future child. Brown (2015) describes the importance of adoptive parents receiving training and long-term support, as well as ensuring the parents have a supportive family network to help them manage their own stress. Cousins (2009) stated that across the UK, disabled children are “hard to place” and that Social Workers were concerned that a diagnosis of a disability would “put adopters off”. Social Workers involved in the adoption process must ensure these children are placed with appropriate, stable family environments. Cousins (2009) also states the importance for Social Workers to ‘show the “whole” child to prospective adopters in a way that is honest, clear and personal’ (Grant & Thomas, 2013, Page 8).

### **Justification for the Research**

Given the increased recognition of FASD internationally, it would be beneficial to explore the attitudes and experiences of the professionals supporting these children. Social Workers’ experiences are a key insight into how the FASD diagnoses may be perceived, managed and

supported in Social Care. It is recognised that there is a large proportion of children with FASD in foster care, however the family environment, parental commitments and legal obligations between foster and adoptive caregivers differ significantly. This may influence the experiences of Social Workers supporting these children. For this reason, Social Workers from only Adoption Services were recruited.

## **Aims**

The aim of the current study is to explore the experiences of Social Workers supporting children with a diagnosis / suspected diagnosis of FASD within Adoption Social Services. This study explores the attitudes and knowledge of the Social Workers, and how both the professionals and the children can best be supported through this complex process.

## **2.4 METHOD**

### Ethical Issues

This study recruited five social workers within Social Services. Consent was obtained from Social Service Management to interview the participants. Ethical approval was obtained through the University of Glasgow. A letter of approval can be found in Appendix G.

### Design

An Interpretative Phenomenological Analysis (IPA) methodology was used to explore and analyse the data. IPA is a qualitative approach to research which aims to explore the lived experience of participants, and the meanings they attach to these experiences. (Smith & Osborn, 2008). Table 1 outlines the inclusion and exclusion criteria for the study.

Table 1: Inclusion and Exclusion Criteria

Inclusion	Exclusion
- Social Workers within Adoption Social Services	- Non-English Speaking
- Experience with supporting children with FASD	- Social Work assistants
- Able to provide informed consent	

### Sample

IPA requires a homogenous sample of participants who can provide rich and meaningful data about their lived experience of the topic. A small number of participants is considered appropriate to fulfil the requirements for IPA research to ensure rich analysis (Smith *et al*, 2009, Smith & Osborne, 2008). Additionally, due to the small number of Social Workers working within adoption teams within the specified area, a small sample size was considered sufficient for this study.

This study recruited Social Workers from one Social Work Service in the West of Scotland; four within an Adoption team, and one within a Kinship Care team. Careful consideration was taken as to whether experiences from the Kinship Care Service should be included within the study. However initial conversations revealed the Kinship Care Social Worker's experiences were of a similar nature to those within Adoption Services, and as such, was not excluded. The participants consisted of four females and one male. For the purpose of protecting the Social Workers' identities, pseudonyms have been used. Furthermore, all the pseudonyms are female to further protect the identity of the one male participant. The Social Workers had between 7 and 18 years working in Social Care, with an average of 14 years' experience. All participants had prior knowledge of FASD and had previously or currently worked with

children with a diagnosis, or suspected diagnosis of FASD. Experience of children with 'suspected' FASD were included i.e. children who have the specific deficits and confirmed exposure to alcohol in utero, but who have not yet received a formal diagnosis. Experiences with these children have been included due to the under-diagnosis of FASD, or they may currently be in the diagnostic process.

### Recruitment

Social Workers' experiences were specifically selected for this study for two reasons. Firstly, Social Workers are at the forefront of the Social Care system, working with some of society's most vulnerable groups. Their understanding and attitudes may directly influence the journeys of children entering into Social Care and their experiences are therefore invaluable. Secondly, anecdotal evidence collected by the research supervisor suggested the Social Work team had expressed their concerns about the lack of support with regards to post-diagnostic management. They had suggested that their role was negatively affected by the increase rate in FASD diagnoses across the West of Scotland. It is possible the participants opted into this study as a result of feeling overwhelmed, seeking additional support and for an opportunity to have their voices heard, rather than the researchers aims of exploring the meaning the participants attach to their experiences.

The study's supervisor, a specialist Clinical Psychologist within an FASD team, was responsible for the initial liaison with the adoption team, and supervision of the recruitment procedure. Following initial discussions of the study's aims with the Social Work manager, the manager agreed to email all Social Workers within the Social Service department. This email attached the Participant Information Sheet which outlined the purpose and aims of the study as well

as what participation would entail (See Appendix I). This email was sent to eight Social Workers in the same locality, four within the Adoption Service and 4 within the Kinship Care Service. Social Workers who had experience of FASD indicated their interest to participate via email to their manager. The names of these participants were forwarded to the main researcher via email. The recruitment process was conducted over one month.

### Semi-Structured Interview Design

A semi-structured interview was developed alongside a specialist Clinical Psychologist working within the FASD team. A literature review was conducted and considered in conjunction with Social Worker's personal narratives of supporting children with FASD within Adoption Social Services. Recurring themes and areas of interest were identified to help structure the development of an interview schedule, using broad, open-ended questions. Additional probes and specific questions were used where necessary to encourage participants to elaborate on what was being said. In line with the style of IPA questioning, the questions were developed with no attempt to test a predetermined hypothesis. However, anecdotal information gathered prior to recruitment regarding the concerning experiences of the participants may have possibly influenced the spirit in which these questions were presented to them. Each interview lasted approximately 45 to 60 minutes, held within the Social Work Department. Prior to the interview commencing, the researcher asked the participant to not disclose personal information or histories of the children to protect their right to confidentiality. It is important to note that the current research shows that there is a high prevalence of comorbid mental and behavioural disorders (Popova *et al*, 2016), and are more likely to be affected by physical, sexual and emotional abuse, neglect, and domestic

violence (Kisiel *et al.*, 2009). This was not discussed as part of the interview, and is considered a limitation in this study. The interview schedule can be found in Appendix H.

### Procedure

The main researcher liaised via email with the identified Social Workers and they were given an opportunity to contact the main researcher via telephone or email to ask any questions about the study. Individual interviews were then arranged within the Adoption Social Service Department. Prior to the interview commencing, the Participant Information Sheet was reviewed again to ensure they understood the purpose of the study, what their participation would entail and they were encouraged to ask any further questions. Written informed consent was obtained for participation in the interview, audio recording of the interview and use of the data collected before beginning the interview (see Appendix J). The interviews were recorded using a Sony Digital Dictaphone and following the interview, all recordings were encrypted and transferred to a Glasgow University computer in password protected files.

### Data Analysis

The qualitative data was analysed using Interpretative Phenomenological Analysis (IPA). Standards for conducting good qualitative research such as sensitivity to context, rigour and transparency were considered whilst doing this (Yardley, 2000). To ensure concepts were constructed from participants' personal perspectives, the transcripts were initially analysed individually and ideographically. The process then began by reading and re-reading the transcript to familiarise the main researcher with the accounts. Line by line coding was then conducted to ideographically construct individual themes. To increase methodological rigour

and adherence to IPA, the initial codes represented different levels of interpretation - descriptive, linguistic and contextual. To ensure the double hermeneutic principles of IPA as incorporated at each stage of analysis (Smith *et al*, 2009), there was continuous movements back and forth through the transcript to reflect on what had previously been said. In this way, meaning was interpreted within the specific text whilst considering the transcript as a whole. Each transcript was analysed separately, and cross cutting themes were constructed by identifying comparisons and contradictions of both the idiographic and the shared nature of the themes across all the participants. Several of the transcripts were reviewed by the supervisors of this research to ensure similar themes were identified.

### **Research Reflexivity**

IPA acknowledges the impact of the researcher upon the analysis, with the researcher's experience facilitating or hindering the quality of analysis (Smith & Osborn, 2008). The main researcher's background as a Trainee Clinical Psychologist is important to consider, particularly the prior interest in FASD and connections to the specialist team in Scotland. As a result of previous discussions within this team regarding Social Worker's narrative anecdotes of FASD, the main researcher was aware that she had developed certain assumptions and biases before entering into this study. She suspected that Social Workers would be struggling to manage the challenges of FASD, would have little resources for support, and as a result would feel frustrated about the additional demands on their service. In line with IPA, the main researcher endeavoured to approach the interviews with an open-mind and remained mindful of a potential biasing within the questioning. During analysis, the researcher actively logged personal thoughts in a reflective journal to ensure reflexivity. Rather than considering the researcher's education, training and interests as hindering the analysis, it is acknowledged

that these are fundamental to developing a subjective interpretation of lived experiences and in the development themes.

## **2.5 RESULTS**

When analysing the experiences of Social Workers within the adoption process, it became clear that this process involves three separate accounts; the personal experience of the Social Worker, the perceived experience of the adoptive parent and the perceived experience of the child with FASD. It has been helpful to think about these accounts in terms of three separate complex journeys, and how these journeys interact with one another through the adoption process.

### Superordinate and subordinate themes

There were four superordinate themes that emerged from the data, consistent across the three parties involved in the adoption process;

1. Lack of knowledge and awareness
2. Managing uncertainty
3. Impact of the diagnosis
4. Vulnerability

Under each of these superordinate themes are several subordinate themes (Table 2) Quotations from the Social Workers' accounts are used to illustrate the themes in greater depth.

Table 2. Superordinate and subordinate themes relating to Social Worker experiences, and adoptive parent and child's perceived experiences of the FASD diagnosis within adoption services.

Subordinate Themes				
Superordinate Theme		Social worker	Adoptive Parent	Child
	<i>Lack of knowledge and awareness</i>	Lack of knowledge Need for training	Learning Adapting	Perceived inevitability of life's journey
	<i>Managing uncertainty</i>	Pressure for answers Protection Adopters	Risk in adopting	Development of difficulties Diagnostic challenges
	<i>Impact of the diagnosis</i>	Fear Emotional Impact	Reduced blame Distancing from child	Reduced blame No adoption
	<i>Vulnerability</i>	Emotional distancing	Desperation for a child Loss of an unknown child	Labelled negatively Lack of support Rejection from others

### **1. Lack of knowledge and awareness**

All the Social Workers had knowledge of FASD, risks of alcohol consumption during pregnancy and the cognitive and behavioural difficulties the children may experience. However, an emerging theme of 'lack of knowledge and awareness' was evident throughout each transcript. There are distinct conceptual differences in subordinate themes within each of the three journeys, as indicated in the table above.

#### ***Social Workers: Lack of knowledge and a need for training.***

Every Social Worker talked in depth about their developing knowledge about FASD over time and resourcing information for adopters. However, there appeared to be an underlying concern that they did not yet have enough information or knowledge to sufficiently manage the demands of supporting these children within a social work context.

*I think as a team we're interested in thinking what we can learn and how we can support people more effectively. But there's a bit of you that thinks 'oh my goodness this is an absolute minefield' and there's been conversations in the team where we say 'how on earth are we going to manage to just respond to this' (May,P2,L13)*

Contextually, the above quote captures this Social Worker feeling overwhelmed when she felt unequipped to manage aspects of FASD. Linguistically, the use of the word 'minefield' suggests a sense of fear towards the diagnosis, and sense of having to tread carefully into an unknown. This is further reflected in the following quote;

*We're finding, feeling our way through it, and I hope that there will be more information coming, erm, but just now I suppose going back to the fact, it feels like it's, it's known unknown (May,P2,L23)*

Again, on a linguistic level it is suggested that the Social Worker feels as if she is in the dark, 'feeling' her way through the diagnostic information. There is also a sense of hope within this quote that as the research develops, she will learn more information and become more knowledgeable about this topic. This theme of 'not knowing enough' information was shared consistently throughout each transcript.

*It's unknown about it, because they're [adoptive parents] saying 'what do you know about it?' Well really, not a lot (Jennifer,P10,L34)*

### ***Adoptive Parents: Learning and adapting***

In the perceived experiences of the adoptive parents, the theme of lack of knowledge was also evident. The adoptive parent's dearth of knowledge was emphasised by their need to

not only learn about the diagnosis, but adapt their expectations, needs and lifestyles to accommodate the diagnosis. Every Social Worker discussed their role to support parents to adapt, and the difficulties this often brought.

*I try and prepare them [adoptive parents] for the worse scenario, you know, this is what you might be presented with. This is what you might be presented with in 10 years' time. This is no gonna be a walk in the park. This is not like parenting your own children. (Margaret,P5,L30)*

The above quotes emphasises the Social Workers' role in trying to prepare the adoptive parents for a child that may differ from their current and long-term expectations. The following quote highlights the need for adoptive parents to adapt their own expectations;

*What adopters want is a child to love and look after and maybe push a pram. The instinct is there and they don't really want the issues, albeit that, that's what they're getting. (Jennifer,P11,L26)*

This shows the perceived desperation for these adoptive parents to have their own child, a typical family ideal. It highlights the challenges faced by Social Workers to work with this expectation, to prepare the family for a different experience.

### ***Child: Perceived inevitability of their life's journey***

The FASD diagnosis brings a sense of inevitability about their journey through the adoption process, frequently ending in the child's adoption process being terminated.

*See as soon as soon as they've got a diagnosis we kinda go 'oh well that's them, oh we'll go through the motions but they're not getting adopted' (Heather,P4,L31)*

*I just think 'awww here is another poor wee child. This is not going to be straight forward'. Their life is already set out for them. They're going to be difficult to parent. Difficult to find a family for (Claire, P3,L17)*

This quote clearly highlights the impact the diagnosis has on the child's perceived future. The feeling of empathy conveyed about the child's condition is over-shadowed by the levels of difficulties that the child will potentially present with throughout the adoption process. However, this is contradicted by a quote from the same transcript.

*I've learned things, I've been told things, I understand all that. But it's just the children are all so different and independent that that's the difficult bit. (Claire, P2,L42)*

This quote highlights the idiosyncratic nature of FASD, given that the presentation depends on the timing, frequency and level of maternal consumption of alcohol during pregnancy. Yet despite the Social Workers' understanding that every child presents differently, the children appeared to be considered diagnostically, rather than individually. This 'inevitability' may stem from a lack of knowledge about the diagnosis and lack of awareness in terms of how to support these children to live fulfilling lives with adoptive families. Furthermore, a sense of fear or anxiety towards the FASD diagnosis and what this may mean for the adopters was evident in most of the transcripts.

*If I had read it, and it was my couple I would be saying 'oh no, don't touch this, I mean look at all this... and she has a diagnosis'. I would be saying...'ohhh, you're setting yourself up here for a difficult life'. (Heather,P4,L38)*

This quote further highlights the need for knowledge and awareness of FASD. On a linguistic level, the above quote emphasises the fear or anxiety towards the diagnosis; 'don't touch this' implies that consideration of taking on this child should be completely avoided, for their own safety.

## **2. Managing uncertainty**

Uncertainty was a dominant theme across all transcripts. The uncertainty emerged in many different subordinate forms and these differed across each of the Social Workers', parents' and children's' journeys. This uncertainty seemed to be amplified by the need for knowledge and awareness.

### ***Social Worker: Pressure for answers and protection of adopters***

All of Social Workers talked about uncertainty by reflecting on the pressure they feel when they don't know what information to provide to the adopters about FASD.

*I... to put it in simple terms...you think....you feel... that you're not going to be able to necessarily provide them with the answers that they're looking for.(May,P4,L8)*

*Trying to come up with an answer, trying to solve it with people...it's horrific. It's absolutely horrendous because I think we go home at night and maybe you worry about it or stress about it, but we don't live it. (Heather,P3,L30)*

The above quotes capture the sense of trepidation and uncertainty in their role when FASD becomes a factor. Heather's quote also reflects on the emotional impact the FASD diagnosis may have on both the adopters and the Social Worker.

Alongside this sense of uncertainty about providing answers, there was also uncertainty about their understanding of the child's future development, and how this may affect the lives of the potential adoptive parents.

*Whereas Fetal Alcohol is a kinda, it's a kinda... 'oh god don't touch this'. I think that's because we don't know what's out there or what....you don't know what the prognosis is. But also you don't know what's available and there's a fear of, for us, in some ways of 'oh no, this will come back to bite us' (Heather,P5,L38)*

### ***Adoptive Parent: Uncertainty of risk involved in adopting a child with FASD***

The uncertainty surrounding the perceived experiences of the adoptive parents appears to centre on the potential difficulties the child *may* develop. Given that FASD symptoms may only emerge as the child develops, the transcripts detailed uncertainty and risk around adopting a younger child.

*I often say to people who are adopting, you know, if you look for a child as young as possible you're taking more of a gamble because you don't know how that child's gonna develop. (May,P10,L17)*

### ***Child: Development of difficulties and challenges of getting a diagnosis***

Within the narrative of the child's journey, the emerging theme of uncertainty centres on the potential development of cognitive and behavioural difficulties.

*I've worked with, have had this wee boy who has been really, really hard work, really, really... very, very difficult right from the word go, and as he's got older it's getting worse and worse. (Heather,P2,L19)*

*If the child is presenting with very difficult, dangerous behaviour, hurting another child in the family, putting themselves at risk, stranger danger, all that kinda stuff that seems to come when they start school (Jennifer,P12,L2)*

### **3. Impact of the diagnosis**

The third superordinate theme that emerged across all of the transcripts and journeys was the impact of the diagnosis. The impact on the Social Worker, the parents and the child can be thought about in terms of both positive and negative factors, often in a very contradictory manner. This may reflect the current state of overall poor knowledge about FASD, lack of adequate support and services, as well as specific expectations of adopters and their future child.

#### ***Social worker: Emotional Impact and relief***

The diagnosis of FASD within the Social Workers' journey reflects an emotional impact the diagnosis has on them, personally and professionally.

*It feels, it feels huge, it feels overwhelming, it feels stressful, uhuh, it does.*

*(Claire,P6,L10)*

*I feel devastated for them. Absolutely devastated (Heather,P6,L30)*

More specifically, at a linguistic level the Social Workers often distanced themselves emotionally from the child's journey when they were given a diagnosis. It is suggested that the emotional distancing is a form of self-care for the Social Workers, given the significant emotional impact of the decisions they make, the complexities surrounding the child's adoption process and rejection from potential adopters.

*It's not a personal feeling I have, it's about my job and I just feel sad that this is what we're dealing with (Claire,P2,L9)*

In the quote above, the Social Worker was discussing the shock and anxiety people feel around the child and the potential rejection the child may face. Linguistic analysis shows the Social Worker appeared to distance herself from the child's situation by refuting her emotions and referring back to her 'job'. This emotional distancing at a linguistic level is evident throughout all of the transcripts, often seen by laughing after verbalising an emotionally loaded account.

*They settle in to 'this is your forever family, and you'll always be here' and then that breaks down. And we've to remove them. I have only done that on one occasion, and I was crying \*laughs\* (Jennifer,P7,L8)*

*So we have to manage that feeling of, erm, trying to find the right family for a child, trying to give them enough information but then not trying to put them off.*

*And trying to hold that. \*laughs\* (May,P9,L21)*

However a child receiving a diagnosis may not always be a negative. It was highlighted through several transcripts that a diagnosis can provide a sense of relief for the Social Workers, the 'unknown' becomes 'known'.

*If they've been given a diagnosis in some ways it's a relief. Because it's almost like, well, we've got something to explain to others out there that 'this is what's wrong with this child' and don't have the same expectations, and you can work with that. (Heather,P2,L8)*

### ***Adoptive Parents: Reduced blame and distancing from child***

In the narrative of the perceived journey of the adoptive parents, again there are both positive and negative impacts to a child receiving a diagnosis. In this subordinate theme, the parents who had already adopted felt the diagnosis reduced the blame and responsibility they felt for their child's behaviour.

*So when you got a diagnosis, you thought it was a kinda breakthrough in terms of instead of a mother feeling 'I'm a rubbish parent, I can't parent this child, I don't know what I'm doing' you know they were able to stand back and see actually this is a child with a hidden disability, and 'I have to learn about that'. (Claire,P2,L21)*

However, if the child is diagnosed prior to the adoption, it is clear that this can have a negative impact on the adoptive parent's attitude to adopting the child.

*What we find is that adopters don't want to take of a child who has been diagnosed with Fetal Alcohol (Jennifer,P1,L18)*

*As soon as they read the paperwork they came back and said 'this wee girl has been diagnosed so there's no way we are taking this further' (Heather,P5,L27)*

### ***Child: Reduced blame and no adoption***

Similarly to the adoptive parent's narrative, receiving a diagnosis reduced the blame on the child for their behaviour. The diagnosis gives an understanding to their behaviour.

*I know there's all the thing about you shouldn't label a child and stuff, but I don't think it's a label. I think it's an understanding. (Heather,P9,L14)*

However, given the potential parents apparent reluctance to adopt a child with FASD, a diagnosis prior to being placed can result in their adoption process being terminated, and being placed back into foster care long term.

*I think it's quite a saddening experience because again I think what we're seeing is that this is something that would discourage people from taking on a child.*

*(May,P5,L32)*

*If the child has a diagnosis prior to adoption, the chances are that what that will mean will be the child won't be adopted. (Claire,P1,L22)*

#### **4. Vulnerability**

Each party's narrative shows an underlying exposure and helplessness within the adoption process. It is suggested that it is this vulnerability that gives way to the other super- and subordinate themes such as emotional impact, uncertainty, loss, desperation, anxiety and rejection.

##### ***Social worker: Feeling judged and self-protection***

One key element of the Social Workers' vulnerability is the weight of responsibility placed on their decisions, and the perceived judgement they receive from others about their personal reactions to these complex processes.

*I think some of the area team workers who are quite devastated by some of these things are like, 'we're quite hard', or 'I'm quite hard cause I'm, you know, I'm 'hard bitch', you know 'she's just...' you know but they don't... cause you don't, erm, put*

*all your...you can't be professional and put all your feelings on display.*

*(Claire,P9,L28 )*

It emerged throughout all of the transcripts that in response to feeling judged and confronted by emotionally challenging situations, the Social Workers have developed methods of emotional distancing, as discussed previously. This is thought to be within the context of self-care, and enables the Social Worker to protect themselves from burn-out.

*I don't allow myself to become too emotionally involved or destroyed by it.*

*(Claire,P9,L11)*

*I think that maybe Social Work tries to protect itself with an armour that's not until you step out that you realise that this job is.... (Margaret,P10.L18)*

On a linguistic level, the word 'armour' sparks particular interest, suggesting the emotional impact the Social Workers endure could be personally damaging, and their body is in need of a strong defence. It emphasises the Social Workers' need for self-protection, potentially against fear of judgement, fear of repercussion of inappropriately placing a child with FASD and fear of the diagnosis.

### ***Adoptive parent: Desperation for a child and loss***

Vulnerability emerging from the adoptive parent's narrative is that of desperation for a child that they were not able to have themselves. Several of the Social Workers talked about the emotional and often traumatic journeys the adoptive parents had been on prior to contacting the Adoption Services.

*If you think about it, before they [adoptive parents] meet us [social workers], they hope to have a birth child. And then they realise they may not have a birth child through natural means, so they go and try get help with that. And they get egg transplantation and fertility treatments and all sorts of things people do before we meet them to try and have a family. And that fails. So that hopes actually.... they have to grieve and get...come to terms with that before they even start in the adoption process. (Claire,P5,L5)*

The Social Workers frequently described 'loss' within the adoptive parent's experience as a consequence of adopting child with FASD. The loss of social support, aspirations and expectations of family life makes these parents very vulnerable.

*Basically a lot of them [adoptive parents] are saying 'we don't have a life, we've lost our life', you know, 'our family have kinda deserted us, our friends have deserted us, we're quite isolated now and we actually dread having to spend a whole day with this child' (Claire,P5,L34)*

***Child: Labelled negatively, rejected and lack of support***

The child with a diagnosis of FASD was described as being vulnerable within the adoption process. The diagnostic label itself offers a contradiction in how it affects the child's vulnerability within families and society. Without the diagnosis, the Social Workers suggested the child would be inappropriately negatively labelled.

*If you can't say 'oh my child has a disability', which in some ways would be easier, you're kinda left with it like 'this naughty child' or 'this badly behaved child' or, you know? They become labelled in a negative way. (Heather,P9,L3)*

Furthermore, without a diagnostic label it was suggested they may be rejected from educational settings and society.

*I am actually really concerned in terms of... I think we are gonna have lots of children out there who are really damaged, and you know, are gonna struggle to function in society because of FASD (Margaret,P11,L34)*

A further vulnerability is the apparent lack of support for the children who do receive a diagnosis, and a lack of early interventions and professionals trained to help these children and their families manage the diagnosis and symptomology appropriately.

*You know, Autism or something then they would get the right support from the disability team, how best to manage that child. If its Fetal Alcohol, you know, they would [social workers] be going back to the book and saying, 'here's what we think you need to do now' (Margaret,P4,L11)*

## **2.6 DISCUSSION**

This study has shown that the attitudes, experiences and decisions of the Social Worker significantly affect the adoptive parent's journeys, and ultimately the future of the child. This study used IPA to explore the experiences of Social Workers supporting children with FASD. Analysis revealed four superordinate themes: lack of knowledge and awareness; dealing with uncertainty; impact of the diagnosis and vulnerability. Three separate experiences of the adoption process were identified: the Social Workers experiences, and the perceived experiences of the adoptive parents and the child with FASD.

The Social Workers described their need to develop their knowledge of FASD, and portrayed an awareness of knowledge they did not possess. Rostill-Brookes *et al.* (2011) study of

placement breakdown in foster care supported this finding describing Social Workers working with FASD as feeling 'disempowered, overwhelmed and blamed'. Much of the literature supports the Social Workers' reported need for training. Caley *et al.*, (2008) interpreted 1902 self-reported questionnaires of a range of professionals in the child protection services. 46% of respondents were unable to identify FAS facial features and 85% felt unprepared to manage the care needed for these children.

Within the perceived experiences of the adoptive parents, there was a strong theme of them having to learn and adapt to the FASD diagnosis. Similarly, Coons *et al.* (2016) IPA study of 84 parents and caregivers supports this within their theme 'understanding FASD' describing the need to learn more about the FASD diagnosis to advocate on their child's behalf. With reference to the current study's theme of adapting, adoptive parents may start their adoption journey with a perceived ideal of the perfect child and have to adapt their expectations and lifestyle to accommodate the children. This was coupled with a sense of loss of the child they had expected. Sanders and Buck's (2010) thematic analysis of 11 foster, adoptive and biological parent's experience of FASD described similar experiences under their subordinate theme of 'grief', where the parents' hopes and dreams are vastly different to the reality of raising a child with FASD. Recognising the adopters' journey as emotional and very stressful was highlighted in Sanders and Buck (2010) study. It was suggested that if a child is already placed within the family, the diagnosis of FASD reduces the blame of the parents, providing relief. The current study also highlighted the perceived vulnerability of the adoptive parents which is evident throughout the literature. For example, the literature highlights the strain placed upon marriages (Morrisette, 2001) and the significant negative impact of FASD on family members' feelings, mental health, and relationships (Sanders and Buck, 2010).

Furthermore, the parenting challenges of managing behavioural difficulties in children with FASD is very demanding and can increase stress and interfere with self-care (Brown, 2004).

Within the child's narrative of perceived experiences, the lack of knowledge and potential fear of the FASD diagnosis of those around them resulted in a perceived inevitability of their journey. Despite the professional's understanding of the idiosyncratic symptomology of children with FASD, accepting the likely negative trajectory appeared to, paradoxically, offer a sense of containment. Similar themes depicting children's anticipated trajectories, being 'doomed to fail' and 'get into trouble in one way or another' can be seen within the literature (Ryan and Ferguson, 2006). However, being undiagnosed or misdiagnosed can lead to the child being negatively labelled as 'naughty' or 'defiant' leading to rejection from society. Ryan and Ferguson's (2006) study described the difficulties children have in escaping the social and cultural stigma that comes with the FASD diagnosis, and supports the current study's suggestion that receiving a diagnosis did not automatically lead to better support or more services. The current study suggests that the diagnosis of FASD may influence the likelihood of the child being adoptive, which supports Cousins (2009) statements that disabled children are "hard to place" and that Social Workers were concerned that a diagnosis of a disability would "put adopters off".

The participants in this study were all keen to talk about their experiences of supporting children with FASD. Understandably, the majority of the experiences they wished to discuss were the times they had felt overwhelmed, under resourced and with families in crisis. It became clear in the early stages of the interview process that there may have been differences in the intended aims for the researcher and the participants. It is felt that these interviews served as a platform for the participant to talk about their frustrations, felt listened

to and hope that positive changes would be made to the current support offered. Although this is valuable information, the researcher's main aim was to explore the meaning the participants attached to their experiences. IPA seeks to understand the participant's thoughts, reactions and understanding of their experiences, both on a professional and emotional level. This deeper level of reflection was evidently uncomfortable for the participants, and it is believed they had felt somewhat unprepared for this style of interview questioning. Recognising this potential discomfort early, expectations of the interview were addressed by the researcher before the final three interviews commenced. However, similar difficulties with open reflection continued to be experienced throughout the remaining interviews, leading to an assumption that this style of reflection was novel within the Social Work team's practice. Two interviews were paused so the researcher could address the evident discomfort the participant felt with the IPA style of questioning. One participant stated after our recording "I was warned by other team members who had already been interviewed that you 'asked about feelings and stuff'. Everyone was laughing saying, 'we're Social Workers! We don't talk about our feelings!'"

### **Implications**

The potential bias in participant selection and cases discussed in each interview must be taken into account when considering the implications of this research. Given the high comorbidity rates with FASD, it would be misinforming to state that the challenges experienced by the Social Workers were specific to FASD. This potential misrepresentation of children with FASD could fuel further stigma which could be damaging to their prospects of being adopted into supportive families. Furthermore, the experiences analysed are from a small number of Social Workers within the same Social Work department. The challenges experienced may be

reflective of systemic difficulties such as access to training and support, rather than specific to FASD.

However, even when considering the potential risk of bias, the Social Worker's attitudes and behaviour were shown to be significantly affected by their experiences and the implications of these results must be considered in help protect this vulnerable group of children.

To best support children with FASD, increased training on FASD screening, interventions and support in relation to social and behavioural challenges is recommended. This recommendation is supported throughout the literature (Fuchs et al., 2007, Fast and Conry, 2009), highlighting that professionals need a greater understanding of FASD to reduce the discrimination, victimisation and mismanagement of the individual's disabilities. Without this training, professionals including Social Workers are left feeling vulnerable and under pressure, which is also supported within the literature (Rostill-Brookes *et al.*, 2011).

Funding has been granted to develop awareness and identification of FASD in Scotland, and a new FASD Awareness Toolkit has been developed. However, given that Health and Social Care services are to work in partnership (Joint Working (Scotland) Act 2014), this study highlights the effect resulting from development within Health Services, independently, with services in Social Care struggling to manage the complexities of supporting these children. This appears to reflect the international research, suggesting that although development of diagnosis and treatment for FASD within the health services is crucial, transition into Social Care services is met with professionals who feel ill-equipped, untrained and anxious about supporting these children. Social Care services must develop their professional knowledge in conjunction with the Health Service developments, and priority must be given to support this. The current research has shown that under-development of one half of the partnership may

result in a poor understanding of complex conditions, lack of appropriate services and may ultimately disadvantage an already vulnerable population of children.

## **Applications**

It is anticipated that this research will contribute to the growing body of literature being developed around FASD and the wider system. It is hoped this research will provide insights into how Health and Social Care partnerships can provide the optimum care and support for children with FASD. Furthermore, it is hoped this research will help better understand the role of the Social Worker in Adoption Services, and how their attitudes and experience of FASD can impact on the adoption process.

## **2.7 CONCLUSION**

It is clear that the attitudes, experiences and decisions of the Social Worker can impact upon the adoptive parents and child's journeys, and ultimately the future of the child. Given the Scottish initiative of Health and Social Care Partnership, Social Care services must develop their professional knowledge in conjunction with the Health Service developments to ensure the best possible care is provided to support a child's diagnostic pathway. It is hoped that given the similarity in prevalence rates and complexities as Autism Spectrum Disorder, development in research, training and support services and increased funding for FASD will follow a similar trajectory, turning the spotlight onto this condition and raising public and professional awareness. Like Autism Spectrum Disorder, it is hoped that with an increase in public and professional understanding of the effects of consuming alcohol during pregnancy, the stigma surrounding these vulnerable individuals will reduce, and potentially reduce the number children being born with FASD in future.

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## **Appendix A Guidelines for submission to the Journal of Research in Developmental Disabilities**

### **DESCRIPTION**

Research In Developmental Disabilities is an international journal aimed at publishing original research of an interdisciplinary nature that has a direct bearing on the understanding or remediation of problems associated with developmental disabilities. Articles will be primarily empirical studies, although an occasional position paper or review will be accepted. The aim of the journal will be to publish articles on all aspects of developmental difficulties using rigorous research methods. Our aim is to publish the best available and most current research possible.

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Psychologists, Social Workers, Rehabilitation Specialists and Sociologists

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All figures (include relevant captions)

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## **PREPARATION**

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Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

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State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

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A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

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Results should be clear and concise.

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This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

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When preparing your manuscript, you will then be able to select this style using the Mendeley plugins for Microsoft Word or LibreOffice. Reference style Text: Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition. References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication

There are different ways to link your datasets to your article. When available, you can directly link your dataset to your article by providing the relevant information in the submission system. For more information, visit the database linking page.

For supported data repositories a repository banner will automatically appear next to your published article on ScienceDirect.

## **AFTER ACCEPTANCE**

### ***Online proof correction***

Corresponding authors will receive an e-mail with a link to our online proofing system, allowing annotation and correction of proofs online. The environment is similar to MS Word: in addition to editing text, you can also comment on figures/tables and answer questions from the Copy Editor. Web-based proofing provides a faster and less error-prone process by allowing you to directly type your corrections, eliminating the potential introduction of errors. If preferred, you can still choose to annotate and upload your edits on the PDF version. All instructions for proofing will be given in the e-mail we send to authors, including alternative methods to the online version and PDF. We will do everything possible to get your article published quickly and accurately. Please use this proof only for checking the typesetting, editing, completeness and correctness of the text, tables and figures. Significant changes to the article as accepted for publication will only be considered at this stage with permission from the Editor. It is important to ensure that all corrections are sent back to us in one communication. Please check carefully before replying, as inclusion of any subsequent corrections cannot be guaranteed. Proofreading is solely your responsibility.

### ***Offprints***

The corresponding author will, at no cost, receive a customized Share Link providing 50 days free access to the final published version of the article on ScienceDirect. The Share Link can be used for sharing the article via any communication channel, including email and social media. For an extra

charge, paper offprints can be ordered via the offprint order form which is sent once the article is accepted for publication.

**Appendix B**

*Electronic Search Strategy*

Database	Search Terms/Fields	Results	Screened	Included	Date Searched
<b>Medline</b>	<p>“Alcohol Related Neurodevelopmental Disorder” OR “Alcohol Related Birth Defects” OR “FAE” OR “Fetal Alcohol Effects” OR “Fetal Alcohol Syndrome” OR “FAS” OR “FASD*” OR “Foetal Alcohol Syndrome” OR “Partial Fetal Alcohol Syndrome” OR “Alcohol-Related Disability” OR “Fetal Alcohol*” OR “Foetal Alcohol” OR “prenatal alcohol exposure” OR “static encephalopathy”</p> <p><b>AND</b></p> <p>“Foster parent” OR “foster*” OR “carer*” OR “guardian*” OR “caretaker” OR “adopt* parent” OR “adoptive” OR “non-biological*” OR “parent*” OR “Family”</p> <p><b>AND</b></p> <p>“Qualitative” OR “Experience*” OR “Understand*” OR “Journey” OR “Narrative” OR “Perspective*”</p>	365	9	1	30/03/18
<b>PSYCHinfo</b>	As above	206	18	6	30/03/18
<b>CINAHL</b>	As above	60	9	4	30/03/18
<b>Psychology and Behavioural Science</b>	As above	34	5	1	30/03/18
<b>Sociological Abstracts</b>	As above	704	3	1	30/03/18
<b>Social Service Abstracts</b>	As above	1230	7	4	30/03/18
<b>SocINDEX</b>	As above	61	6	2	30/03/18
<b>EMBASE</b>	As above	642	8	3	30/03/18

**Appendix C Walsh & Downe (2006): Adaptation of Summary Criteria for Appraising Qualitative Research Studies**

<b>Walsh &amp; Downe (2006): Adaptation of Summary Criteria for Appraising Qualitative Research Studies</b>	<b>Quality Rating Criteria</b>	<b>Overall Quality Rating</b>
<u>Studies</u>		
<b>Authors:</b> <b>Date:</b> <b>Title:</b>	Possible Score of 24: - <b>Good</b> = 18 or more (75%) - <b>Acceptable</b> = 12 or more (50%) - <b>Inadequate</b> = 11 or less (under 50%)	<b>Total Points Awarded:</b> <b>Percentage:</b> <b>Quality Rating:</b>

Stages	Essential Criteria	Specific Prompts	Points Awarded
			- Criterion Fully Met (2 points) - Criteria Partially Met (1 point) - No Evidence Criterion has been Met (0 points)
<b>Scope and Purpose</b>	Clear statement of, and rationale for, research question/aims/purposes	<ul style="list-style-type: none"> <li>• <i>Clarity of focus demonstrated</i></li> <li>• <i>Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing</i></li> <li>• <i>Link between research and existing knowledge demonstrated</i></li> </ul>	
	Study thoroughly contextualized by existing literature	<ul style="list-style-type: none"> <li>• <i>Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both</i></li> </ul>	
<b>Design</b>	Method/design apparent, and consistent with research intent	<ul style="list-style-type: none"> <li>• <i>Rationale given for use of qualitative design</i></li> <li>• <i>Discussion of epistemological/ontological grounding</i></li> <li>• <i>Rationale explored for specific qualitative method (e.g., ethnography, grounded theory, phenomenology)</i></li> <li>• <i>Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims</i></li> <li>• <i>Setting appropriate</i></li> </ul>	
	Data collection strategy apparent and appropriate	<ul style="list-style-type: none"> <li>• <i>Were data collection methods appropriate for type of data required and for specific qualitative method?</i></li> </ul>	

		<ul style="list-style-type: none"> <li>• <i>Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?</i></li> <li>• <i>Was triangulation of data sources used if appropriate?</i></li> </ul>	
<b>Sampling Strategy</b>	Sample and sampling method appropriate	<ul style="list-style-type: none"> <li>• <i>Selection criteria detailed, and description of how sampling was undertaken</i></li> <li>• <i>Justification for sampling strategy given</i></li> <li>• <i>Thickness of description likely to be achieved from sampling</i></li> <li>• <i>Any disparity between planned and actual sample explained</i></li> </ul>	
<b>Analysis</b>	Analytic approach appropriate	<ul style="list-style-type: none"> <li>• <i>Approach made explicit (e.g., thematic distillation, constant comparative method, grounded theory)</i></li> <li>• <i>Was it appropriate for the qualitative method chosen?</i></li> <li>• <i>Was data managed by software package or by hand and why?</i></li> <li>• <i>Discussion of how coding systems/conceptual frameworks evolved</i></li> <li>• <i>How was context of data retained during analysis</i></li> <li>• <i>Evidence that the subjective meanings of participants were portrayed</i></li> <li>• <i>Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</i></li> <li>• <i>Did research participants have any involvement in analysis (e.g., member checking)</i></li> <li>• <i>Evidence provided that data reached saturation or discussion/rationale if it did not</i></li> <li>• <i>Evidence that deviant data was sought, or discussion/rationale if it was not</i></li> </ul>	
<b>Interpretation</b>	Context described and taken account of interpretation	<ul style="list-style-type: none"> <li>• <i>Description of social/physical and interpersonal contexts of data collection</i></li> <li>• <i>Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena</i></li> </ul>	

	Clear audit trail given	<ul style="list-style-type: none"> <li>• <i>Sufficient discussion of research processes such that others can follow 'decision trail'</i></li> </ul>	
	Data used to support interpretation	<ul style="list-style-type: none"> <li>• <i>Extensive use of field notes entries/verbatim interview quotes in discussion of findings</i></li> <li>• <i>Clear exposition of how interpretation led to conclusions</i></li> </ul>	
<b>Reflexivity</b>	Researcher reflexivity demonstrated	<ul style="list-style-type: none"> <li>• <i>Discussion of relationship between researcher and participants during fieldwork</i></li> <li>• <i>Demonstration of researcher's influence on stages of research process</i></li> <li>• <i>Evidence of self-awareness/insight</i></li> <li>• <i>Documentation of effects of the research on researcher</i></li> <li>• <i>Evidence of how problems/complications met were dealt with</i></li> </ul>	
<b>Ethical Dimensions</b>	Demonstration of sensitivity to ethical concerns	<ul style="list-style-type: none"> <li>• <i>Ethical committee approval granted</i></li> <li>• <i>Clear commitment to integrity, honesty, transparency equality and mutual respect in relationships with participants</i></li> <li>• <i>Evidence of fair dealing with all research participants</i></li> <li>• <i>Recording of dilemmas met and how resolved in relation to ethical issues</i></li> <li>• <i>Documentation of how autonomy, consent, confidentiality, anonymity were managed</i></li> </ul>	
<b>Relevance and Transferability</b>	Relevance and transferability evident	<ul style="list-style-type: none"> <li>• <i>Sufficient evidence for typicality specificity to be assessed</i></li> <li>• <i>Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies</i></li> <li>• <i>Discussion of how explanatory propositions/emergent theory may fit other contexts</i></li> <li>• <i>Limitations/weaknesses of study clearly outlined</i></li> <li>• <i>Clearly resonates with other knowledge and experience</i></li> <li>• <i>Results/conclusions obviously supported by evidence</i></li> <li>• <i>Interpretation plausible and 'makes sense'</i></li> <li>• <i>Provides new insights and increases understanding</i></li> <li>• <i>Significance for current policy and practice outlined</i></li> <li>• <i>Assessment of value/empowerment for participants</i></li> </ul>	

		<ul style="list-style-type: none"><li>• <i>Outlines further directions for investigation</i></li><li>• <i>Comment on whether aims/purposes of research were achieved</i></li></ul>	
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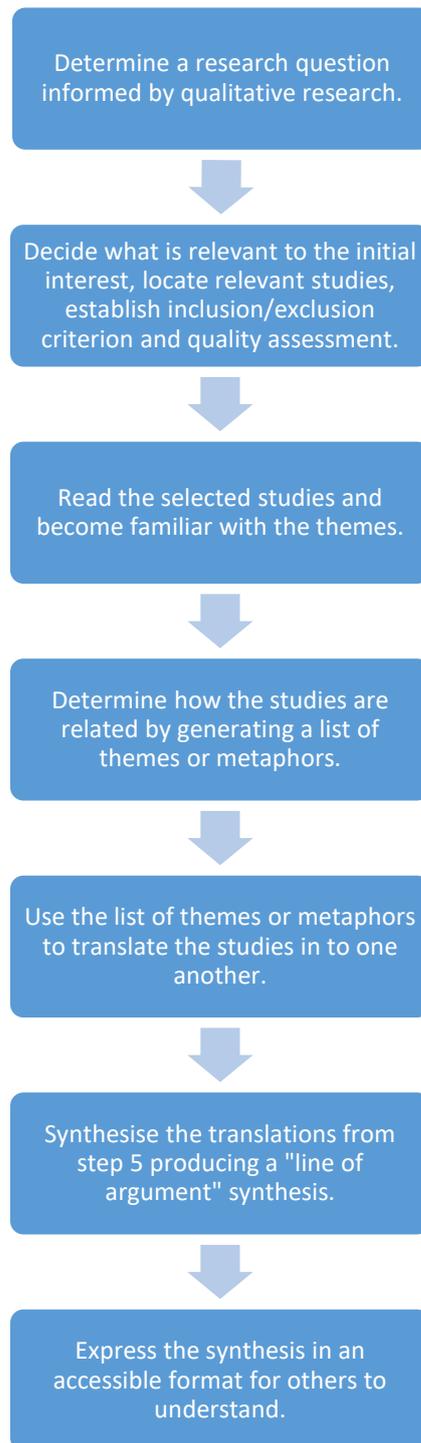
**Appendix D: Quality ratings per study**

**Quality Rating Criteria**

Possible Score of 24:  
 - **Good** = 18 or more (75%)  
 - **Acceptable** = 12 or more (50%)  
 - **Inadequate** = 11 or less (under 50%)

Stages	Essential Criteria	Included Papers						
		Brown et al (2005)	Brown et al (2007)	Brown et al (2007)	Chamberlain et al (2017)	Gardner (2000)	Granitas (2004)	Morrisette (2001)
<b>Scope and Purpose</b>	Clear statement of rationale	2	2	2	2	2	2	2
	Contextualized by existing literature	2	2	2	2	2	2	2
<b>Design</b>	Method/design apparent, and consistent with research intent	1	2	2	2	1	2	2
	Data collection strategy apparent and appropriate	2	2	2	2	2	2	2
<b>Sampling Strategy</b>	Sample and sampling method appropriate	1	2	2	2	1	1	2
<b>Analysis</b>	Analytic approach appropriate	1	2	2	1	1	2	2
<b>Interpretation</b>	Context described and taken account of interpretation	0	2	2	2	2	2	2
	Clear audit trail given	2	1	1	2	2	2	2
	Data used to support interpretation	1	1	1	2	1	1	1
<b>Reflexivity</b>	Researcher reflexivity demonstrated	0	0	1	0	0	1	2
<b>Ethical Dimensions</b>	Demonstration of sensitivity to ethical concerns	1	1	1	1	0	2	2
<b>Relevance and Transferability</b>	Relevance and transferability evident	1	1	1	2	1	1	2
<b>Score</b>		14	18	19	20	15	20	23
<b>Percentage</b>		58%	75%	79%	83%	62%	83%	95%
<b>Description</b>		Accept	Good	Good	Good	Accep	Good	Good

**Appendix E: Seven steps to meta-ethnography (Noblit & Hare, 1998)**



## Appendix F *Original themes*

Author and Date	Original article themes
<b>Brown, Sigvaldason &amp; Bednar (2005)</b>	Social support Materials Structured Environment Professionals Foster Parents Understand FASD Personality Organisation Skills
<b>Brown, Bednar &amp; Sigvaldason (2007)</b>	Conduct Problems Exhaustion Child does not adapt Harm to family Insufficient information Taken for granted
<b>Brown, Bednar &amp; Sigvaldason (2007)</b>	Child's positive change Make contribution Parenting experiences Obligation Confidence in ability Help children
<b>Chamberlain, Reid, Warner, Shelton &amp; Dawe (2016)</b>	Carers aspirations and actions to enhance their child's future Increased caregiver uncertainty Caregiver knowledge and understanding of FASD Lack of societal knowledge and recognition of FASD Assessment provided validation and understanding Process of diagnosis as empowering
<b>Gardner (2000)</b>	Cognitive concerns Behavioural management Coping with daily realities
<b>Granitas (2004)</b>	Feeling delight upon adoption Not knowing Identifying problems, concerns and difficulties Feeling frustrated Feeling devoted Feeling pride
<b>Morrisette (2001)</b>	Constant vigil Effects on marriages Child management Parental issues Interactions with the professional community Emancipation concerns Medical implications

## Appendix G



8<sup>th</sup> August 2017

Dear Dr Jackson

### **MVLS College Ethics Committee**

**Project Title:** Social Workers' experiences of supporting with children exposed to alcohol in utero; an Interpretative Phenomenological Analysis

**Project No:** 200160165

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. It is happy therefore to approve the project, subject to the following conditions:

- Project end date: 31 January 2018
- The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research:  
([http://www.gla.ac.uk/media/media\\_227599\\_en.pdf](http://www.gla.ac.uk/media/media_227599_en.pdf))
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Yours sincerely

## Appendix H



### PARTICIPANT INTERVIEW SCHEDULE

"Firstly thank you very much for meeting with me today, I appreciate your interest in participating in this study. As you're already aware, I'm Louise, a trainee Clinical Psychologist at the University of Glasgow and this study is part of my training. I would like to spend some time together today talking about your unique experiences of supporting children with FASD within the Fostering and Adoption Services. I'm mindful that this might be an emotive topic to discuss, however I would like to remind you that there are no right and wrong answers. I am interested in your own experiences in your own words. If you do not want to answer some of my questions, that's ok, just let me know"

"I hope that our interview today will last around 45 minutes, however you can let me know if you wish this to be shorter, and there is an option to meet more than once if you would prefer."

"To make sure that I correctly hear, remember and understand the information you give, with your permission I would like to record our interview (*show the equipment and give the participant the opportunity to examine the digital recorder*). After our interview, I will be the only person to listen to the tapes and I will type up our interview on a secure computer. All the recording will be kept safe and confidential. Are you happy for me to record our interview? (*If participant consents I will start recording*)."

"Finally, do you have any questions before we begin?"

*Overview:* Can you tell me about your role? Can you tell me how long you have been working within your role? What are your main responsibilities? Have you worked with children who have had a (suspected) diagnosis?

Following the overview the interview will move into exploring the knowledge and attitudes of Social Workers with regards to FASD. The aim here is to elicit how familiar the participants are with the diagnosis and any specific feelings they have toward children receiving this diagnosis.

1. Can you tell me about FASD? (Supplementary questions if necessary; how did you hear about FASD?) How do you feel about the children receiving this diagnosis? (Supplementary questions if necessary; have you received any training in FASD? Are there any guidelines that inform your practice?)

The following section focuses on exploring the particular experiences of supporting children with a (suspected) diagnosis of FASD.

2. Can you tell me about your experiences of working with children with a diagnosis, or suspected diagnosis, of FASD? (Supplementary questions if necessary; have these experiences differed from supporting other children within your service?)

The following section focuses on exploring the participants' experiences and confidence in sharing the diagnosis of FASD with potential foster and adoptive parents.

3. Can you tell me your experiences of sharing the diagnosis of FASD with potential foster and adoptive parents? (Supplementary questions if necessary; how do you feel about sharing this diagnosis? What is your experience of how potential parents have received this information?)

“Thank you very much for your time today”

## Appendix I



### PARTICIPANT INFORMATION SHEET

#### **Social Workers' experiences of supporting with children exposed to alcohol in utero; an Interpretative Phenomenological Analysis**

##### **Introduction**

My name is Louise Gordon and I am a Trainee Clinical Psychologist at the University of Glasgow. The following study is part of my training towards my qualification. You are invited to take part in my research which aims to better understand the experiences of Social Workers supporting children with a diagnosis, or suspected diagnosis of Fetal Alcohol Spectrum Disorder (FASD). The following Participant Information sheet will tell you a little more about the research and explains what would be involved if you wished to participate. Please take time to read the following information carefully and you are encouraged to ask me any questions that you might have.

##### **What is the research about?**

This research aims to develop an account of Social Workers' experiences supporting children in the Fostering and Adoption Service with a diagnosis of FASD. I am interested in your views about the diagnosis and your experience of discussing this diagnosis with potential foster and adoptive parents. It is hoped that exploring your unique experiences will help to have a deeper understanding of how the FASD diagnosis affects the roles of the professionals around the child. It may also help to identify any future training needs of the professional team supporting these children.

##### **Why have I been asked to take part?**

I am asking Social Workers in Ayrshire who work in the Fostering and Adoption Services. Participants will have previous or current experiences of supporting children with a diagnosis, or suspected diagnosis, of FASD.

##### **Do I have to take part in this study?**

No, you do not have to take part in this study at all. Participation in this study is voluntary so it is up to you to decide whether to participate or not. If you decide to take part and later change your mind

that is also OK. You have the right to withdraw from the study at *any stage*. You do not need to give any reasons if you wish to withdraw.

If you decide to take part you will be given this Participant Information sheet to keep and you will be asked to sign a Consent Form. The Consent Form will ensure you understand what the study involves and how the information you provide will be used in the study.

### **What does participation in this research involve?**

If you wish to participate in this study, you will be asked to meet with me for a short interview at the Social Work department at a time that is convenient to you. At our meeting you will be encouraged to ask any questions you have about the study or any concerns you may have. I will then ask you if we can record our discussion using a digital recorder. You will be free to stop the recording at any time. During the interview, I will ask about your role, views and understanding of FASD. I will then ask about your experiences of supporting children with FASD which may include both positive and more challenging experiences. I will then ask if you have any experiences of discussing this diagnosis with potential foster and/or adoptive parents.

There are no right or wrong answers. It is your own experiences that I would like to hear. It is hoped that the discussion will last approximately 45 to 60 minutes, however this can be flexible depending on your experience of the interview process.

### **Why are the interviews being recorded?**

The interview will be recorded so I can listen back to our conversation at a later date and try to carefully understand your experiences. During our conversation I will check with you that I have understood correctly.

### **What do I have to do?**

After reading this information, if you decide to take part in this study please feel free to contact me on the phone number or email below. You can ask any questions and we will arrange a time to meet.

If you *do not* wish to participate in this study you do not need to contact me, and thank you for considering this study.

### **Will the information I provide be confidential?**

Yes, all information provided during the interview process will be treated confidentially and not shared with others. You will be given a pseudonym that will be used throughout the report. Some

demographic information will be collected and used in the report (e.g. your role, years of professional experience etc.) however you cannot be identified with this information. In the final report, your Social Work Service department will be referred to as 'West of Scotland Social Work Services' to assure anonymity. Using the audio recording, our interview will be written up and I will ensure I carefully remove any identifiable information. The audio recording will be destroyed and all written information will be stored securely in a password protected computer. Direct quotations from the interview *may* be used in my report at the end, however your name will not be associated with these quotations.

If you share information that makes me concerned for your safety or the safety of other people, I may be required to tell others involved (e.g. my supervisor, social work manager). I will endeavour to notify you beforehand if I am going to do this, and explain why.

### **Are there any benefits to taking part?**

I cannot guarantee that there are any direct benefits to you in taking part in this study. The information we learn from this study will help to plan future research and help us to understand the impact an FASD diagnosis has not only on the child, but with the professionals working with the child. This study will provide new knowledge and a better understanding of how the needs of both the child and the professionals can be met.

### **Are there any risks or downsides to taking part?**

It is possible that during our meeting we may discuss topics that are difficult or distressing for you to talk about. If you become upset or uncomfortable during the interview, you will be reminded that you can end the interview or take a break *at any time*.

### **What will happen to the results of the research study?**

The final results and conclusions of the study will form part of my qualification in Clinical Psychology and it is hoped that will be published in a scientific journal. In any publications, information will be provided in such a way that you cannot be identified.

### **Who is organising and funding the research?**

The University of Glasgow will be organising and funding the research.

### **Who has reviewed the study?**

The study has been reviewed by the Institute of Health and Wellbeing at Glasgow University to ensure that it meets important standards of scientific and ethical conduct.

**If you would like more information on this study, please contact:**

**Main Researcher:**

**Miss Louise Gordon**

Trainee Clinical Psychologist

Institute of Health and Wellbeing

University of Glasgow

[l.gordon.1@research.gla.ac.uk](mailto:l.gordon.1@research.gla.ac.uk)

**Or**

**Academic Supervisor:**

**Dr Alison Jackson**

Senior Lecturer Institute of Health and Wellbeing

University of Glasgow

[alison.jackson@glasgow.ac.uk](mailto:alison.jackson@glasgow.ac.uk)

**Or**

**Field Supervisor**

**Dr Jennifer Shields**

Clinical Psychologist

Fetal Alcohol Assessment & Support Team (FAAST)

Rainbow House

Ayrshire Central Hospital

[jennifer.shields@aapct.scot.nhs.uk](mailto:jennifer.shields@aapct.scot.nhs.uk)

01294 323070

**Thank you very much for reading this information sheet and for your consideration in this study.**

Appendix J



CONSENT FORM

Centre Number:

Project Number:

Subject Identification Number for this trial:

**Title of Project:** 'Social Workers' experiences of supporting with children exposed to alcohol in utero;  
an Interpretative Phenomenological Analysis'

**Name of Researcher:** Louise Gordon

I confirm that I have read and understand the Participant Information sheet dated 18<sup>th</sup> June 2017 (version 1) for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I understand that the interview will be tape recorded solely for the purposes of the research study as described in the Information Sheet

I agree that fully anonymised quotations may be used in publications and other materials arising from the study

I agree to take part in the above study.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Name of subject*

*Date*

*Signature*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

*Researcher*

*Date*

*Signature*

**Appendix K Major Research Project Proposal**



**DOCTORATE IN CLINICAL PSYCHOLOGY**

**SUBMISSION FRONT PAGE**

**Name:** Louise Gordon

**Matriculation Number:**

**Name of Assessment:** MRP Proposal

**Title of Assessment:**

**Social Workers' experiences of supporting with children exposed to alcohol in utero;  
An Interpretative Phenomenological Analysis**

**University Supervisor:** Dr Alison Jackson

**Field Supervisor:** Dr Jennifer Shields

**Submission Date:** 16 June 2017

**Version Number:** 1

**Word Count:** 3217

**Maximum Word Count:** 3000

For Office Use Only

Date Received:

## Abstract

*Background:* Foetal Alcohol Spectrum Disorder (FASD) is the 'umbrella-term' given to a group of permanent, life-long disabilities resulting from maternal consumption of alcohol during pregnancy. The Scottish Government estimates there may be currently over 10,000 children and young people affected by FASD in Scotland, with children in Social Services being a particularly vulnerable population. With regards to fostering and adoption of these children, there is evidence that children with disabilities, in which FASD may be described, are "hard to place" and a diagnosis of a disability would "put adopters off". Social Workers within Fostering and Adoption Services must ensure children with FASD are placed with appropriate, stable family environments. *Aims:* The study aims to understand and explore Social Workers' experiences of supporting children with a (suspected) diagnosis of FASD. Social Workers' confidence in discussing the child's FASD diagnosis with potential foster and adoptive parents will be explored. *Method:* Using semi-structured interviews, 5-8 participants will be recruited from North Ayrshire Fostering and Adoption Services. Each interview will be transcribed and the data will be analysed using Interpretative Phenomenological Analysis. *Application:* It is hoped that this study will enhance understanding and help gain insight into experiences of Social Workers working directly with children with FASD.

## Introduction

Foetal Alcohol Spectrum Disorder (FASD) is the 'umbrella-term' given to a group of permanent, life-long disabilities resulting from maternal consumption of alcohol during pregnancy. Foetal Alcohol Syndrome (FAS) is the diagnosis given to the most severely affected children on the spectrum (Jones & Smith, 1973), which accounts for approximately 20-25% of individuals under the FASD umbrella (O'Malley & Nanson, 2013). It is estimated that, worldwide, FASD may have a prevalence rate of up to 1 in every 100 births, making it the most common non-genetic, preventable cause of developmental disability and birth defects in the world (May & Gossage, 2001). The Scottish Government estimates there may be currently over 10,000 children and young people affected by FASD in Scotland (Children in Scotland, 2011). The current population of young people under the age of 18 years in Scotland is 1,033,183 (National Record of Scotland, 2015), which suggests FASD is estimated to affect approximately 1% of young people in Scotland. The Scottish government currently advises '**women who are trying to become pregnant or are pregnant should avoid drinking alcohol. There is no 'safe' time for drinking alcohol during pregnancy and there is no 'safe' amount.'** (The Scottish Government, 2017)

Children with FASD have atypical neurodevelopmental difficulties including deficits with sensory-motor abnormalities (Connor *et al.* 2006), attention, cognition and executive function (Kodituwakku *et al.* 2001), academic achievement (Mattson *et al.* 1997), social skills (Greenbaum *et al.* 2009), language (Becker *et al.* 1990) and memory (Uecker & Nadel 1996). However, the diagnostic process of FASD remains challenging as each child's presentation relies solely on the timing, frequency, and quantity of alcohol exposure (Astley, 2004), creating a huge variation in symptomology. The dearth of research has resulted in poor knowledge and unclear evidence-based professional practice (Chudley *et al.*, 2005, Mukherjee *et al.*, 2006). This may result in potential misdiagnosis, such as Autism and Attention Deficit Hyperactivity Disorder (O'Malley & Nanson, 2013) and will limit opportunities for appropriate early intervention. Furthermore, misdiagnoses may lead to "secondary disabilities" for example, mental health problems and inappropriate medical, psychological and social interventions (Chudley *et al.*, 2005). Long-term, misdiagnosis may cause adults to be poorly understood and supported, leading to potential marginalisation and social maladjustment (Fagerlund *et al.*, 2011).

Children within Social Services are a particularly vulnerable population. There is evidence of a direct predictor between the severity of FASD and the likelihood of these children being placed into Social Services. Kvigne *et al.* (2004) concluded that children with a diagnosis of FAS were 64 times more likely to be removed from their mother compared to children with no diagnosis. Furthermore, children with a diagnosis of FASD were 14 times more likely to be removed from their mother compared to other children. The research also highlights the increased risk of mothers who have a diagnosis of FASD consuming alcohol during their pregnancy. Streissguth *et al.* (1996) investigated a sample of 415 mother with FASD and found that 17% of their children had a diagnosis of FASD, 13% has a suspected diagnosis of FASD, and 57% of children had been removed from their care. There is currently no data to indicate the number of children with an FASD within Social Services in the UK. Studies from Canada's Child Welfare Service have estimated that approximately 6% of children have Fetal Alcohol Syndrome (FAS), and 16.9% of children would meet FASD diagnostic criteria. (Lange *et al.*, 2013).

The British Association for Adoption and Fostering's (BAAF) briefing paper on 'The adoption of disabled children' (Grant & Thomas, 2013) refers to 'disability' as 'range of physical and sensory impairments, learning disabilities or emotional and behavioural problems' (Bunt, 2013). FASD can be considered under this definition. Research into children within Social Services has found that disabled children were adopted after a greater delay compared to non-disabled children (Baker, 2007). Furthermore, children in foster care with learning, but no other, impairments were less likely to be adopted than other children, even after age was taken into account (Baker, 2007). Cousins (2009) stated that across the UK, disabled children are "hard to place" and that Social Workers were

concerned that a diagnosis of a disability would “put adopters off”. Social Workers involved in the adoption process must ensure these children are placed with appropriate, stable family environments. The BAAF paper also states the importance for Social Workers to ‘show the “whole” child to prospective adopters in a way that is honest, clear and personal’ (Grant & Thomas, 2013). This paper highlights the importance of Social Workers having knowledge of the child’s condition, in order to best place them with appropriate parents;

*‘Social workers and adopters in the Adoption of Disabled Children study reported that during matching, negative aspects of a child’s impairment and its implications were heavily emphasised (Bunt, 2013). From the social workers’ perspective, this was a way of “testing” whether adopters could cope and were committed, but it could create anxiety for adopters and felt out of proportion to the impairments of the child whom they went on to adopt.’ (Grant and Thomas, 2013, page 8)*

## **Aims**

The study aims to understand and explore Social Workers’ experiences of supporting children with a (suspected) diagnosis of FASD. Social Workers’ confidence in discussing the child’s FASD diagnosis with potential foster and adoptive parents will be explored. It is hoped that the results of this study may enhance the understanding of the impact FASD diagnoses has on the roles of the professionals supporting these children.

## **Plan of Investigation**

### **Participants**

The study will be conducted with Social Workers working in Ayrshire’s Fostering and Adoption Services. All participants will have prior knowledge of the FASD diagnosis and have previously or currently be working with children with a diagnosis, or suspected diagnosis of FASD. Experience of children with ‘suspected’ FASD have been included i.e. children who have the specific deficits and confirmed exposure to alcohol in utero, but who have not yet received a formal diagnosis. Experiences with these children have been included due to the under-diagnosis of FASD, or they may currently be in the diagnostic process.

### Exclusion Criteria

Social Work Assistants will be excluded from this study as their role in supporting children may differ to a Social Worker's role. As the interview will be conducted in English, the participants will be excluded if they do not have a good understanding of the English language

### Recruitment Procedures

The field supervisor, Dr Jennifer Shields, is a Clinical Psychologist working in NHS Ayrshire and Arran. Dr Shield works within a specialist FASD team and will be responsible for the initial liaison with the Ayrshire Fostering and Adoption teams, and supervision of the recruitment procedure. Dr Shield's initial informal discussions with the management of the Social Work teams has indicated full support for the recruitment of Social Workers for this study.

There are approximately 10 Social Workers within the Fostering and Adoption Services across Ayrshire. The managers will be asked to email all Social Workers within the services with the Information Sheet attached. The Information Sheet will detail the aims and requirements of participation in the study. Social Workers who have experience of FASD can indicate their interest to participate via email to their manager. This information will be passed to the main researcher. The main researcher will liaise with the identified Social Workers via phone call or email and arrange either individual or group meetings. This meeting will give the potential participant an opportunity to ask any questions about the study. They will have the opportunity to opt in to the study at this meeting, or contact the main researcher at a later date via the contact information provided on the Information Sheet. A suitable time will be arranged for the interviews to be conducted. Before commencing the interview, written informed consent will be obtained for participation in the interview, audio recording of the interview and use of the data collected.

### Design

An Interpretative Phenomenological Analysis (IPA) methodology will be used to explore and analyse the data. IPA is a qualitative approach to research which aims to explore the 'lived experience' of participants, and the meanings they attach to these experiences. (Smith & Osborn, 2008).

A semi-structured interview will be developed using broad, open-ended questions. This will allow in-depth exploration of the full range of Social Workers' views and experiences. Probes and specific

questions will be used where necessary to encourage participants to elaborate on what is being said. Each interview is proposed to last between 45-60 minutes and will be transcribed verbatim.

### Interview

Initially the interview will focus on the Social Workers' role within the service, year of experiences and previous experiences of supporting children with FASD.

*Overview:* Can you tell me about your role? Can you tell me how long you have been working within your role? What are your main responsibilities? Have you worked with children who have had a (suspected) diagnosis?

Following the overview the interview will move into exploring the knowledge and attitudes of Social Workers with regards to FASD. The aim here is to elicit how familiar the participants are with the diagnosis and any specific feelings they have toward children receiving this diagnosis.

4. Can you tell me about FASD? (Supplementary questions if necessary; how did you hear about FASD?) How do you feel about the children receiving this diagnosis? (Supplementary questions if necessary; have you received any training in FASD? Are there any guidelines that inform your practice?)

The following section focuses on exploring the particular experiences of supporting children with a (suspected) diagnosis of FASD.

5. Can you tell me about your experiences of working with children with a diagnosis, or suspected diagnosis, of FASD? (Supplementary questions if necessary; have these experiences differed from supporting other children within your service?)

The following section focuses on exploring the participants' experiences and confidence in sharing the diagnosis of FASD with potential foster and adoptive parents.

6. Can you tell me your experiences of sharing the diagnosis of FASD with potential foster and adoptive parents? (Supplementary questions if necessary; how do you feel about sharing this diagnosis? What is your experience of how potential parents have received this information?)

## Data Analysis

The qualitative data will be analysed using Interpretative Phenomenological Analysis. Standards for conducting good qualitative research such as sensitivity to context, rigour and transparency will be considered whilst doing this (Yardley, 2000). To ensure concepts were constructed from participants' personal perspectives, the transcripts will be initially analysed individually and ideographically. The process will begin by reading and re-reading the transcript to familiarise the researcher with the account. Line by line coding will then be conducted to ideographically construct individual themes. To increase methodological rigour and adherence to IPA, the initial codes will represent different levels of interpretation - descriptive, linguistic and contextual. To ensure the double hermeneutic principles of IPA will be incorporated at each stage of analysis (Smith *et al*, 2009), there will be continuous movements back and forth through the transcript to reflect on what had previously been said. In this way meaning could be interpreted within the specific text whilst considering the transcript as a whole. Each transcript will be analysed separately, and cross cutting themes will be constructed by identifying comparisons and contradictions of both the idiographic and the shared nature of the themes across all the participants.

## Justification of sample size

IPA requires a homogenous sample of participants who can provide rich and meaningful data about their lived experience of the topic. A small number of participants is considered appropriate to fulfil the requirements for IPA research to ensure rich analysis (Smith *et al*, 2009, Smith & Osborne, 2008). This study therefore aims to recruit between 5-8 Social Workers working within Ayrshire Fostering and Adoption teams. Previous IPA research (Rostill-Brookes *et al*, 2011) also used a small sample size of 5 Social Workers to explore their experiences of working with children in foster care. Additionally, due to the small number of social workers working in these teams within Ayrshire, a small sample size is considered justified.

## Settings and Equipment

Interviews will be conducted within the Ayrshire Social Work services. The interview will be recorded using a digital recording device, and recordings will be encrypted and transferred to a Glasgow University computer. Transcriptions will be made from each recording and saved on University computers in password protected files.

## **Health and Safety Issues**

### **Researcher Safety Issues**

Due to the potential sensitive nature of the interview topic, the researcher will ensure regular supervision is sought from the field supervisor who has expertise in the research area. This will ensure the researcher's wellbeing is maintained.

### **Participant Safety Issues**

All participants will receive an Information Sheet detailing the aims and objectives of the study, as well as the interview procedures the participants can expect. The participants will be given every opportunity to ask questions about the study before deciding to take part. It is not anticipated that the interview topic will cause any participant distress, however should this arise, the participants will be given the opportunity to pause or take a break. Should the participant wish to suspend or terminate their participation at this point, they will be fully supported in doing so. If they have a desire for further support, the researcher will liaise with the appropriate Social Work management. All participants will be informed that they have the right to withdraw from the study at any time.

The participant will be given clear information of the terms of confidentiality of both the information they provide about themselves and the children they support. The terms of confidentiality will be presented within the Information Sheet prior to taking part. Each participant will sign a consent form and it will be made explicit how the study will intend to use the information they provide. Participants will be asked to not to disclose any client identifiable information, for example, the histories of the children to protect their identity.

## **Ethical Issues**

Given that no NHS patients will be approached in this study, the researcher will obtain ethical approval for the research through the University of Glasgow. Audio data will be anonymised and stored in line with the University of Glasgow policy on confidential data. After the interview, data that is stored on the digital voice recorder will be erased following transcription to encrypted, password protected University or NHS computers, accessed only by the researcher. As the initial transcriptions will be verbatim, they will include identifiable information. This information will be systematically documented and then pseudonyms will be used to ensure complete anonymity. As this is a qualitative study, there will be anonymised quotes used within the final report.

### **Financial Issues**

Travel to potential sites will be claimed from the NHS employer. The main costs incurred will be for the photocopying of consent and information forms.

### **Timetable**

<b>Date</b>	<b>Document</b>
12 <sup>th</sup> May	Outline submission
1 <sup>st</sup> June	Draft Proposal submission
15 <sup>th</sup> June	Full proposal submission
25 <sup>th</sup> June	Submission to ethics
15 <sup>th</sup> August	Initiate recruitment
15 <sup>th</sup> August	Begin data analysis
15 <sup>th</sup> September	Finish recruitment
1 <sup>st</sup> October	Complete data analysis
1 <sup>st</sup> November	First draft MRP
1 <sup>st</sup> December	Second draft MRP
1 <sup>st</sup> January	MRP submission

### **Practical Applications**

It is hoped that this study will enhance understanding and help gain insight into experiences of Social Workers working directly with children with FASD.

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## **Appendix L MRP Proposal Plain English Summary**

### **Social Workers' experiences of supporting with children exposed to alcohol in utero; an**

#### **Interpretative Phenomenological Analysis**

##### **Background**

Foetal Alcohol Spectrum Disorder (FASD) is the 'umbrella-term' given to a group of permanent, life-long disabilities resulting from maternal consumption of alcohol during pregnancy. Children within Social Services are a particularly vulnerable population. Adverse environmental circumstances may increase their odds of alcohol exposure in utero, making this population of children at high risk of receiving an FASD diagnosis (Lange *et al*, 2013). Research into children with Social Services has found that disabled children (which may include children with FASD) were adopted after a longer period of time in comparison to non-disabled children. Furthermore, children in foster care with learning disability were less likely than others to be adopted (Baker, 2007). Cousins (2009) stated that across the UK, disabled children are "hard to place" and that Social Workers were concerned that a diagnosis of a disability would "put adopters off". This highlights the importance of Social Workers having an understanding of FASD, to ensure they can show the "whole" child to prospective adopters in a way that is honest, clear and personal (Grant & Thomas, 2013).

##### **Aims**

The study aims to understand and explore Social Workers' experiences of supporting children with a diagnosis of FASD. Social Workers' confidence in discussing the child's FASD diagnosis with potential foster and adoptive parents will be explored. It is hoped that the results of this study may enhance the understanding of the impact FASD diagnoses has on the roles of the professionals supporting these children.

## **Method**

The study will be conducted with 5-8 Social Workers working in Ayrshire Fostering and Adoption Services. All participants will have experience of supporting children with FASD. Each participant will be interviewed for 45 minutes about their experiences, and their interview will be recorded. Audio recordings will be transcribed verbatim, and the data will be analysed using a technique called Interpretative Phenomenological Analysis. All data will be recorded according to local ethical guidelines. Social Work Assistants will be excluded.

## **Key ethical issues**

Given that no NHS patients will be approached in this study, ethical approval will be obtained through the University of Glasgow.

## **Application**

It is hoped that this study will help gain insight into the complex experiences of Social Workers supporting children with FASD through the fostering and adoption process. This will highlight how the FASD diagnosis impacts on the roles of the professionals supporting the child.

**Word count: 489**

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**Appendix M Health and Safety Form**

**WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW  
DOCTORATE IN CLINICAL PSYCHOLOGY  
HEALTH AND SAFETY FOR RESEARCHERS**

1. Title of Project	'Social Workers' experiences of supporting with children exposed to alcohol in utero; an Interpretative Phenomenological Analysis'
2. Trainee	Louise Gordon
3. University Supervisor	Dr Alison Jackson
4. Other Supervisor(s)	Dr Jennifer Shields
5. Local Lead Clinician	Dr Jennifer Shields
6. Participants: (age, group or sub-group, pre- or post-treatment, etc)	5-8 Social Workers working in Ayrshire Fostering and Adoption Services will be sought. All participants will have prior knowledge and experience of supporting children with an FASD diagnosis.
7. Procedures to be applied (eg, questionnaire, interview, etc)	A semi-structured interview will be developed with broad, open-ended questions which will allow in-depth exploration of the full range of Social Workers' views and experiences. Probes and specific questions will be used where necessary to encourage participants to elaborate on what is being said. Each interview is proposed to last between 45-60 minutes and will be transcribed verbatim. The interview transcripts will be explored using Interpretative Phenomenological Analysis.
Setting (where will procedures be carried out?)	Interviews will be conducted within the Ayrshire Social Work services.
ii) Are home visits involved	No

<p>Potential Risk Factors Considered (for researcher and participant safety):</p> <ul style="list-style-type: none"> <li>i) Participants</li> <li>ii) Procedures</li> <li>iii) Settings</li> </ul>	<ul style="list-style-type: none"> <li>i) This participant sample is not normally associated with dangerous or unpredictable behaviour.</li> <li>ii) Due to the potential sensitive nature of the interview topic, participants may find the children’s circumstances difficult to discuss.</li> <li>iii) Interviews will be conducted in Ayrshire Fostering and Adoption Services. They have procedures in place to minimise risk to staff and these are thought to be adequate in the context of the proposed study.</li> </ul>
<p>10. Actions to minimise risk (refer to 9)</p> <ul style="list-style-type: none"> <li>i) Participants</li> <li>ii) Procedures</li> <li>iii) Settings</li> </ul>	<ul style="list-style-type: none"> <li>i) All participants will receive information about the study prior to opting in. Each participant will sign a consent form and be able to opt out of the study at any point.</li> <li>ii) It is not anticipated that the interview topic will cause any participant distress, however should this arise, the participants will be given the opportunity to pause or take a break. Should the participant wish to suspend or terminate their participation, they will be fully supported in doing so. If they have a desire for further support, the researcher will liaise with the appropriate social work management.</li> <li>iii) Interviews will be conducted in quite, private rooms within Ayrshire Fostering and Adoption Services.</li> </ul>

Trainee signature: ..... Date: .....

University supervisor signature: ..... Date: .....

## Appendix N Cost and Equipment

### RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES

**Trainee:** Louise Gordon

**Year of Course:** 3<sup>rd</sup> year

**Intake Year:** 2014

		Cost or Specify if to Request to Borrow from Department
Stationary	N/A	
Postage	N/A	
Photocopying and Laser Printing (includes cost of white paper)	Printing and photocopying for information sheets for prospective participants: <ul style="list-style-type: none"> <li>• Estimated 2 pages for 10 prospective participants</li> <li>• 10 x 2 x 0.05p per sheet.</li> </ul> Printing and photocopying for consent forms: <ul style="list-style-type: none"> <li>• Estimated 3 pages for 6 participants</li> <li>• 3 x 6 x 0.05p per sheet</li> </ul>	£1.00  90p  <b><u>Total: £1.90</u></b>
Equipment and Software	Digital Recorder Laptop & cable Foot pedal for transcription	Request to borrow from department
Measures	N/A	
Miscellaneous		
<b>Total</b>		<b>£1.90</b>

For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:

Trainee Signature..... Date.....

Supervisor's Signature .....Date .....