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"Nobody knew what to do with her and that's what we've found all the way along": A guide for Educational Psychologists (EPs) when working with young people with Foetal Alcohol Spectrum Disorder (FASD) and their families

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This study captured the voice of nine adoptive parents and foster carers who parent a child with a confirmed diagnosis of Foetal Alcohol Spectrum Disorders (FASD). During semi-structured interviews, they shared their experiences of the family-school interaction, their perceptions of their child's experience of school, as well as their experiences of Educational Psychologist (EP) involvement with their child. Using Braun and Clarke's (2006; 2022) six phases of Reflexive Thematic Analysis (RTA), four themes were identified: 'Understanding the Individual', 'Sense of Belonging', 'Collaboration and Communication' and 'Knowledge and Awareness of FASD'. The findings highlighted that parents/carers of individuals with FASD consider school to be overwhelmingly challenging for their children. Recommendations for how EPs could undertake a more supportive role in this context are provided.

Keywords: FASD, adoption, fostering, educational psychology, parental voice, school experience

Introduction

Foetal Alcohol Spectrum Disorder (FASD) is an umbrella term which describes complex physical and/or neurological difficulties resulting from prenatal alcohol exposure (PAE) (Blackburn & Whitehurst, 2010; Millar et al., 2017). Research has drawn a clear link between FASD and developmental differences, however, the effects of FASD are not always visible. Only approximately 10% of cases present with distinct physical features (Blackburn & Whitehurst, 2010; Streissguth & O'Malley, 2000). These can include microcephaly (below average head size), small palpebral fissures (narrowing of the opening between the upper and lower eyelids), flattening of the philtrum (mid-line groove between the nose and mouth) and a thin vermillion border (upper lip). This is one of many obstacles to obtaining an accurate diagnosis, as individuals are "clinical masquerades" whereby it can be difficult to 'see' the difficulties they experience (O'Malley, 2007, p.185). Furthermore, there are additional complications with diagnosis given the many similarities with more widely recognised neurodivergent presentations, such as Attention Deficit Hyperactivity Disorder (ADHD) (Bruer-Thompson, 2016; Petrenko et al., 2014).

Whilst the global prevalence of FASD may be anywhere between 2-20% (Petrenko & Alto, 2017), within the United Kingdom (UK), the estimated prevalence is around 3.2% (Schölin et al., 2021). It is not possible to draw definitive prevalence rates for a multitude of reasons, some related to the diagnostic challenges already described. Additionally, one must rely upon accurate self-reporting of alcohol consumption (Schölin et al., 2021). This is especially difficult when approximately half of all pregnancies may be unplanned (Aiton, 2015), as women might have consumed alcohol when they were unknowingly pregnant and cannot reliably disclose this information retrospectively. Whilst caution should be applied when considering the prevalence of FASD, even this tentative statistic is higher than better understood neurodevelopmental disorders, such as Autism, which is thought to affect at least 1% of children (NICE, 2020). FASD disproportionally affects adopted and care experienced children (Adoption UK, 2018), with at least 85% of children and young people (CYP) with FASD being care experienced (Carpenter, 2011). In a sample of UK based, adopted families, 8% of CYP had a confirmed diagnosis of FASD and a further 17% had suspected FASD (Adoption UK, 2020). This suggests that the prevalence of FASD may be even higher amongst this vulnerable population.

Neither the profile nor developmental trajectory of those with FASD is heterogeneous (Blackburn & Whitehurst, 2010), because multiple factors affect its presentation. This includes the pattern of drinking, volume of consumption, and occurrence of PAE in line with sensitive periods throughout a foetus' Central Nervous System (CNS) developmental timeline (Blackburn et al., 2012). This results in primary differences across at least nine distinct areas: executive functioning, sensory and

motor development, academic skills, brain structure, adaptive living and social skills, focus and attention, cognition, communication and memory (National Health Service (NHS), 2019, p.6). It is therefore unsurprising that research has consistently highlighted education as arduous for students with FASD and their parents alike (Duquette et al., 2007; Duquette & Orders, 2013; Edmonds & Crichton, 2008; Knorr & McIntyre, 2016).

Understanding FASD

To date, FASD is understood as a 'within-child' condition, the physical effects of which are irreversible (Blackburn & Whitehurst, 2010). FASD is a well-established diagnostic term, and researchers thus far have largely considered diagnostic proponents and areas of challenge within a medical model. This is noteworthy given that the developmental profile of those with FASD is characterised by not only significant difficulties, but under-acknowledged extreme strengths too (Blackburn et al., 2012, p.65). Indeed, a critical review by Flannigan et al., (2021) identified only two studies which adopted a strengths-based approach when considering children with FASD. Consequently, they highlighted that the current literature base pathologizes FASD as an 'abnormality' which should be fixed and concluded that a dearth of literature exists which explores a strengths-based perspective of individuals with the condition.

The systems around an individual with FASD are undeniably complex, particularly for those who are care experienced (Coggins et al., 2007). Despite this, the application of a systemic perspective when considering FASD and education in research is in its infancy. Price (2019) identified two distinct overarching themes: 'The Child' and 'The System', when analysing the broad experiences of parents who had adopted a child with FASD. However, these findings only partly related to the educational context. Despite its seeming relevance, to the author's knowledge, only one study (Poth et al., 2014) has adopted Bronfenbrenner's (1979) Bioecological Theory of Human Development (BTHD) to better understand positive classroom experiences of individuals with FASD. BTHD offers a valuable framework for understanding FASD as it posits that CYP do not develop in isolation, instead, they are positioned within a "set of nested structures, each contained in the next like a set of Russian dolls" (Bronfenbrenner, 1979, p.3). Consequently, it recognises that development is dynamic. Poth et al., (2014) found that an inclusive school environment for students and parents was important within the microsystem (the places and people within an individual's immediate environment), as were student-teacher relationships. The home-school relationship in the context of FASD was also identified as being essential, thus mapping directly onto Bronfenbrenner's (1979) mesosystem (the interrelations of two or more microsystems). Findings also mapped onto the exosystem (connections between a social layer that the individual is not part of); this included accessing additional funding and support mechanisms.

It is noteworthy that the recognition of protective factors being both within the child and within wider systems, mirrors trauma-informed practice (TIP) (Carter & Borrett, 2023). This is pertinent given that the concept of trauma was born primarily out of seminal research into Adverse Childhood Experiences (ACEs) (Felitti et al., 1998), and for individuals with FASD, their experiences in the womb are their first 'classroom' into life (Treisman, 2018). Questions about the intersections of FASD and ACEs/trauma have been raised in recent literature, however, researchers have neglected to acknowledge FASD as itself being 'trauma in utero'. For example, Price (2019) distinguished between the effects of FASD and trauma, as two separate entities, on cognitive and behavioural functioning. Participants either had a diagnosis of FASD, had PAE with experience of maltreatment, had PAE with no experience of maltreatment, or were part of a control group where birth mothers drank less than two small drinks in a week. He found no statistical difference between those who had single (exposure to alcohol or trauma) or dual (exposure to alcohol and trauma) exposure. Moreover, those with dual exposure had cognitive and behavioural functioning (e.g. executive functioning, IQ and working memory) more closely related to those who had single exposure to alcohol only, rather than trauma only, concluding that the effects of PAE are more damaging than trauma. Whilst this further highlights the need for FASD informed support, our advanced understanding of trauma relative to FASD clearly warrants further consideration for how we position FASD within the context of ACEs.

The Parental Experience

The family system for individuals with FASD is multifaceted, often including relationships with biological, foster and adoptive parents or carers (Blackburn et al., 2009). Consequently, nuanced experiences exist within the literature dependent on the position of the respondent. Overall, caregivers to those with FASD consistently cite school as one of the biggest family stressors (Corrigan et al., 2019). The importance of partnership working between families and schools has been emphasised (Cleversey et al., 2017), however research suggests that the reality is that parents often feel unheard, their views and expertise are unacknowledged and they experience judgement and blame directed towards them (Balcaen et al., 2021; Duquette et al., 2012; Job et al., 2013; Whitehurst, 2011). Where caregivers are given a voice, they describe their experiences as a "battle" (Whitehurst, 2011, p.190).

The Role of EPs

There exists even less acknowledgement of the role of EPs in this context. This is a significant oversight given that those with FASD are described as facing 'educational jeopardy' (Carpenter, 2011). A literature review by Westrup (2013) identified no research which considered FASD and educational psychology practice together. Since then, only one Canadian study (Pei et al., 2013), and one unpublished thesis (Campbell, 2019), have explored the role of EPs or school psychologists supporting this population. When examining the practice of three UK EPs, Campbell (2019), identified a role for EPs to highlight the possibility of FASD when other formulations have been exhausted, conduct holistic assessments, facilitate a shift away from diagnosis towards need, develop shared understandings and enable collaborative processes across systems. However, one prominent barrier to achieving this was EPs' self-disclosed limited working knowledge of FASD. Likewise, EPs reported mixed views around their role in gathering developmental histories with parents in the context of FASD. They were especially concerned by issues of stigma, although it is likely that this was also informed by their confidence given that they consider themselves to have insufficient understanding. The need for future research to understand the full scope of the EP contribution from key stakeholders, such as parents/carers, was highlighted within the conclusions drawn by Campbell (2019). So far, this has been addressed only on a small scale, and formed one discrete element of a much larger project into FASD, in which participants mentioned EPs' knowledge of FASD in passing, only when asked more broadly about their experiences of collaborating with professionals (Blackburn, 2010).

The Current Study

The study, completed as doctoral research by Griffiths (2022), addressed the following research questions (RQs):

- RQ1: How do parents perceive their child's experience of school?
- RQ2: What are parents' experiences of the family-school interaction?
- RQ3: What are parents' experiences of EPs supporting the educational experiences of their child?

A primary aim of this paper is to draw upon broader findings to inform the direction of future research, and the development of effective practice within the field of educational psychology. The study used a 'solution-oriented' approach (O'Hanlon & Weiner-Davis, 2003) to capture a range of experiences including those that were difficult, positive and any nuances which were positioned in-between. This was considered important as it balanced the narrative by acknowledging the mixed reality of FASD (Flannigan et al., 2021).

Methodology

This research was granted ethical approval by the University of East Anglia (UEA) Ethics Committee and was conducted in accordance with the British Psychological Society (BPS) Codes of Ethics and Conduct (2018) and Human Research Ethics (2021). A purposive, criterion sampling strategy was used to recruit participants who were adopters or foster carers of individuals who had a confirmed diagnosis of FASD. Their child was aged between 5 and 16 years old at the time of recruitment and accessed educational provision within the South East of England. Recruitment was supported by a regional centre which, at the time, provided assessment, diagnosis and post-diagnostic support to families locally and nationally. The centre distributed a recruitment poster inviting prospective participants to take part and make initial contact with the researcher. Eligible participants were then sent a participant information sheet and consent form. Eight adopters and one foster carer were recruited. Demographic information is presented in Tables 1 and 2. It should be noted that in this study the term 'parent' is used for both adopters and foster carers, as all participants were fulfilling a parenting role for a child/young person with FASD.

An exploratory qualitative research design was employed, with participants sharing their experiences through individual, semi-structured interviews. Video interviews were conducted remotely via Microsoft Teams due to ongoing COVID-19 restrictions at the time of data collection (April-August 2021). Interviews were structured using a solution-oriented framed interview schedule (see Appendix A) (O'Hanlon & Weiner-Davis, 2003) which was refined following consultation with key professionals in the field of FASD. Appendix A also shows additional ethical precautions which were taken at the beginning and end of each interview. A follow-up email containing the researcher's and research supervisor's contact details was also sent, should participants have required a debrief or experienced any concerns, or psychological distress, following their participation in the research. The researcher also signposted participants to numerous FASD charities and support networks which could assist with anything beyond the scope of the interviews. Interview transcripts were analysed using Braun and Clarke's (2006; 2022) 'Six Phases of Reflexive Thematic Analysis'. The data collected was managed in line with requirements of the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Each interview was anonymised at the point of transcription. Participants were given a number, and identifying information relating to schools, their child,

Adoptive parent (AP) or foster carer (FC)	Age of Child	Sex of Child	Age at Adoption/ Final Foster Placement	Placements Prior to Adoption/ Final Foster Placement	Age at Diagnosis	Additional Diagnoses
AP 1	13	M	16 months	1	12	X
AP 2	9	M	14 months	1	8	ASD
AP 3	11	F	12 months	1	7	ADHD
AP 4	9	M	18 months	2	8	ADHD pending and SPD
AP 5	16	M	17 months	1	13	AD pending
AP 6a	14	F	<1 month	0	9	ASD, ADHD, AD and SPD
AP 6b	12	F	<1 month	0	7	Inattentive ADHD pending
AP 7	17	M	13 months	2	10	X
AP 8	10	M	13 months	1	6	ADHD and ODD
FC 9	16	M	60 months (5 years old)	multiple	8	X

Table 1

Participant Characteristics of Each Participant and Their Child(ren)

Relationship	Education Settings attended	EHCP	EP Involvement
AP 1	• Mainstream nursery, primary, secondary (year 7 & 8). • Specialist private school currently (year 9).	✓	✓
AP 2	• Dual placement (mainstream and one day a week alternative provision)	Pending	X
AP 3	• Mainstream primary until year 2 • Specialist primary currently	✓	✓
AP 4	• Mainstream primary	Pending	✓
AP 5	• Mainstream primary until year 2 • Specialist private school (year 2 to year 9) • 18 months without educational provision • Education other than at school (EOTAS) Tuition and life skill placements currently	✓	✓
AP 6a	• Mainstream throughout but in specialist 'room'	✓	✓
AP 6b	• Mainstream throughout	X	✓
AP 7	• Mainstream throughout	Ceased	✓
AP 8	• Mainstream primary (currently)	✓	✓
FC 9	• Mainstream primary and secondary (currently)	X	✓

Table 2

Participant Characteristics of Each Participant and Their Child(ren) continued

professionals, or other organisations, including the local authority (LA), were redacted.

Findings

Four themes, with corresponding sub-themes were identified. These are shown within the thematic map in Figure 1. It is important to appreciate the interconnectedness of the themes throughout the parents' narratives.

Theme one: Understanding the Individual

The theme 'Understanding the Individual' reflected

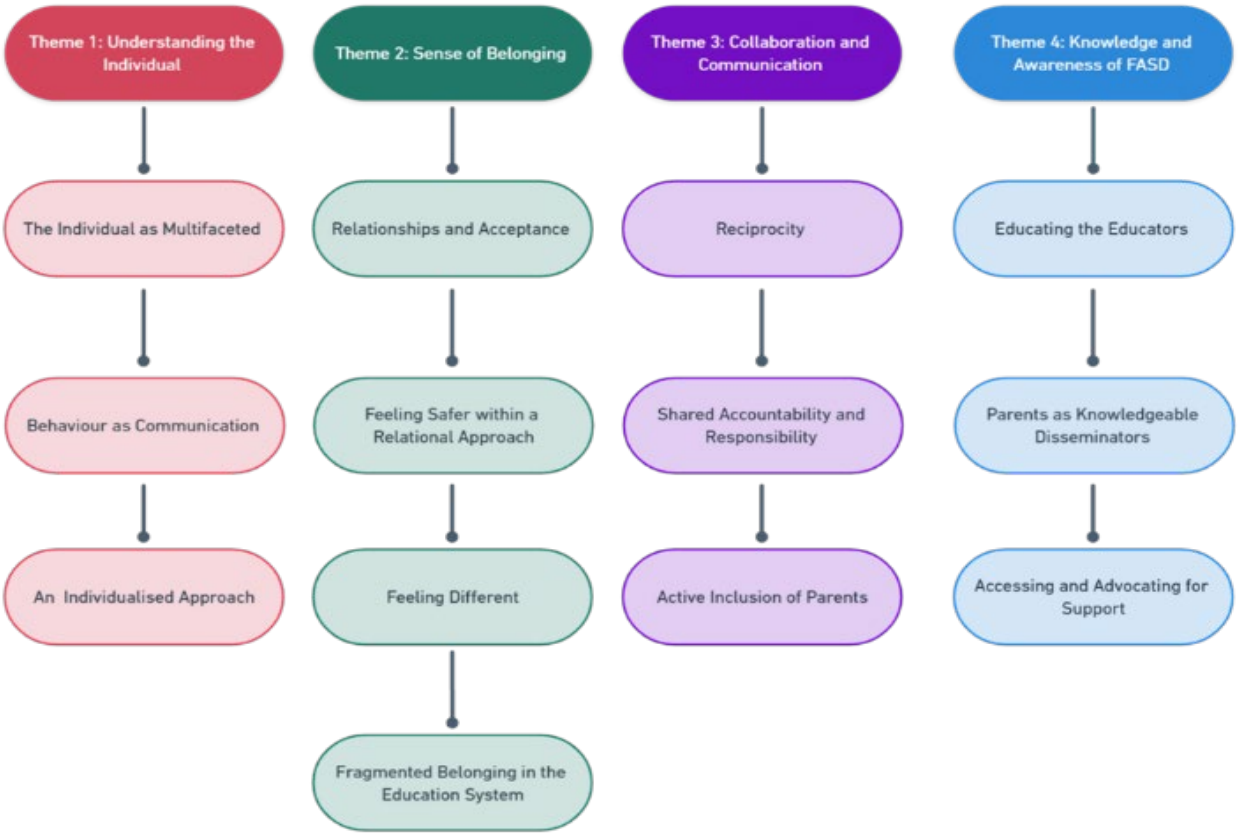

Figure 1.

Thematic Map Illustrating Themes and Subthemes

parents' feelings that their child held several identities due to their multi-faceted profile. This is clearly illustrated in Table 3. Parents recognised FASD as a within-child condition, with participants describing it as an "*organic impairment*" and an "*invisible disability*". For participants, a diagnosis of FASD established a *golden thread* between their child's varying needs. Although it was not easier to manage following diagnosis, it was easier to understand their child's unique needs. School was consistently framed as an overwhelmingly challenging experience. Even those who spoke with a more positive narrative felt that their child would suggest school is "*something to be endured*". However, participants were hopeful that their child could achieve successful outcomes if "*given the right support…school can be a goer for them*".

Rigidity of the curriculum was highlighted as a barrier, a 'one size fits all' approach to learning often meant that their child's strengths were overlooked. Interest led learning, often consisting of practical activities (e.g., science, sport, art, and cooking) was described as facilitating engagement with learning and opportunities for their child to experience success. Difficulties associated with curriculum 'pinch points' and increasing expectations only worsened as participants' children grew older. Many examples of school non-attendance, masking, and the adoption of coping mechanisms were also given. School non-attendance especially demonstrated the climax of behavioural escalation, a last resort, when their child simply could not communicate how distressed they were through any other means. For instance, "*there was one occasion she had cut up her school uniform because she thought if she cut it up then she wouldn't have to go to school*". It was noted by several parents that masking had further implications for the recognition of their child's needs. "*He would just remember one person from his form that was in his next lesson and follow them… that's how he found his own way around by just following one person… if they were off then he struggled*". As this participant notes, it was not until a coping strategy was removed, that the extent of difficulty was realised.

Primary Difficulties	Adoptive Child 1	Adoptive Child 2	Adoptive Child 3	Adoptive Child 4	Adoptive Child 5	Adoptive Child 6a	Adoptive Child 6b	Adoptive Child 7	Adoptive Child 8	Foster Child 9
Emotional Literacy	✓	✓								
Emotional Regulation	✓	✓	✓	✓	✓			✓	✓	✓
Memory	✓	✓		✓	✓			✓		✓
Speech and Language	✓									
Executive Functioning	✓					✓	✓	✓		✓
Social Interactions			✓		✓	✓	✓		✓	✓
Fine Motor Skills		✓								✓
Attention		✓	✓		✓	✓	✓	✓		
Sensory Sensitivities				✓	✓			✓	✓	
Hyperactivity					✓					
Life Skills					✓	✓	✓			✓
Processing						✓	✓	✓	✓	
Working Memory						✓	✓			✓
Visual-Spatial Processing										✓

Table 3.

Participant Information Relating to Primary Difficulties

Fundamentally, parents felt that what worked well to support their child was unique to the individual. The importance of an individualised approach to behaviour management was emphasised wholeheartedly with parents reporting variations in which strategies were, and were not, effective. Whilst some felt that 'typical' behaviour management strategies were not appropriate for use with students with FASD (e.g., rewards and consequences), others noted that their child thrived off such approaches. The consensus was that knowing the child well was essential to ascertain what would and would not work, thus reiterating the need for "*thinking outside the box*". Nearly all parents reflected on occasions where their child's behaviour had been addressed in school through universally punitive approaches. Participants reflected that insistent use of inflexible behaviour policies did not account for their child's individual profile, and it was clear that parents perceived this to be challenging.

Theme two: Sense of Belonging

The theme 'Sense of Belonging' captured parents' view of school as a place which both fostered and severed their child's belief that they belonged. Parents identified peer relationships as being "*pretty much*" the only positive aspect of school from their child's perspective. Alongside this, being a "*people pleaser*" contributed towards their child's vulnerability and desire to be accepted by others. This was a source of angst for many participants which extended into their fears for adulthood, specifically being led "*down the wrong path*". This was also very much a present issue, with parents describing occasions where coercion had resulted in disciplinary action in school and with the law. Consequently, parents recognised that their child required ongoing support "*to filter out… so-called friends*".

From Special Educational Needs Coordinators (SENCOs) who "*made all the difference*" and were there to "*fight her corner*" to Teaching Assistants (TAs) who "*know him really well*", parents placed huge importance on there being an adult championing their child in school. For many, secondary school brought additional challenges where teachers have not "*remained the same*" each year and there were multiple relationships for their child to manage.

Parents emphasised that beyond having key relationships with adults in school, a whole-school relational approach was supportive in promoting feelings of safety and security. Parents noted how "*if you approach him with … empathy… understanding … calm…. Kindness …other things instantly get much easier*" compared to how "*any kind of shouting or raising voices…. doesn't work at all…he just crumbles under that*". Parents also emphasised the importance of a relational approach extending to professionals' interactions with their child. Many mentioned that 'one-off' visits from EPs were not conducive to this.

Parents described how their child often felt 'different' in school. This was attributed in part to learning

accommodations (e.g., being taken out of class for interventions) and behaviour management procedures (e.g., use of isolation rooms and other 'public' strategies). Participants were especially concerned by the ramifications of this for their child's emotional wellbeing and self-esteem, leaving them feeling "*triggered*", "*blamed*" and "*really alone*".

Parents discussed how feeling 'different' could be mitigated by their child attending a setting where their peers had similar needs. One may interpret this as pertaining to specialist provision, however, participants held conflicting views around whether mainstream or specialist settings were most appropriate for their child, instead emphasising the individualised suitability of each education placement. Nearly all participants spoke about a time when their child attended a small school as their most positive educational experience. Importance was placed on the quiet and nurturing environment this provided. Other successful adaptations included flexibility around formal examinations (e.g. taking fewer options, foundation level) and creative curriculums (e.g. forest school, practice-based learning, life skills).

Recalling educational experiences holistically highlighted the multitude of school transitions that participants had supported their child through (see Table 2). This contributed to the consensus that those with FASD did not have an obvious 'place' or 'fit', resulting in a fragmented sense of belonging within the education system. Parents shared their disillusion that there was more availability of school places for those with other neurodevelopmental conditions compared to FASD, as "*nobody knew what to do with her and that's what we've found all the way along*". Identifying a 'best fit' school was a responsibility which parents recognised they needed additional support with, whether that be from an EP or other professional.

Theme three: Collaboration and Communication

The theme 'Collaboration and Communication' reflected parents' desires to have a collaborative working relationship, underpinned by effective communication, with their child's educational setting. This was found to be facilitated and hindered by the presence of and lack of 'Reciprocity', 'Shared Accountability and Responsibility' and 'Active Inclusion of Parents'.

All participants undertook an active role in supporting their child's school. For some, it was believed that there existed an assumption that parents should be "*available*" to school, which often meant having a physical presence, not only to support their child, but also to relieve educators "*when they couldn't cope*". Whilst some perceived that their active contributions furthered effective collaboration with schools, the primary narrative centred around inequalities in the reciprocity of support parents received back from school, likened to "*banging my head against a brick wall*". Parents felt that responsibility was often weighted towards them, despite often falling clearly within school remits (e.g. refusal to have the child on school premises without parental accompaniment). Participants described how "*I've just got used to that*". In turn, a lack of transparency and action perpetuated parental distrust fuelling some to "*record every meeting, who's there…vaguely what is said, what are the action plans, what are the time frames…I've felt like I've had to chair a lot of the meetings that we've had over the years…*". This led parents to advocate for schools to accept accountability, which at times was a perceived barrier to maintaining collaborative relationships between the two, because "*people think it's a bit intimidating*".

Issues relating to accountability for parents were two-fold, as they too felt that they were held to account by schools. Parents overwhelmingly felt blamed, particularly around the influence of their parenting on their child's needs. As this parent notes, "*people blame me, and I can't do any better… I've found that if I then lie and say she's got autism, people then become understanding and back off, but why do I have to lie? It's not autism…the only way I can get understanding is to lie*". This extract demonstrates misunderstandings associated with the aetiology of FASD. Experiences of blame often extended into interactions with professionals and the wider community also. Parents were often left feeling powerless in interactions with teachers and senior leadership where their participation was deemed tokenistic and inauthentic. "*You might as well have been speaking in another language because you could see them switch off… you got the impression that you'd spent your time going there to talk about your child and they hadn't listened to a word you had said*". As this extract illustrates, parents simply did not feel heard. Parents described further battles with the Local Authority to request EP assessments and identify suitable school placements. Parents often asked professionals, including Social Workers or Counsellors, to attend meetings to further the likelihood of being listened to by schools.

Parents did not consistently feel included, or their contributions valued, in involvements with EPs either. This fuelled anxiety around how the professional had understood their child and their needs, something which parents would have liked to have clarified with them. For some the experience was "*hierarchical*" whereby "*she was the professional…it didn't really matter what we felt*". Others had a dissimilar experience however, largely attributing this to their view that EPs were better listened to in school, and their views held more weighting than that of parents.

Theme four: Knowledge and Awareness of FASD

The need for improved 'Knowledge and Awareness of FASD' across systems was reiterated throughout parents' interviews. One parent shared their frustrations that "*you wouldn't expect a child who's in a wheelchair to get up and run 100m, but you're expecting someone whose brain…doesn't function properly, to understand what you're telling them*". This extract reflects the views of all participants who considered education professionals to have a particularly poor level of knowledge of FASD in both mainstream and specialist settings.

It was noted that limited understanding had considerable implications for their child's experience of school. This included assumptions about the presupposed impact of trauma and/or attachment given their child's status as an adopted or cared for child. Parents also raised frustrations that teachers often misinterpreted their child's behaviour as a deliberate choice, resulting in their child being blamed and punished when "*she just wasn't capable of doing any better, she was doing the best she could*". Furthermore, this impacted upon their child's sense of self and value as a member of the school community because it formed the opinion amongst their children "*that a lot of the teachers hate me…I think he genuinely believes that*". This was a particular concern for parents when considering the transition to secondary school as it was felt that knowledge and awareness of FASD was less than in primary schools.

Participants described how diagnosis helped their child better understand themselves because "*he thought he was bad…it's brain damage…it's not that he's bad. He's been told for years that he was a bad boy*". Yet it was reported that diagnosis alone had a negligible impact on teachers' understanding, who still "*tell her she's childish…tell her she's lazy, they've told her that she's not doing enough work…. even though they're well aware of her diagnosis*". Diagnosis was described by parents as the beginning of their journey to becoming more knowledgeable about FASD themselves. This enabled them to advocate for their child because diagnosis could not unlock access to support pathways which simply were not available. Consequently, participants consistently strove to better inform teachers. One participant described this as "*trying to educate the educators on how to educate, and it is just like a constant battle, and it's exhausting because you're constantly having to fight their corner*". This extract captures how parents' undertaking in this area was extensive, time-consuming, and emotionally challenging. The role was varied, and their efforts took many forms including: disseminating knowledge about strategies and signposting to relevant organisations, websites, or other sources of information at a more general level. Parents also shared information which was unique to their child, such as diagnostic reports, medical information and social services reports.

The value of EPs supporting schools' understanding was raised by participants and is illustrated by the following quote. "*I think for them it was…kind of a validation of why he behaves the way he does…for some of them it takes a bit of convincing that they're not naughty children, we're not just parents going excuse excuse excuse… there's a valid reason… I think having it from somebody who is in education, coming into the school and physically saying yes this is what is needed…it's kind of credible isn't it*". This demonstrates how parents noticed that EPs were considered experts who had the power to instigate change. Parents felt strongly that all teaching staff should attend training; an avenue of support that they believed EPs could offer. However, parents felt that simply an understanding of FASD was not enough. How knowledge was translated into practice, 'who' had that knowledge and the proximity with which they worked with their child was also important.

Parents undoubtedly acknowledged a role for EPs in educating the educators, however, they also raised concerns that EPs knowledge and awareness of FASD was also not yet sufficient. It was felt that EPs need to "*get a really good understanding of what FASD is, what it looks like, what the difficulties are and ways that schools can manage it….that's what needs to happen isn't it*".

Discussion

For parents in this study, the overall narrative was suggestive of education being uniquely challenging for CYP with FASD and their families, owing primarily to limited knowledge and understanding of the condition across systems, missed opportunities for joint working between schools and parents, lack of regard for individual needs, and use of a 'one size fits all' approach. This is largely consistent with parental perspectives gathered outside of a UK context also (Duquette et al., 2007; Poth et al., 2014). Whilst participants acknowledged the impact of 'within-child' factors on their child's experience of school, greater focus was given to systemic factors within the school system. This illustrates that parents seemingly feel their child's experiences need not be pre-determined or fixed but are potentially malleable. This juxtaposes the current understanding of 'permanence' surrounding FASD and gives hope for change, providing further weighting to emerging arguments for the need to consider FASD within a systemic perspective (Flannigan et al., 2021; Poth et al., 2014; Price, 2019).

The primary objective of this paper is to identify what role EPs can take moving forwards, thus answering Westrup's (2013) call to better understand EPs work in this area. According to parents within the study, EP involvement in the context of FASD is not yet maximised. This is consistent with Campbell's (2019) findings, whereby EPs themselves reflected that their contributions were not FASD-informed. The remainder of this discussion focuses

Individual Level	
Continuous Professional Development	• Improved knowledge of FASD amongst EPs, including myth busting what FASD is and isn't. Awareness is needed of the breadth of what needs are covered by FASD (see Table 3). • Recognition of EPs' own biases and assumptions, including the influence these have upon their practice within the context of FASD.
Working with Individuals and Their Families	• Adoption of a relational approach, considering how relationships may be best developed over multiple visits. • Ensuring parental views are gathered, making effort to minimise the impact of power differentials/imbalances and hierarchy. • Include questions relating to maternal alcohol consumption/ experiences during pregnancy when gathering developmental histories in consultation (e.g., "tell me about your experiences during pregnancy"), including where other conditions such as ADHD, AD or ASD are suspected.
Organisational/ System Level	
Developing School Practice	• Facilitate clear communication between the family and school systems as a bridge between the two, including holding joint consultations wherever possible. • Advocate for a narrative shift around behaviour and inclusivity for those with FASD, including reviewing behaviour policies. • Advocate for SENCOs to be a member of school leadership to enable the best interests of those with FASD to be represented amongst key stakeholders. • Whole school training to myth bust what FASD is and isn't and provide recommendations for provision, including how to implement strategies. • Offer clinical supervision to school staff to reflect on and develop their practice. • Upskilling staff in use of tools such as One Page Profiles (OPP) which will support understanding of the individual with FASD. • Use of tools such as video enhanced reflective practice (VERP) to support staff reflection. • Support school staff to operationalise the principles of trauma-informed practice (TIP) through an FASD informed lens.
Supporting Parents/Carers and Families	• Explore ways of working within the family system, by providing/signposting support to parents (pre & post diagnosis). • EP services should reflect upon how accessible and 'user-friendly' their offer is to families (pre & post diagnosis).

Table 4.

Summary of Considerations for EPs

on implications for EP practice and Table 4 outlines some recommended next steps for EPs at an individual and organisational level. Discussion around each area is expanded upon below. For ease of reference, corresponding resources to use in practice are also provided in Appendix B. The reader is directed to the original study write up (Griffiths, 2022) should they wish to read a more detailed overview of findings related to each RQ in turn.

Individual Level

Parents' reflections that EPs demonstrated a distinct lack of knowledge around FASD, echoed those previously highlighted in research (Blackburn, 2010; National Organisation for FASD, 2018), including from EPs themselves (Campbell, 2019). This was a frustration for parents, especially when they felt their views were not captured during EP involvement. This is a concerning finding given the emphasis placed upon gathering parental views within the SEND Code of Practice (Department for Education, 2015). Parents reflected that this further perpetuated the issues of unequitable power dynamics they experienced as families (Balcaen et al., 2021). This extended into interactions with CYP too and parents shared that building relationships when working with their children needed to be given greater priority by EPs. This is consistent with Treisman (2018) who argues that this relationship is the glue which makes activities meaningful and purposeful. This recommendation falls directly within EPs unique skillset in building rapport (Beaver, 2011), and therefore

curiosity is needed to better understand why this was not reflected in participants' experiences of EPs in the context of FASD.

Organisational/System Level

Participants in the study felt that EPs were powerful professionals in school, thus agreeing with Frederickson and Cline (2015) that EPs are often positioned as experts. To this end, parents felt that EPs were helpful in shaping an improved understanding of FASD, however, this related more to their positioning, rather than to them holding a secure understanding of FASD to advise appropriately.

Parents commented that there was a role for EPs to offer training to schools (Campbell, 2019; Westrup, 2013). In addition to recommending suitable strategies, parents reflected that EPs should provide practical support around implementation for schools and reiterate the importance of monitoring and evaluating to ensure accountability. In time, understanding in school may be suitably supported by an EP with a working knowledge of FASD. As a minimum, it will be important for EPs with a specialist role in supporting adoptees and children looked after (CLA) to engage with continuous professional development in this area. This aligns with recommendations made previously by Campbell (2019). This study highlighted that parents are seeking a professional to reclaim the role of educating the educators and advocating for the educational rights of children with FASD. There is therefore a clear remit for EPs working at a systemic level as well as with individual pupils and families. Campbell (2019) identified that some EPs are offering a 'holistic perspective' which accounts for strengths and needs when supporting those with FASD, however, findings suggest this needs to be further embedded across EP practice. It would be beneficial for EPs to support schools to audit and evaluate their behaviour policies and inclusive ethos, accounting for the needs of students with FASD as part of an individualised, relational approach.

The findings of this study also support observations that there exists a need for EP involvement to bridge the family and school system (McGuiggan, 2021). This is consistent with the notion that EPs are 'meta' and are in a "unique position to work with the immediate systems around the child" (Beaver, 2011, p. 16; Dowling & Osbourne, 2018). This should include work to support schools to authentically capture the views of parents and caregivers. Fundamentally, the efforts, knowledge, and invaluable contribution that parents make at present is under-acknowledged.

Limitations and Future Research

The study contributes to a limited UK research base around FASD and education, however, several limitations are identified. Firstly, there is no 'right' interpretation of the data (Braun and Clarke, 2022). Another researcher, who holds an alternative ontological position, may have identified different themes and drawn other conclusions. However, this is also a strength of effective reflexive TA as the researcher's subjectivity is an analytic resource (Braun and Clarke, 2022). In a similar vein, the limitations of qualitative research should be noted. It is important to consider how participants may have varied in their understanding of the 'truth'. It is therefore not appropriate to draw wider conclusions about the population of students with FASD, not least because of the heterogeneous nature of the condition (Blackburn & Whitehurst, 2010). Alongside this, the study captured the parental/caregiver perspective only. It will be necessary for future research to expand upon these findings by gathering the views of pupils with FASD, educational professionals and EPs also. Furthermore, the inclusion criteria of the research meant that the experiences of birth parents were not elicited, nor were those who have not yet obtained a diagnosis of FASD. It is likely that further nuances exist in these specific contexts, and this should therefore be prioritised by additional research. Given that participants were adopted parents or foster carers, their experiences and their children's experiences are likely affected by issues relating to intersectionality akin to their status as an adoptee or CLA. It was not possible, nor was it an aim of this research, to tease these apart, however, this is an area for research to pursue.

Conclusions

This study offers an insight into how a sample of adoptive parents and foster carers, who had a child with a diagnosis of FASD, perceived their child to experience school (RQ1), experienced the family-school interaction (RQ2) and experienced EP involvement (RQ3). To the author's knowledge, this is the first UK based research to exclusively study the above through a caregiver's perspective. Overall, it was identified that education is overwhelmingly challenging for CYP and their families and EP support in this context barely scratches the surface. As such these findings help to extend understanding of FASD in educational contexts and recommendations for EP practice.

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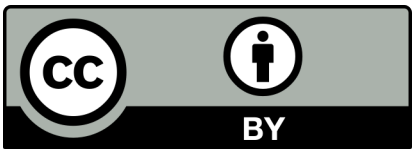

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Appendix A

Interview Schedule

- Thank you for agreeing to take part in my research.
- The purpose of this research is to explore parents' experiences of education when their child has a diagnosis of FASD.
- There are no right or wrong answers to any of the questions I will ask you today you did not have to answer any questions that you do not wish to. I am purely interested in your view; you are the expert of your experience.
- Do you have any questions so far?
- You will have noted this on the consent form which you have signed and returned to me. The content of our interview today is confidential unless something that you share with me is a safety concern and there is a risk of harm to yourself or others. You can switch off your video and/or audio stream at any time should you wish too and if at any point you wish to stop the interview, please let me know.
- Are you happy for me to begin recording?

1. Why don't we start by you telling me a little about your family?

Developmental History

How old was your child when you adopted them?

How many foster/adoption placements did your child have before you adopted them?

Has your child had any previous school placements before their current school? If so, how many? (e.g., pre-school, primary school, or a different secondary school if applicable and known).

At what age did your child receive their diagnosis of FASD?

Does your child have any additional diagnoses alongside FASD?

Does your child have an Education, Health and Care Plan?

What would you describe as being your child's main needs?

Thinking about school positively then…

What do you think your child enjoys most about school?

What is going well in school for your child currently?

How about in the past, what has gone well in their current school (and/or a previous school such as pre-school, primary school, or different secondary school if applicable and known) for your child?

What is it that has contributed to your child's positive experiences at school?

Can you tell me a bit more about a time when school (either current and/or previous school such as pre-school, primary school, or different secondary school if applicable and known) was especially positive for your child?
What do you think contributed to this?

How do you think school could become a more positive experience for your child?

Thinking about some of the difficulties in school…

Can you tell me a little more about what difficulties, if any, does your child currently experience in school?

How about in the past? What difficulties have they experienced in their current school (and/or a previous school such as pre-school, primary school, or different secondary school if applicable and known).

Can you tell me about a time when school (and/or a previous school such as pre-school, primary school, or different secondary school if applicable and known) was especially difficult for your child?
What do you think contributed to this/ any particular triggers?

To what extent do you think these challenges/ needs experienced in school are specifically related to their diagnosis of FASD?

To what extent do you think these challenges/ needs experienced in school are specifically related to their status as an adopted child/ child in foster care?

Do you have any concerns for your child's education in the future?

Are those concerns directly related to their diagnosis of FASD?

What do you think would be helpful to support the difficulties your child experiences in school?

What do you think about your child's current (and/or a previous school such as pre-school, primary school, or different secondary school if applicable and known) school's understanding and knowledge of FASD?

EP involvement…

Does your child receive any extra support in school or have they in the past> (and/or a previous school such as pre-school, primary school, or different secondary school if applicable and known)?

Has your child received any support from external professionals?

Have you and your child been involved with an Educational Psychologist?
If yes, can you tell me a little more about their involvement?

If yes, how helpful did you find the Educational Psychologist involvement?
If yes, what support from the Educational Psychologist did you find to be most helpful?

If yes, what did you think about the Educational Psychologist's understanding and knowledge of FASD?

Close:
I think you've answered all of the questions that I had hoped to ask you today, have you got anything else you'd like to say or any final thoughts that you'd like to share? Are you happy for the interview to end and for me to stop the recording?

- Thank you again for taking part.
- It has been brilliant to speak to you and listen to your experiences.
- Transcript… you have selected to review your transcript; this will be sent to you via email before September.
- I will send you an email after this interview with the contact details of different organisations that you can speak to if you require any additional support in relation to FASD and education.
- If you wish to contact me in the future about the interview you are also more than able to do so.
- Do you have any questions?
- Thank you for your time.

Appendix B

Key Considerations for EPs and Recommended Resources

Individual Level		**Recommended resources**
Continuous Professional Development	• Improved knowledge of FASD amongst EPs, including myth busting what FASD is and isn't. Awareness is needed of the breadth of what needs are covered by FASD (see Table 3). • Recognition of EPs' own biases and assumptions, including the influence these have upon their practice within the context of FASD.	National Organisation for FASD: UK Preferred Language Guide National Organisation for FASD: What is FASD? National Organisation for FASD: Mythbuster National Organisation for FASD: How it Presents National Organisation for FASD: Over 400 Conditions Co-occur FASD United: Language and Stigma Guide FASD: The Parent Perspective & Role of Educational Psychologists with Dr Rebecca Griffiths
Working with Individuals and Their Families	• Adoption of a relational approach, considering how relationships may be best developed over multiple visits. • Ensuring parental views are gathered, making effort to minimise the impact of power differentials/imbalances and hierarchy. • Include questions relating to maternal alcohol consumption/ experiences during pregnancy when gathering developmental histories in consultation (e.g., "tell me about your experiences during pregnancy"), including where other conditions such as ADHD, AD or ASD are suspected.	National Organisation for FASD: Recognising FASD FASD In Focus: Characteristics by Age The Coventry ASD vs Attachment Problems Grid
Organisational/ System Level		**Recommended resources**
Developing School Practice	• Facilitate clear communication between the family and school systems as a bridge between the two, including holding joint consultations wherever possible. • Advocate for a narrative shift around behaviour and inclusivity for those with FASD, including reviewing behaviour policies. • Advocate for SENCOs to be a member of school leadership to enable the best interests of those with FASD to be represented amongst key stakeholders.	6 Things Educators and School Staff Should Know About FASD National Organisation for FASD: Educators FASD In Focus: Education Profile FASD In Focus: Tips for Educators National Organisation for FASD: Teaching a Student with FASD

	• Whole school training to myth bust what FASD is and isn't and provide recommendations for provision, including how to implement strategies. • Offer clinical supervision to school staff to reflect on and develop their practice. • Upskilling staff in use of tools such as One Page Profiles (OPP) which will support understanding of the individual with FASD. • Use of tools such as video enhanced reflective practice (VERP) to support staff reflection. • Support school staff to operationalise the principles of trauma-informed practice (TIP) through an FASD informed lens.	Adoption UK: EDUCATIONAL TRANSITIONS - STARTING A NEW SCHOOL/EARLY LEARNING AND CHILDCARE SETTING National Organisation for FASD: PRIMARY FRAMEWORK: TEACHING AND LEARNING STRATEGIES TO SUPPORT PRIMARY AGED STUDENTS WITH FOETAL ALCOHOL SPECTRUM DISORDERS (FASD) National Organisation for FASD: SECONDARY FRAMEWORK: TEACHING AND LEARNING STRATEGIES TO SUPPORT SECONDARY AGED STUDENTS WITH FOETAL ALCOHOL SPECTRUM DISORDERS (FASD) Adoption UK: Strengths of Learners with FASD Adoption UK: Flexible FASD Support Strategies for Education Staff Sharing EP Practice I VERP: A Powerful Tool for Practice (edpsyched.co.uk) Introducing ourselves to children and young people: what they want to know - edpsy.org.uk Creating a trauma sensitive classroom - edpsy.org.uk Using the Applied Trauma Responsive Classroom observation schedule - edpsy.org.uk Treisman, K. (2021). A treasure box for creating trauma informed organizations: A ready-to-use resource for trauma, adversity, and culturally informed, infused and responsive systems. Jessica Kingsley Publishers. Bomber, L. (2020). Know Me to Teach Me: Differentiated discipline for those recovering from Adverse Childhood Experiences. Worth Publishing.

Supporting Parents/Carers and Families	• Explore ways of working within the family system, by providing/signposting support to parents (pre & post diagnosis). • EP services should reflect upon how accessible and 'user-friendly' their offer is to families (pre & post diagnosis).	FASD UK Alliance- United Together for Social Change National Organisation for FASD: Getting a Diagnosis National Organisation for FASD: After a Diagnosis Adoption UK: FASD GUIDE FOR PROSPECTIVE ADOPTERS/FOSTER CARERS Adoption UK: FASD Guide for Kindship Carers Sleep Scotland and Adoption UK: FASD and Sleep Adoption UK: Transitions in Education- Top 10 Tips for Parents and Carers National Organisation for FASD: All Shapes of Families National Organisation for FASD: Caregiver Wellbeing National Organisation for FASD: Parenting Tips