Foetal Alcohol Spectrum Disorders (FASD): The Parent Perspective on Education and Implications for Educational Psychologists (EPs)

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Summary

This thesis contains three chapters: a themed narrative literature review, an empirical review and a reflective account. The first chapter comprises a broad review of the existing literature around foetal alcohol spectrum disorders (FASD), and more specifically FASD in the context of education, from parents', pupils', education professionals' and educational psychologists' (EPs') perspectives. Next, the empirical chapter consists of a qualitative study based on the experiences of eight adoptive parents and one pair of foster carers who are raising children with FASD. Reflexive thematic analysis was used to analyse the participants' accounts of how their children experience school, how they themselves experience the family-school interaction, and their view on any support they have received from EPs. This section concludes with future directions for research and recommendations for schools and EP practice. The closing chapter provides a personal, yet critical reflective account of the research experience, detailing why decisions were made at key timepoints. The entire research process is discussed including identification of an area of interest, reviewing the literature and the research design. The paper is drawn to a close through further consideration of the implications of the research findings, how these will be disseminated, and how this contributed to the researcher's development.

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Glossary of Terms

ACE	Adverse childhood experiences
AD	Attachment disorder
ADHD	Attention deficit hyperactivity disorder
AP	Adoptive Parent
ARBDs	Alcohol related birth defects
ARND	Alcohol related neurodevelopmental disorder
ASD	Autism Spectrum Disorder
ASF	Adoption Support Fund
BMA	The British Medical Association
BPS	British Psychological Society
BPSEM	Biopsychosocial Ecological Model
BTHD	Bioecological Theory of Human Development
CF	Cognitive Functioning
CNS	Central nervous system
CP	Clinical Psychologist
CPD	Continuous professional development
CR	Critical realism/ realist
CYP	Children and young people
DECP	Division of Educational and Child Psychology
DoH	Department of Health
DfE	Department for Education

EF	Executive functioning
EHCP	Education, health, and care plan
EHCNA	Education, health, and care needs assessment
EOTAS	Education other than at school
EP	Educational Psychologist
EPIP	Educational Psychology in Practice
FAS	Foetal alcohol syndrome
FASD	Foetal alcohol spectrum disorders
FC	Foster carer
GDPR	General Data Protection Regulation
GST	General Systems Theory
HCPC	Health and Care Professions Council
IEP	Individual education plan
IPA	Interpretative phenomenological analysis
ITT	Initial teacher training
LA	Local authority
LAC	Looked after children
ND-PAE	Neurobehavioural disorder associated with prenatal alcohol exposure
NHS	National Health Service
NICE	The National Institute for Health and Care Excellence
ODD	Oppositional Defiant Disorder

OT	Occupational Therapist
PAE	Prenatal alcohol exposure
PE	Physical education
pFAS	Partial foetal alcohol syndrome
PHE	Public Health England
PRU	Pupil referral unit
RAD	Reactive Attachment Disorder
RQ	Research question
SALT	Speech and language therapist
SDT	Self-Determination Theory
SEMH	Social, emotional and mental health
SEN	Special educational needs
SENCO	Special educational needs coordinator
SEND	Special educational needs and disabilities
SEND CoP	Special educational needs and disabilities code of practice
SIM	Student Integration Model
SIGN	Scottish Intercollegiate Guidelines Network
SPD	Sensory processing disorder
TA	Thematic analysis
TEP	Trainee educational psychologist
UEA	University of East Anglia
UK	United Kingdom

USA	United States of America

Chapter One: Literature Review

Introduction

Diagnosis and Diagnostic Challenges

Foetal alcohol spectrum disorders (FASD) describe multifaceted physical and neurological difficulties that are a direct result of prenatal alcohol exposure (PAE) (Blackburn & Whitehurst, 2010; Millar, et al., 2017). Alcohol is a ‘teratogen’; a substance which may cause multileveled difficulties for an unborn child (West & Blake, 2005). Alcohol which enters the foetus’ blood stream via the placenta, affects the baby’s development as the ability to break down the alcohol is not yet present (Blackburn et al., 2012). Historically FASD was an umbrella term used to incorporate various diagnostic labels used over time (Scottish Intercollegiate Guidelines (SIGN) 156, 2019). It offered a description of a hypothetical spectrum of the results of exposure to alcohol in utero (Coles, 2011). By contrast, foetal alcohol syndrome (FAS) was a clinical label, first given to a cluster of PAE related birth defects in 1973 (Jones & Smith, 1973). FAS was often positioned as being on the “most severe end” of the FASD spectrum (Aiton, 2015, p.270), however, it is likely that this pertained to the fact that FAS was the most clinically recognisable form of FASD. FAS was broadly characterised by the following diagnostic criteria (Blackburn et al., 2012; British Medical Association (BMA), 2016; SIGN 156, 2019):

(1) Evidence of PAE.

(2) Abnormalities within the central nervous system (CNS). This included structural, neurological, and functional differences or a combination of all, resulting in microcephaly (below average head size) and learning difficulties or developmental delays.

(3) A specific pattern of three facial differences and delays in pre- and post-natal growth. This included 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).

(4) Individuals diagnosed with FAS typically had below average height, weight, or both since birth. This was measured as being below the 10th percentile.

Not all those affected by PAE met the prescriptive criteria for a diagnosis of FAS (Astley et al., 2002). Other diagnostic terms included, but were not limited to, partial foetal alcohol syndrome (pFAS), alcohol related birth defects (ARBDs), alcohol related neurodevelopmental disorder (ARND), and neurobehavioural disorder associated with prenatal alcohol exposure (ND-PAE) (Aiton, 2015; BMA, 2016).

In 2019, the first clinical diagnostic guidelines for children and young people (CYP) born to alcohol exposed pregnancies in the United Kingdom (UK) were published (SIGN 156, 2019). The standardisation of terminology was a primary focus of this guidance, resulting in three new, well-defined, clinical diagnostic and descriptive terms: FASD with sentinel facial features (diagnostic term), FASD without sentinel facial features (descriptive term) and CYP at risk of neurodevelopmental disorder and FASD associated with PAE (descriptive term). Table 1 details each diagnostic criteria and a diagnostic algorithm is available in Appendix A.

Table 1

Diagnostic Criteria as Determined by SIGN 156 (2019)

Term	Criteria
FASD with sentinel facial features	• Simultaneous presentation of three facial differences: small palpebral fissures, a thin upper vermillion and elongated philtrum. • No evidence of PAE necessary. • Evidence of pervasive and long-standing brain dysfunction, defined as severe impairment in three or

	more areas of neurodevelopment, detailed in Figure 1. This is evidenced by a global score, or major sub-domain score on any standardised neurodevelopmental measure that is ≥ 2 standard deviations below the mean.
FASD without sentinel facial features	• Confirmation of PAE required. • Evidence of pervasive and long-standing brain dysfunction. This is defined and evidenced as outlined above. • Absence of facial differences necessary for diagnosis of 'FASD with sentinel facial features'.
CYP at risk of neurodevelopmental disorder and FASD associated with PAE	• Confirmation of PAE required. • Some indication of impairment within areas of neurodevelopment, however, this is insufficient to meet the criteria for the previous two diagnostic terms. This should be evident in combination with a plausible explanation as to why the neurodevelopmental assessment results failed to meet the criteria for significant impairment.

Figure 1

Nine Brain Domains Affected by PAE from National Health Service (NHS), 2019, p. 6.

Those with FASD are heterogenous and whilst distinct physical features may support early identification, approximately only 10% of cases present with these recognisable differences (Blackburn & Whitehurst, 2010; Streissguth & O’Malley, 2000). Where physical differences are absent, there is a greater reliance on knowledge surrounding maternal alcohol consumption. This brings its own challenges regarding pregnant women accurately self-reporting their alcohol consumption (Schölin et al., 2021). This is 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. Moreover, guidance around alcohol consumption for expectant mothers has been inconsistent. No research has identified a threshold or ‘safe’ quantity of alcohol consumption during pregnancy. Aiton (2015) attributed this to practical challenges in ‘assessing’ significant PAE and identifying who to follow up in longitudinal research. Prior to 2016, guidelines suggested that one to two units of alcohol, once or twice a week, would cause no harm to an unborn child. Whilst it is still believed that the risk of harm is likely to be ‘low’ if only consuming ‘small’ amounts of alcohol (SIGN 156, 2019), the quantification of ‘low’ and ‘small’ remains unclear. As such, abstinence from drinking throughout pregnancy is the safest approach (Department of Health (DoH), 2016).

A comprehensive multi-disciplinary assessment is required to obtain a diagnosis in the UK. This assessment may be informed by paediatricians, speech and language therapists (SALTs), clinical psychologists (CPs), EPs, health visitors and occupational therapists (OTs), amongst other professionals (SIGN 156, 2019). Historically, a lack of clarity has existed amongst diagnostic professionals. Mukherjee et al., (2015) found that whilst 66.5% of participants agreed that community paediatricians were the relevant professional for referral when FASD was suspected, they also concurred that no clear pathway existed following this referral. Whilst current researchers (e.g. Schölin et al., 2021) note that this may have improved since the introduction of the UK diagnostic guidelines, the lack of knowledge amongst health professionals is cited within that document as posing a “significant challenge to the implementation of a comprehensive and consistent approach to the management of FASD” (SIGN 156, 2019, p.14). This is evidenced by research which found that 72.5% of health professionals reported having insufficient information to advise pregnant women about safe alcohol consumption (Mukherjee et al., 2015). In 2021, 19% of midwives were not recommending total sobriety to expectant mothers, because they followed previous guidelines (Smith et al., 2021). This may relate to Mukherjee et al’s., (2015) finding that not all health professionals, including some midwives, felt that FASD was relevant to their role. The implications of which are highlighted in research by Public Health England

(PHE) (2019). They identified that whilst the smoking record was ‘known’ for 87.8% of expectant mothers, this was lower for the drinking status which was ‘known’ for only 56.9%. This translates into systemic barriers to diagnosis (Petrenko et al., 2014; Whitehurst, 2011), a process which parents describe as a drawn out, ongoing battle (Balcaen et al., 2021; Brown, 2015; Sanders & Buck, 2010). For instance, one study found that birth mothers, who were aware of their own alcohol consumption, struggled to be heard or believed by health professionals and thus experienced obtaining a diagnosis for their child as a challenge (Thomas & Mukherjee, 2019). Recently, The National Institute for Health and Care Excellence (NICE) stipulated that the onus should shift from expectant mothers and towards professionals, who are able to populate a comprehensive medical history by asking relevant questions. This year they have published guidance stipulating that alcohol consumption should be recorded on maternity records and later transferred to the child’s health record (NICE, 2022). The proposals were met with retaliation by those advocating for the maternal right to privacy (British Pregnancy Advisory Service (BPAS), 2020). However, the suggestion is in recognition of previous research which has evidenced that FASD is easily misdiagnosed due to the significant overlapping characteristics with other conditions, including attention deficit hyperactivity disorder (ADHD), sensory processing disorder (SPD), autism spectrum disorder (ASD) and reactive attachment disorder (RAD) (Bruer-Thompson, 2016; Petrenko et al., 2014).

Prevalence

Literature indicates that global prevalence of FASD may be between 2 and 20% (Petrenko & Alto, 2017). Reliable figures within the UK remain unclear, although previous estimates were that the prevalence of FASD amongst births in the UK within the early nineties could be between 6 and 17% (McQuire et al., 2019). This is consistent with global findings; however, this statistic was produced using screening algorithms for FASD which is not equivalent to formal diagnosis. More recently, data from Lange et al., (2017) which indicated that 41.3% of women consume some alcohol during their pregnancy, was used by Schölin et al., (2021) to propose a UK estimated prevalence of 3.2%. This is consistent, although at the higher end, of figures (between 1.8 and 3.6%), reported by McCarthy et al., (2022). However, caution should be applied as McCarthy et al's., (2022) estimation was reached using selective sampling within one area of the UK, meaning that it is not possible to draw conclusions towards overall population prevalence. This study was also part of a prevention and awareness initiative within the local area, which is suggestive of wider concerns around alcohol consumption amongst pregnant women in that locality. However, the authors describe their findings as conservative as it was assumed that all those who were not examined did not have FASD, and their figures align with those reported previously.

Whilst it is not possible to draw definitive prevalence rates, current research is indicative of a prevalence rate that is higher than other neurodevelopmental disorders, including ASD which has a prevalence amongst children of at least 1% (NICE, 2020), yet FASD is significantly under researched by comparison (Westrup, 2013). FASD also disproportionally affects adopted and looked after children (LAC) (Adoption UK, 2018), with 85% of CYP with FASD being placed in care (Carpenter, 2011). In a survey of 5000, UK based, adopted families, 8% of CYP had a confirmed diagnosis of FASD and a further 17% had suspected FASD (Adoption UK, 2020). This is representative of well documented barriers to receiving a diagnosis (Adoption UK, 2019), and suggests that prevalence of FASD may be even higher amongst this population.

Aims of the Literature Review and Terminology

The following literature review provides an overview and critical analysis of research related to FASD and education. This is a themed narrative review which uses themed subheadings to collate existing research findings together to improve understanding of the topic (Collins & Fauser, 2005). This includes discussion of the implications of FASD for learning, experiences of and within education settings for all stakeholders, and the scope for future educational psychology practice. The overall aim is to formulate appropriate recommendations for future research. Whilst more typical of a systematic literature review, to enhance transparency and rigour, information regarding literature searches including search terms, dates, and search engines is provided in Table 2.

Table 2

Literature Review Search Terms

Search terms	foetal/ fetal alcohol spectrum disorder/ foetal/ fetal alcohol syndrome/ FASD/ partial foetal/fetal alcohol syndrome/ prenatal/ pre-natal alcohol/alcohol related neurodevelopmental disorder/ alcohol related birth defects *and* voice/ perspective/ experience/ education/ school/ parent
Date of search	November 2020-March 2022
Search engines	Google Scholar, ERIC, EBSCO Host
Inclusion/Exclusion Criteria	- Research which was published,

	peer-reviewed, and conducted within the UK was preferred, however, the sparse literature resulted in the inclusion of studies which provided an interesting insight despite not meeting these criteria. For example, the inclusion of international and ‘gray’ literature. • Research studies dated from the year 2000 onwards were selected to ensure that the information was as relevant as possible. Some earlier references were also included due to their significance in the field. • Medical studies using animals were excluded because their validity in relation to human participants is questionable, with under 50% successfully predicting human outcomes (Langley, 2009).

The initial search focused on Google Scholar and organisational reports, advice and guidance from sources including, but not limited to, NICE, PHE, Adoption UK, SIGN, BMA, the National Organisation for FASD, and the BPAS. These are referenced given their pertinence to the topic. These searches informed a broad understanding of terminology and facilitated the identification of the search terms. For instance, spelling of the word ‘fetal’ reflects international medical usage and is adopted by NICE and SIGN. However, the spelling ‘foetal’ is favoured. The literature search was extended through use of a snowballing strategy where relevant material cited within the original publications was accessed, this included other journal articles and books that the author conveyed as relevant.

Whilst the author acknowledges terminology used in the previously discussed current UK diagnostic guidance, this review continues to use the term FASD as an umbrella term to encompass the range of effects of PAE. Thus, placing equal value on each individual experience within the spectrum of FASD, regardless of diagnostic label. This adheres to the recommendations of the ‘FASD: UK Preferred Language Guide’ (National Organisation for FASD, 2020), which informed use of language throughout this review. Similarly, use of the term FASD accounts for the recency with which the UK clinical guidelines have been introduced, as the updated terminology is not yet reliably used within the literature.

Given the prevalence of FASD amongst the adopted and looked after population, this review overwhelmingly draws upon findings from participants within this context. As such, the author uses the term ‘parents’ to encompass all caregivers, including adopters, foster carers and birth parents, respectively. However, where relevant, research findings involving biological parents are noted.

Theoretical Framework: A Systems Perspective to FASD and Education

A systems way of thinking originates from the initial workings of von Beralanffy, who in 1950 developed general systems theory (GST). Dowling and Osbourne (2018) describe a systems perspective as a means of viewing an individual within the context in which they exist. The idea of context is one of five key principles of GST, alongside circular causality, punctuation, homeostasis, and information and feedback. Within GST the individual is positioned as one component of a system (context), which both affects and is affected by other components within the system (circular causality). The nature of circular causality is one which makes identification of cause and effect challenging. Consequently, the way in which this is interpreted or perceived is dependent on how reality is understood (punctuation). Homeostasis supports understanding around how a continuation of behaviour is maintained by resistance to change. The relevance of information and feedback to social sciences is perhaps the clearest. The component, in this instance the individual, is modified or affected by its interactions with another component of the system. This is done through a circular process, known as a feedback loop of information exchange (Dowling & Osbourne, 2018).

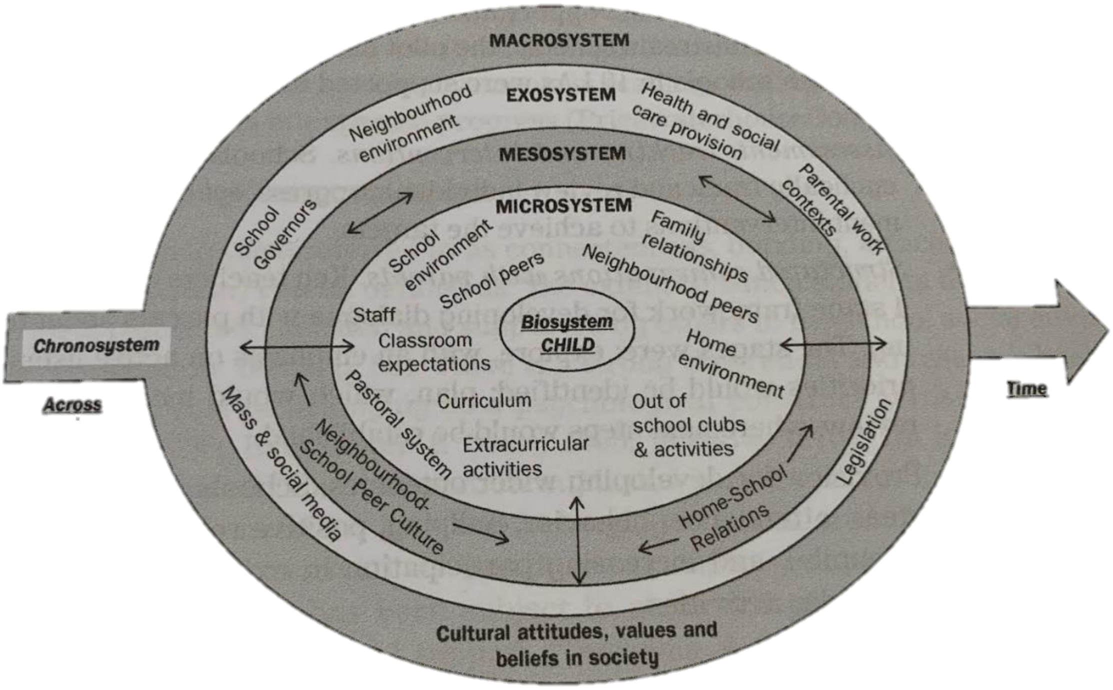
The systems around an individual with FASD are undeniably complex, particularly for those who have experienced social care involvement. Prevalence rates suggest that a considerable percentage of those with a diagnosis will have multiple layers to their family system. Based upon early experiences in the formative years, this includes a combination of adoptive, foster, and birth relatives (Coggins et al., 2007). Moreover, support from social services enrols the individual within another system. The adverse childhood experiences (ACEs) study identified seven categories of childhood experiences which are ‘risk factors’ for a multitude of negative life outcomes, this includes having lived with an alcohol or drug abuser

(Felitti et al., 1998). Amongst a sample of 374 adopted children, 42% were identified as having experienced at least four ACEs (Anthony et al., 2019). One should hold in mind that no confirmed safe limit of alcohol consumption within pregnancy currently exists, so it is not accurate to suggest that all birth mothers of a person with FASD are, or were, ‘alcohol abusers’ during pregnancy. Similarly, it is not the intention of this review to attribute blame, particularly as birth mothers have noted contextual factors, beyond their control (e.g. family history, mental health difficulties and poor health guidance), which influence their drinking habits (Thomas & Mukherjee, 2019). Indeed, the National Organisation for FASD (2020) stipulates the need to recognise alcohol, not the consumer, as the catalyst. However, research has found that children of alcoholics are more likely to have experienced all other categories of ACE, including abuse and neglect, compared to children of non-alcoholics (Anda et al., 2002). Living with an alcohol abuser may relate to a birth father instead of birth mother, and consequently their alcohol consumption is unlikely to cause damage in utero. The contextual circumstances surrounding FASD can be understood through adopting the lens of Bronfenbrenner’s Bioecological Theory of Human Development (BTHD) (1979) (see Figure 2). This is a supportive framework when considering the pathways of development for CYP with additional needs. BTHD 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. Bronfenbrenner (1979) proposed four layers of contextual systems, which interact reciprocally with each other and the developing individual. Central to Bronfenbrenner’s model, is the individual and any child-related factors. The microsystem contains the immediate systems within which a CYP is positioned (e.g.

family and school). It is the layer closest to the child and the one with which they have direct relations. The mesosystem is concerned by the interactions between microsystems (e.g. relationship between home and school). The exosystem consists of one or more settings that indirectly affect a child's development but within which the developing individual is not an active participant. The macrosystem encompasses societal factors and the political climate. The chronosystem represents changes in all systems across time. Despite its seeming relevance, to the author's knowledge, Poth et al., (2014) is the only study that has used the bioecological model to better understand positive classroom experiences for children with FASD. They 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 funding.

Figure 2

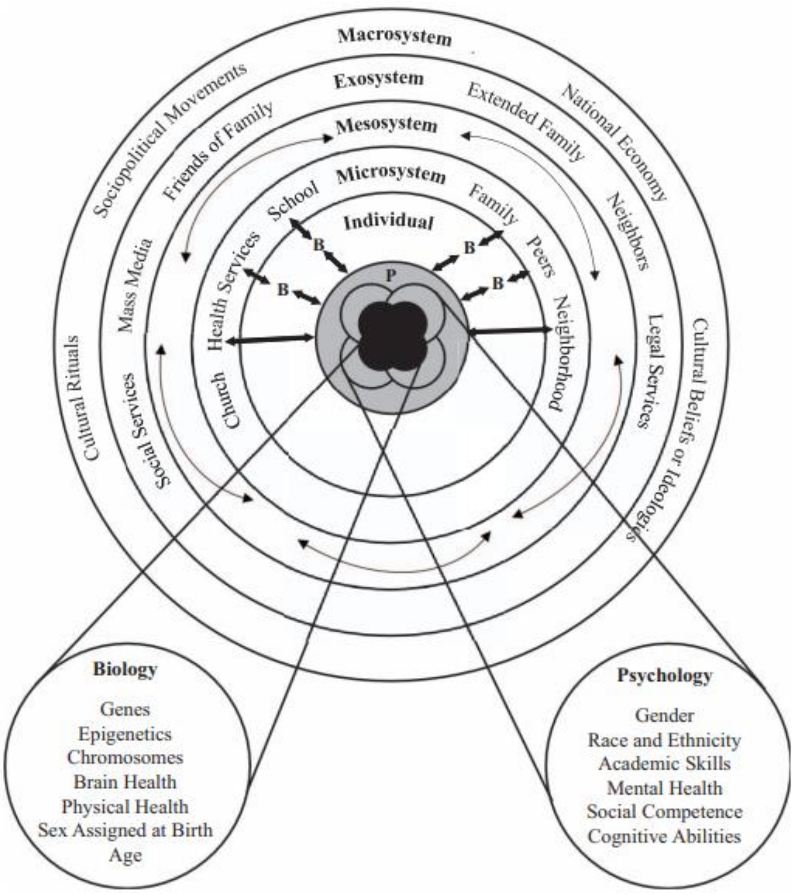
Bronfenbrenner's (1979) Bioecological Model of Human Development. Image from Frederickson and Cline (2015, p. 215).



Despite the clear application of BTHD to FASD, questions about the intersectionality of FASD and traumatic childhood experiences have been raised in recent literature. A potential limitation of the BTHD in relation to FASD exists as it fails to provide space to consider the biological associations between alcohol consumption and FASD. This is significant as Price (2019) distinguished between the effects of FASD and trauma on cognitive and behavioural functioning. A sample of forty CYP was used. They 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 (EF), IQ and working memory) more closely related to those who had single exposure to alcohol only, rather than trauma only, suggesting that the effects of PAE are more damaging than trauma. Mukherjee et al., (2019) corroborated this finding, as postnatal neglect did not make developmental outcomes any worse for CYP with FASD, suggesting that PAE influences these outcomes independently. Consequently, The National Organisation for FASD (2020) now adopt a position whereby support for those with FASD and traumatic childhood experiences must be FASD informed first. These findings, alongside the boundaries of this review, mean that the impact of trauma will not be discussed further. Moreover, they indicate an increasing need to acknowledge biological factors in the aetiology of FASD, even when adopting a systemic perspective. It is therefore plausible to view the individual with FASD through the Biopsychosocial Ecological Model (BPSEM) (Sameroff, 2010) (see Figure 3), although this has not previously been done, most likely owing to the recency with which the BPSEM was developed. Whilst the BPSEM is certainly informed by BTHD, at its core is the broader debate around the influence of nature vs nurture. Sameroff's (2010) overall aim in devising this model was to provide 'unification' of developmental theories. What sets it apart from its predecessors is the emphasis placed on the complexity of 'the individual', describing the self as a "set of interacting psychological and biological processes" (Sameroff, 2010, p. 17). In this model, biological processes include genes, chromosomes, sex assigned at birth, physical health, and of most relevance to FASD, brain health. The psychological constructs encompass knowledge and skills/ functioning, meaning the primary difficulties associated with FASD such as those outlined in Figure 1. The detail of these is elaborated further in the next section of this review. Since initial publication, Kranzer et al., (2020) revised the BPSEM to incorporate the physical features of the individual (e.g., height, weight and facial features), these are represented by the central grey circle in Figure 3. This also contains the overlap of biological factors (black circles in Figure 3) and psychological factors (grey circles). If the reader reminds themselves of the diagnostic criteria for FASD, the relevance of the inclusion of physical features is evident.

Figure 3

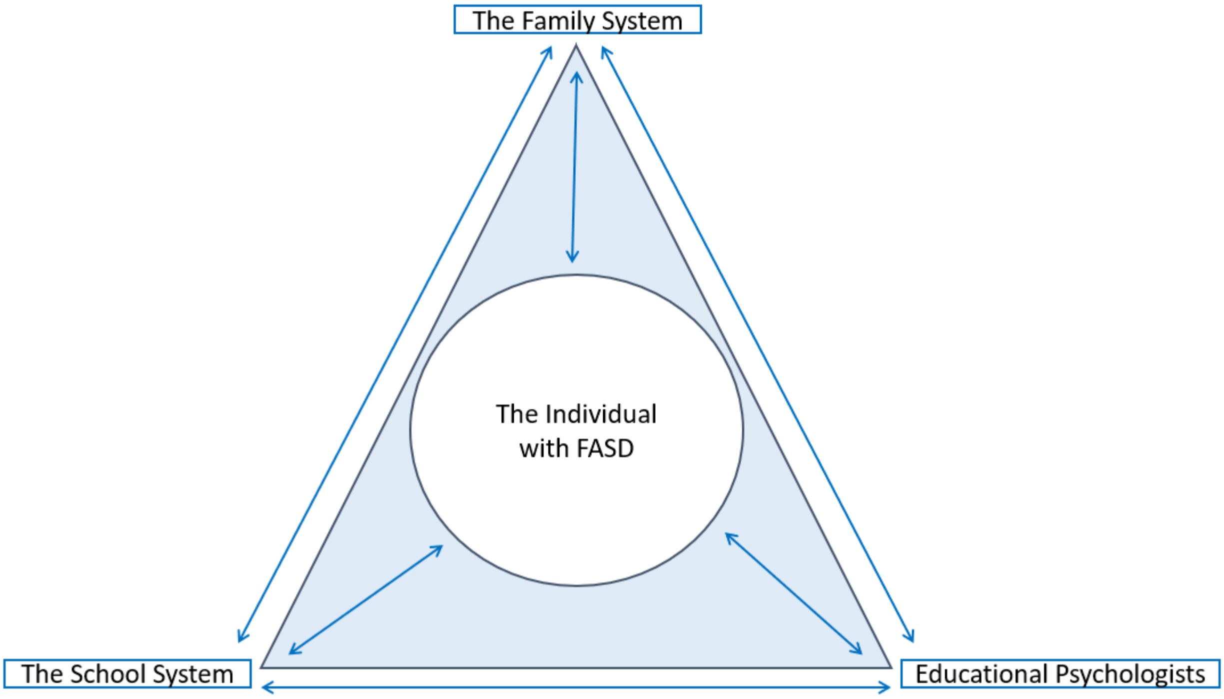
The Biopsychosocial Ecological Model (Kranzler et al., 2020, p. 421).



This review seeks to expand upon discussions within the limited global literature base that explores education in relation to those with a diagnosis of FASD. It is beyond the scope of this review to consider the interweaved, multiple relationships, across systems for CYP with FASD (Coggins et al., 2017). Instead, those of relevance to FASD and education are prioritised. Drawing upon the principles of GST, this literature review provides a critical discussion of the developing individual with FASD, specifically in the context of education. The review adopts a magnified view of one small subsection of the systems surrounding an individual with FASD, which is centralised to align with the BTHD and BPSEM. Particular attention is paid to the role of the family and school systems, the relationship between the two, the role of EPs as ‘meta’ to both systems, and the individual with FASD as a central component of the above (Beaver, 2011; Dowling & Osbourne, 2018). This is illustrated by Figure 4 which depicts the foci of this review and the systems that this review will discuss further.

Figure 4

Literature Review Focus: Applying GST to FASD and Education



The Individual with FASD

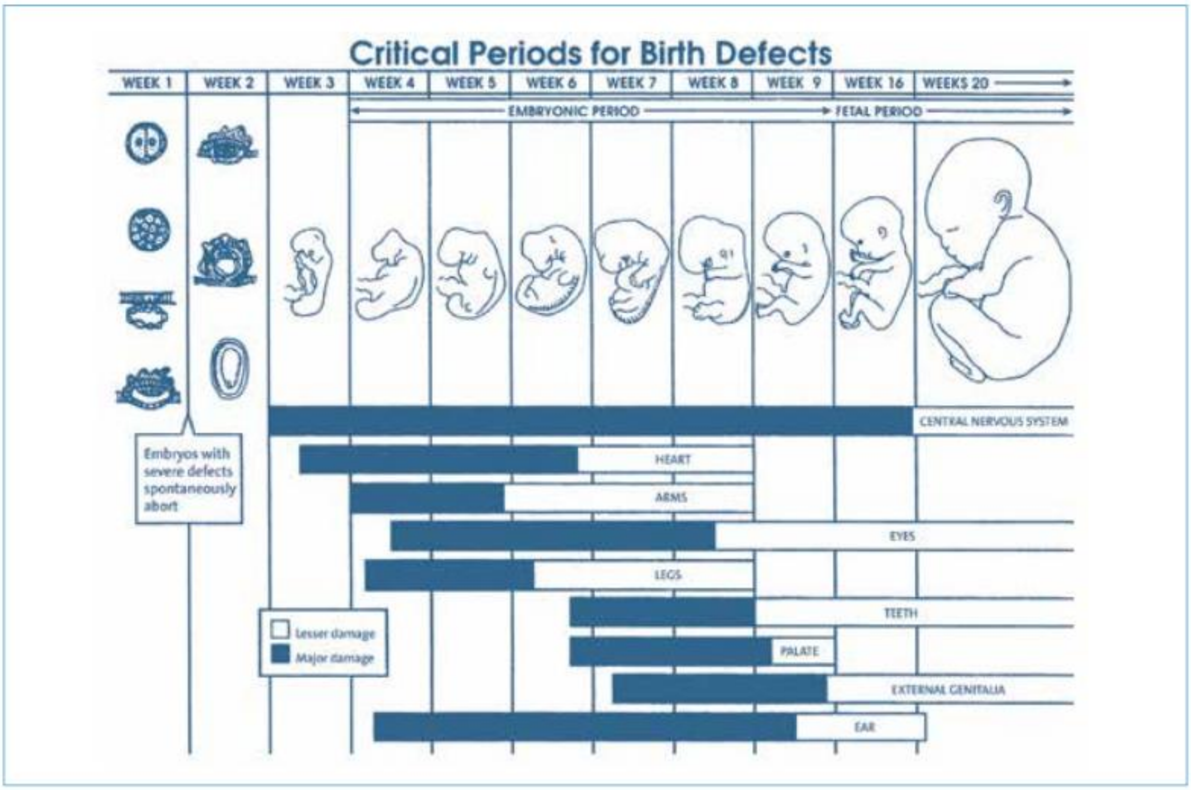
The developmental profile of people with FASD is hugely variable because multiple factors affect the presentation. This includes the pattern of drinking, timing of alcohol exposure, blood alcohol level, genetic influences, and a mother’s demographic information (Blackburn et al., 2012; Carpenter, 2011; Gray et al., 2009; Maier & West, 2001; May et al., 2009; Streissguth & O'Malley, 2000). The cooccurrence of PAE and foetal development is particularly important, as there are sensitive periods throughout gestation where specific regions of the body are developing (Blackburn et al., 2012; O'Neil, 2011). Consequently, maternal consumption of alcohol at certain times is likely to affect the developmental processes of that time. This is illustrated in Figure 5. As outlined earlier, the physical effects of PAE are present in only a small proportion of cases, resulting in FASD being colloquially termed an 'invisible disability' (Blackburn & Whitehurst, 2010; Millar et al, 2017. Streissguth & O'Malley, 2000). As Figure 5 highlights, development of the CNS, consisting of the brain and spinal cord, extends throughout pregnancy, and the duration of a sensitive period where considerable damage is probable, is longer than any other area of development. Consequently, the effects of PAE are highly individualised and determined by which area of the brain is damaged (Blackburn et al., 2012).

Figure 5

Fetus Vulnerability to Birth Defects During Various Periods of Development,

(National Organisation for Foetal Alcohol Syndrome, n.d.).

https://www.staffsscb.org.uk/wp-content/uploads/2020/04/Foetal-Alcohol-Spectrum-Disorder.pdf



Note. The dark bars represent the most sensitive period of development, where alcohol is likely to result in major abnormalities. The lighter bars indicate difficulties to a lesser extent within a less sensitive period of development.

The Developmental Profile. The physical brain damage caused by PAE is referred to as a ‘primary disability’ (Blackburn et al., 2012). This is thought to relate to nine distinct brain domains (see Figure 1). A sample of these are described below to provide the reader with an overview.

- Brain Structure. For a minority of individuals with FASD, PAE results in physical damage to the brain structure, namely a small head circumference (<3rd percentile), and/or other brain structural abnormalities identified via brain imaging (SIGN 156, 2019). This is illustrated in Figure 7.
- Executive functioning (EF). Mattson et al., (1999) found that those with PAE, irrespective of diagnosis, demonstrate difficulties with EF in the domains of planning and impulsivity control, over and above a control sample who had

not experienced PAE. EF difficulties occur in both those with and without average IQ levels (Kerns et al., 1997).

- Sensory and Motor. Research has identified significant difficulties within sensory regulation and sensory processing for those with FASD (Jirikowic et al., 2008). These differences are across a continuum, with some individuals experiencing sensory sensitivities and others displaying sensory seeking behaviours (Millar et al., 2017). Children with FASD have also been shown to experience specific challenges when using visual-motor skills, especially fine motor skills (Jirikowic et al., 2008; Mattson et al., 1999).
- Focus and Attention. Children with FASD experience difficulties with attention and concentration (Millar et al., 2017), consequently they are frequently initially diagnosed with ADHD (Petrenko et al., 2014). However, as Petrenko et al., (2014) noted, such a diagnosis may ‘fit’ a discrete element of the individual’s profile but does not account for the child’s needs in their entirety.
- Communication. Research has identified difficulties with receptive language amongst individuals with PAE, when compared to same aged peers without PAE (Korkman et al., 1998). Conversely, strong expressive language skills can conceal these difficulties (Brown, 2015). Beyond speech and language, Coggins et al., (2007) described social communication difficulties as a particular deficit for those with FASD.
- Cognitive Functioning (CF). CF amongst this population is wide-ranging (Millar et al., 2017). Jirkowic et al., (2008) found that those with FASD scored significantly lower on standardised achievement tests than typically developing peers, whilst others have demonstrated an IQ within the average

range, meaning their overall learning needs may go undetected (Streissguth & O'Malley, 2000).

Individuals with FASD often display a 'spikey' profile characterised by extreme strengths and significant difficulties (see Figure 6). Whilst their needs may be both complex and extensive, these are accompanied by areas of strength (Flannigan et al., 2021). However, as is alluded to throughout this section, for some, this facilitates misidentification of need.

Figure 6

*The Developmental Profile of an 18-Year-Old with FASD (*Blackburn et al., 2012, p.65).

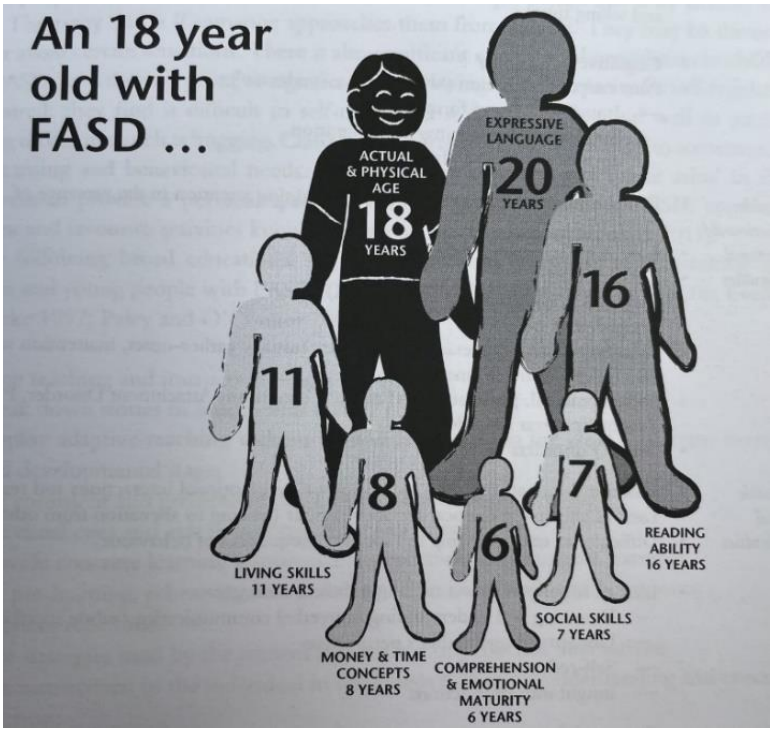
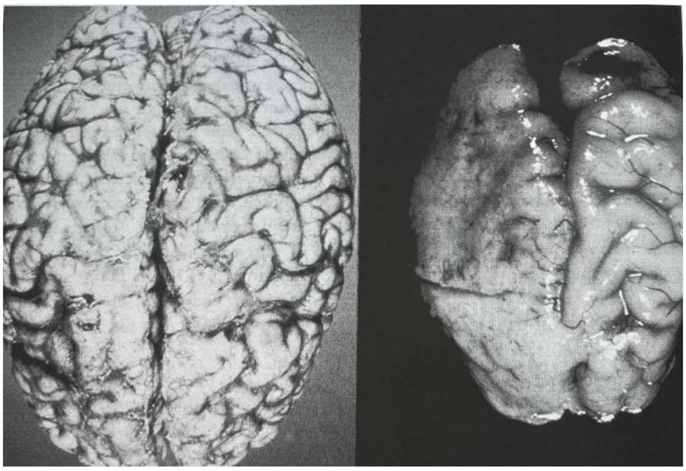


Figure 7

Comparison Between the Brain of a Typically Developing Baby and That of a Baby With FAS (Carpenter, 2014, p. 124)



The compounding difficulties across brain domains for those with FASD can limit progress and affect academic attainment across the curriculum (Millar et al., 2017). They also impact the lifelong outcomes of individuals, as the likelihood of developing a ‘secondary disability’ (now termed ‘associated difficulty’ (National Organisation for FASD, 2020)), is high (Blackburn et al., 2012; Petrenko et al., 2014). Research has identified that adults with FASD are at a greater risk of homelessness, chronic unemployment, experiencing trouble with the law, battling alcohol and/or drug addiction, and not completing their education (Kelly, 2009; Steissguth et al., 2004). One of the strongest predictors of life outcomes was the age at which an individual received their diagnosis (Steissguth et al., 2004). This echoes Petrenko et al., (2014) who found that diagnosis at a later age was more likely to result in additional difficulties. This is concerning when most CYP with FASD are diagnosed close to halfway through their education, in the later years of primary school (Novick Brown, 2011, as cited in Blackburn et al., 2012), owing to the diagnostic challenges discussed previously.

Implications for Education. A growing body of research gathering the perspectives of those with FASD, has revealed a narrative which positions the experience of school as being overwhelmingly challenging and intricately complex

(Duquette et al., 2007; Duquette & Orders, 2013; Edmonds & Crichton, 2008; Knorr & McIntyre, 2016). However, this body of research is not without its broad limitations. The literature is reliant upon retrospective accounts, outside of the context of the UK education system. Similarly, much of the research has only gathered the views of those who are of secondary school age or older, the views of younger children are neglected. Whilst expanding, the same contributors overwhelmingly dominate the current literature. This demonstrates a limitation in terms of the breadth of research available, thus highlighting an area of interest for future researchers. Moreover the use of Tinto's (1975; 1997) student integration model (SIM) by Duquette and colleagues, as a theoretical underpinning should be noted. The SIM offers a framework of school persistence which includes academic and social integration as two core elements. The positioning of findings within such a framework, raises questions around Duquette et al's (2007) claims of inductivity in the analysis of their findings. As such it will be important for future research to establish whether the issue of 'academic' and 'social' integration occur authentically in the experiences of others. Nevertheless, their findings are discussed below due to their relevance to the field.

Duquette et al., (2007) interviewed eight adolescents and sixteen parents to explore factors which support CYP's perseverance and continued engagement with education when they have FASD. Not only did students require considerable support to access learning, but the curriculum was cited as one of two key reasons behind pupils considering or deciding to drop out of school, with the other contributor being teachers. Memories of school were positively framed when individuals had felt able to participate academically (Duquette et al., 2007). This positions those with FASD as akin to pupils with other special educational needs and disabilities (SENDs), in demonstrating that successful outcomes are possible when appropriate adaptations have been identified and implemented, i.e. inclusion. This message is not necessarily prevalent amongst research situated within a medicalised model, which attributes ‘within-child’ factors, contained within a diagnostic label, as the leading cause of educational difficulties (Booth & Ainscow, 2017). Whilst the above findings provide hope, and recommendations for differentiated learning have been offered (Duquette et al., 2006; Duquette & Orders, 2013), the phenomenological methodology of the described research means that the priority was to capture the lived experience of participants. The aim was not to seek a pragmatic and thorough exploration of what works, this remains an area for future research.

Research suggests that pupils with FASD experience difficulties particularly in less-structured environments. These increase as students progress through education, meaning school often becomes increasingly difficult with age (Duquette et al., 2007). This relates to reports by parents and pupils of numerous incidences of externalised anddysregulated behaviours in school (Duquette et al., 2007). Malbin (2004) argues that these behaviours should be considered only as symptoms, or means of expressing such difficulties, because FASD is a brain-based, physical condition. Yet research suggests that pupils’ behaviour in school often resulted in disciplinary action, including multiple suspensions and expulsions (Duquette et al., 2007; Knorr & McIntyre, 2016; Sanders & Buck, 2010). This is suggestive of behaviour not yet being recognised as a means of communication. This is fuelled by the ‘within-child’ approach which deflects away from barriers occurring within the systems surrounding the child. As Booth and Ainscow (2017, p.44) argue, “barriers to learning can occur in interaction with any aspect of a school”. Students with FASD have themselves recognised the complexities of the school system through their descriptions of school as an environment consisting of multiple components; physical, social and academic. The ‘academic’ element has been highlighted in this review thus far, however, students report a multitude of challenges across them all (Duquette et al., 2007). Research demonstrates that often these difficulties provide context to the behaviours displayed in school. For instance, adolescents explained how they disguised their learning difficulties through a persona as the “class clown” or offering an “f-you image” (Knorr & McIntyre, 2016, p.62). This relates to findings from Petrenko et al., (2014) that individuals with FASD hold an inherent dislike of feeling different in school. Another study found that because of their diagnosis of FASD, individuals saw themselves as different to their peers, which led to resistance in engaging with learning support (Knorr & McIntyre, 2016).

The role of peers is consistently identified as influential to the individual experience of school; however, this extends across two opposing constructs. On the one hand, students describe peer relationships as important and cite them as a significant factor for social integration within school (Duquette et al., 2007). Contrastingly, friendships are also an aspect of school which proves challenging (Duquette et al., 2007), a difficulty expressed by younger children also (Blackburn, 2010a). Individuals amongst this population are at a greater risk of bullying and ostracism amongst their peer group (Knorr & McIntyre, 2016; Kully- Martens et al., 2012). Indeed, Corrigan et al., (2019) recognised ‘social exclusion’ as one form of discrimination that children with FASD experience. Adults with FASD have also recalled how a desire to fit in, belong, and develop friendships, drove their behaviour and led them to succumb to peer pressure whilst at school (Knorr & McIntyre, 2016). This was also captured in research exploring parental concerns around the appropriateness of certain friendships and their child’s vulnerability and impressionability within them, including the ability to distinguish between friends and acquaintances (Duquette et al., 2007; Duquette & Orders, 2013; Sanders & Buck, 2010). Feeling like they do not ‘belong’ is a recurring theme in the literature relating to the experiences of education for those who have FASD (Duquette et al., 2006; 2007; 2012). According to Maslow’s Theory of Motivation (1943), belongingness is important for one to achieve their full potential. The need to belong is a fundamental human motivation, characterised by high-quality interpersonal relationships (Baumeister & Leary, 1995). This has strong associations with Bowlby’s (1969) Attachment Theory, in which the need to form relationships with primary caregivers has evolutionary underpinnings and forms the basis for future relationships. McMillan and Chavis (1986) describe four key elements that contribute to a sense of belonging: membership, influence, reinforcement, and shared emotional connection. In the context of FASD, membership and shared emotional connection are most pertinent, and described by Duquette et al., (2006; 2007; 2012) as ‘social integration’. Membership involves feeling part of a group and is consistent with Tajfel’s (1979) proposal that belonging to a particular ‘group’ relates to self-esteem and pride. A shared emotional connection involves positive interactions and developing strong bonds. Hammond (2021) explored experiences of belonging amongst primary school aged pupils with FASD, thus addressing a gap exposed by research which gathered the views of older students only (Duquette et al., 2006; 2007). They identified students who did feel that they belonged; however, this finding is not supported by previous literature. This likely relates to a further novel finding, that friendships provided emotional, physical, and academic support to them through a ‘peer advocacy role’. As Hammond (2021) acknowledges, this provides hope that intervention may combat difficulties associated with social integration and FASD, however, again this calls for additional research.

The School System

Educating Pupils with FASD. What is clear from research exploring the professional view from the classroom, is that the difficulties associated with education are not simply academic (Blackburn, 2010a; Carpenter, 2008, as cited in Carpenter, 2011), thus reiterating findings discussed previously. It is therefore unsurprising that meeting the educational needs of these individuals is difficult (Whitehurst, 2011). Teachers indicate that the challenges of supporting those with FASD in the classroom are wide-ranging, including hyperactivity, short attention spans, mood swings, poor memory and retention, impulsivity, limited social skills, auditory processing, visual sequencing, sensory integration difficulties, and difficulties relating to numeracy and literacy (Blackburn, 2010a; Carpenter, 2008, as cited in Carpenter, 2011). It is noteworthy that only two of the identified challenges relates to a specific subject, thus illustrating how it is the breadth of cognitive functioning which makes learning a difficult experience for many with FASD. Undoubtedly this presents an enormous task for educational professionals supporting these CYP. Educators in South Africa have described feelings of helplessness, exhaustion, and frustration at what they are able to achieve within the scope of the child’s abilities and systemic expectations (Van Schalkwyk & Marais, 2017). Given that these experiences exist in a country where prevalence is high and understanding of FASD is well-established, significant concerns are raised in terms of the effects on wellbeing amongst UK teachers.

Brown (2015) noted that questions are often asked around the ‘type’ of school that those with FASD should attend and be educated in, however, research exploring this is sparse. Speaking to individuals with FASD, Duquette et al., (2007) found that they are educated in a variety of placements, both mainstream and specialist. Millar et al., (2017) argue that this may relate to the wide variance amongst cognitive functioning for these individuals, as the allocation of specialist school placements is often reliant on IQ or standardised measures. Given the ‘spikey profile’ of FASD, pupils may perform well on assessments, despite experiencing other learning challenges. Thus, they may not qualify for specialist support. Conversely, not all individuals with FASD will require specialist provision, owing to the heterogenous developmental profile. Research suggests that many thrive with adequate intervention, adaptations and understanding (Carpenter, 2011, Millar et al., 2017). To the author’s knowledge, Popova et al., (2016) is the only study to seek to ascertain the prevalence of students with FASD that were educated in special schools. They received concrete data specifically related to FASD, rather than generalised SEND information, from only two regions of Canada, however, they made a provisional estimate of 9%. Whilst they positioned this as a conservative figure, it is indicative of students with FASD in Canada being largely educated in mainstream settings. There exists a need for further research to assess prevalence elsewhere and establish a clearer picture of where individuals with FASD are educated.

Adaptations within the learning environment remain a consistent recommendation in the literature (Duquette et al., 2007; Hammond, 2021), yet there exists a clear shortfall in guidance for teachers on how to educate children with FASD in the UK. This leaves educational professionals pedagogically bereft and presents a barrier to successful implementation of adaptations in the classroom (Carpenter, 2011). It was not until recently that frameworks for use in the classroom for children with FASD became available, comprising of teaching and learning strategies and environmental considerations (Blackburn, 2010a). Distinct recommendations have been offered for those in early years (Blackburn, 2017), primary school (Blackburn, 2010b) and secondary settings (Blackburn, 2010c). To the author's knowledge, Blackburn's (2010a) project is the largest, UK based research which considered parents', students', and teachers' perspectives on FASD and education. The frameworks provide strategies and guidance for teachers in relation to the following areas: being healthy, staying safe, enjoying and achieving, making a positive contribution and achieving economic wellbeing. The authors helpfully draw distinctions between the presentation of FASD in earlier and later years, thus supporting teachers who work throughout the sector. Whilst the findings are thought provoking and insightful, attention must be drawn to the fact that this was published prior to the updated SEND Code of Practice (CoP) (Department for Education (DfE), 2015). Findings may not necessarily be reflective of current educational experiences from these stakeholders. For instance, since the SEND CoP (DfE, 2015), there has been greater emphasis on collating and listening to the views of individuals with SEND and their parents. Whilst the previously described frameworks do discuss the importance of schools developing partnerships with parents, this could be developed further to provide actionable next steps of how schools might achieve these. As such, it is important for future research to seek to provide updated perspectives. Similarly, despite their availability, it remains unclear whether teachers are aware of the previously described resources, particularly as they have been driven by a select number of key researchers in the field and remain 'unofficial'. Consequently, their accessibility remains a barrier to wider use.

As has been demonstrated by this review, FASD spans across a breadth of professions, including health, education and social care. As such, it is evident that the multi-professional approach advocated for by the SEND CoP (DfE, 2015) is especially pertinent to this condition. Whilst a multi-professional team is required as part of the diagnostic process (SIGN 156, 2019), this joined up working does not cease once a diagnosis is obtained. Green (2007) highlights that teachers, psychologists, SALTs, OTs, and education support staff, all play a key role in facilitating academic success for pupils with FASD, through intervention. However, Petrenko et al., (2014) found that parents experienced numerous systems-level barriers to accessing such support for their child. Parents felt that FASD was not an established category of need, pertaining to difficulties qualifying for support services. Often no services were available, or if there was, the implementation was questionable due to inadequate resourcing and poor knowledge of the condition. Similarly, where diagnosis of FASD is delayed, and attributions of need are assigned to another condition, children regularly received interventions which simply did not address the specificity of their needs. The breadth of learning difficulties experienced by those with FASD specifically makes the choice of intervention difficult, not least for educational settings (Blackburn et al., 2012). As observed by Berger (2014), there is no official guidance on educational strategies to support pupils with FASD. This may relate to the fact that there is seemingly no one uniform approach to supporting these individuals, although traditional methods are typically unsuccessful (Roberts, 2015). Researchers who have attempted to design prescriptive educational interventions have primarily been based in Canada or the United States of America (USA), meaning findings are not necessarily transferable to other countries. In an international review of FASD interventions, Petrenko and Alto (2017) identified that whilst research considering appropriate interventions was increasing, only six out of twenty-four were appropriate for use in education settings. This suggests that whilst education is an identified concern, it is not yet a priority. Three of the interventions identified by Petrenko and Alto (2017) targeted attention and self-regulation difficulties (Kerns et al., 2010; Riley et al., 2003; Vernescu, 2009), whilst the others focused on adaptive functioning, specifically literacy and language training (Adnams et al.,2007), maths support (Coles et al., 2009; Kable et al., 2007; Kable et al., 2015), and safety (Coles et al., 2007; Padgett et al., 2006). These all had varying levels of success. For instance, Kerns et al., (2010) evaluated the effects of a computerised attention training programme for children aged thirteen to fifteen years old with FASD. They found that over a period of nine weeks, there was an improved cognitive performance on measures of distractibility, sustained attention, divided attention, working memory, maths and reading. However, the assessments used to measure the pre and post data were designed for use with younger children, meaning they may have been less sensitive for detecting change amongst their recruited participants. Similarly, the study was conducted over a relatively short period of time and the sustained effects over time remain unknown. This is an ongoing issue with interventions supporting this population and a limitation shared with Kully- Martens et al's., (2018) research which found that after ten mathematics intervention sessions, over a period of 6-8 weeks, those with FASD improved their score on the 'Key 3 Math Diagnostic Assessment'. However, it was not possible to identify a causal relationship. It is also likely that the delivery of the intervention functioned as a mediating variable. The intervention took place on a 1:1 basis which may have supported attention and concentration. Similarly, when one considers Maslow's Hierarchy of Needs (1943), it seems probable that the relational nature of close working may have been a supportive factor. Individuals with FASD have themselves named individual support and attention as being a valuable part of their school experience (Edmonds & Crichton, 2008; Hammond, 2021). Furthermore, participants received ten sessions of thirty minutes over a brief period. This likely supported difficulties associated with memory and retention. Consequently, findings provide evidence for the need for repetitive learning opportunities rather than an ‘off the shelf’ intervention. Whilst these questions might be addressed by longitudinal research, the nature of FASD, means that the effects of PAE are irreversible, it remains unclear the extent to which the associated difficulties can be improved longer term. For instance, Adnmans et al’s., (2007) research concluded that those with FASD can benefit from language and literacy training which is designed for those who have other additional needs or are ‘at risk’ of working below same aged peers, although the gains varied from very small to large. Interestingly, they identified a significant association between teacher’s assessments of behaviour and the early literacy scores of individuals with FASD. Indeed, poor behaviour was linked to less developed early literacy scores. However, whilst early literacy scores saw the greatest improvement following intervention, improvements in behaviour were not reported. It is unclear whether this information was measured or simply unreported in the publication, nonetheless, it raises questions around the impact of such interventions. On the other hand, parents have expressed exasperation at interventions and/or support being removed once positive outcomes become evident (Petrenko et al., 2014), suggesting that caregivers have observed improvements and believe support should be ongoing. However, when one considers the contents of this review, we are reminded that the learning profile of those with FASD is uneven and varies from day to day (Blackburn et al., 2012; Roberts, 2015; Westrup, 2013). As such, it may not be appropriate to seek to devise a uniform intervention, instead individualised interventions which consider personalised learning pathways may be most helpful (Blackburn et al., 2012; Poth et al., 2014). According to the evidence base outlined previously, there is seemingly greater benefit from use of adaptations to learning (Duquette et al., 2007; Hammond, 2021), rather than the use of interventions which seek to reduce, or reverse, the permanent, ‘primary disabilities’ associated with FASD.

An Individualised Approach. There is an emerging evidence base which highlights a role for engagement in educating students with FASD. When CYP with FASD were asked to describe which subjects they enjoyed the most, both numeracy and literacy received the highest ratings, alongside art and physical education (PE) (Blackburn, 2010a). This occurred despite teachers observing specific difficulties within the former two subjects. This offers an opportunity to reflect and distinguish between ability, as assessed by teachers, and engagement, as being pertinent to supporting those with FASD. Engaging a particular pupil requires an understanding of the individual, the essence of an individualised approach. Within Edmonds and Crichton’s (2008) research, individuals valued learning which related to their personal interests, and lessons which were deemed interesting, including creative and practical learning opportunities. This was echoed by others who shared that boredom and uninteresting lessons inhibited their desire to persist with education (Duquette et al., 2007). It is important to consider a personalised learning programme which recognises both strengths and areas of interest to support educational attainment for these CYP (Blackburn et al., 2012; Job, et al., 2013; Pei et al., 2013).

Carpenter (2011) argues that the focus should not be on identifying the difficulties of those with FASD, but how teachers optimise learning. The challenge for teachers is to recognise and identify the developmental level of each individual child

(Blackburn et al., 2012). A tailored and individual approach to support was cited as being valued by four primary aged participants with FASD, educated in the UK, in Hammond's (2021) research. They noted that when educators understood their needs, they were better able to implement an individualised approach, which in turn facilitated belonging. Educators have also reported success in the classroom when consideration is given to their learner's unique competencies, including learning within their abilities and doing more of what they do well (Van Schalkwyk & Marais, 2017). However, whilst teachers expressed an ardent desire to empower their students, they cited a lack of professional knowledge and support as barriers to achieving optimal learning potential (Van Schalkwyk & Marais, 2017). Flannigan et al., (2021) attribute this to what they term the overbearing medicalised approach to FASD research, resulting in the exploration of educational strengths being neglected.

In their critical review, Flannigan et al., (2021) identified only two studies which adopted a strengths-based approach when considering children with FASD, a further eight involved adolescents, and nine included adult participants. Flannigan et al's., (2021) review showcased the breadth of positive attributes which exist within those with FASD. They demonstrated self-growth, including notable progress with their use of manners, understanding consequences of their actions (Timler & Olswang, 2001), strong self-awareness (Burles et al., 2018) and personal characteristics of hard-work and talent in areas such as art and sport (Duquette et al., 2006; Duquette et al., 2007). However, research adopting a strengths-based approach remains an area for future research to prioritise. Flannigan et al., (2021) highlighted the need for the recognition of meaningful strengths which may be associated with positive outcomes, as opposed to surface level qualities which appear prominent in what little literature does exist.

Knowledge and Understanding. Petrenko et al., (2014) noted a pervasive lack of knowledge around FASD which permeates multiple systems, including education. In Blackburn's (2010a) research, 90% of the teachers cited the internet as their primary source of information about FASD, 80% sought advice from more experienced colleagues, and 40% required parents to share their knowledge. Only one teacher gained information by attending a special educational needs (SEN) seminar. This exposes a potential limitation of initial teacher training (ITT) and continuous professional development (CPD) opportunities. Blackburn (2009) as cited in Blackburn and Whitehurst (2010), found that 78% of early years managers, in one region of the UK, reported knowing 'nothing' or 'very little' about FASD. This is not entirely unexpected when we consider how unclear information is provided to the public. More positively, Blackburn (2010a) identified that in a sample of ten teachers, eight rated themselves as 'reasonably confident' or higher when asked about their confidence in supporting a student with FASD in their classroom. However, none of the teachers had heard of FASD prior to teaching their current student, which raises concerns around the implications for those without a diagnosis. As Carpenter (2011) noted, many education settings are not aware that they have CYP with FASD in their pupil population. This strengthens the argument, outlined by Mukherjee et al., (2006), that an effective outcome of diagnosis could be an improved understanding of the learning profile of those with FASD. The need to improve teachers' knowledge is further evidenced by Duquette et al., (2007). They found that parents felt teachers did not consistently differentiate their teaching, particularly when their knowledge of FASD was poor. As such, where FASD is not understood, educational attainment is likely to be negatively affected (NICE, 2019). This is because if teachers are unaware of this group, it is not possible for them to plan specifically to meet their learning needs (Carpenter, 2011).

Research suggests that the impact that teachers have on those with FASD extends beyond facilitating attainment outcomes. Pupils with FASD have recalled how their teachers were of upmost importance for supporting or diminishing school persistence (Duquette et al., 2007), and were sources of strength whilst riding the wave that is education (Knorr & McIntyre, 2016). However, one mediating variable across the literature pertains to the level of knowledge and understanding that one's teacher held in relation to FASD (Duquette et al., 2006; Duquette et al., 2007), particularly around behaviour. This review has highlighted that understanding around behaviour features heavily in the individual's experience of education when they have FASD, yet the relationship between this and teacher's knowledge is yet to be discussed.

A poor understanding of FASD results in assumptions and inaccurate labelling which may lead to lifelong, associated conditions (Roberts, 2015). Whilst Roberts (2015) described difficulties for pupils to 'conform' to social norms and rules, one must recall Malbin's (2004) argument that behaviours are merely symptoms. However, the application of such an argument is not yet evident in schools. For instance, adolescents and adults have described their teachers' perceptions of them as 'stubborn' or 'unmotivated', as failing to recognise that they were struggling to cope with overwhelming sensory input (Salmon & Buetow, 2012). This reiterates the finding that self-awareness is a relative strength amongst this population (Burles et al., 2018) and reveals that their understanding of behaviour exceeds those who are supposed to support them. This highlights the value in the SEND CoP's (DfE, 2015) rationale that one must capture and listen to pupil voice. Knorr and McIntyre (2016) found that teachers' misattributions resulted in fractious student-teacher relationships. Individuals described feeling disliked by their educators, and whilst some did feel bonded to their teacher, many did not. Students with FASD in Duquette et al's., (2007) study, named teachers as one of the main influencing factors affecting disengagement with education. In research by Poth et al., (2014), teachers, members of school leadership, relevant professionals, and caregivers, noted the importance of 'understanding the whole student' and interacting with the individual to develop strong relationships. These are emotive findings when viewed alongside those of Flannigan et al., (2021), that capacity for human connection is a particular strength amongst individuals with FASD. Moreover, social integration, a vital component of the individual school experience, was more often achieved through peer relationships than those with teachers (Knorr & McIntyre, 2016). This is particularly troubling when we consider the importance of student-teacher relationships for all learners (Hattie, n.d.).

Corrigan et al., (2019) highlighted the stereotypes, prejudice and discrimination experienced by individuals with FASD as part of a community based participatory research project. Stakeholders included two biological mothers, an individual with FASD, one adoptive mother, a researcher and four health professionals. Whilst views were collated using a small, unrepresentative group, the findings that individuals are viewed as 'different', 'immature', 'lazy' and 'unable to learn', make for difficult reading, not least because this merely represents a proportion of views. This evidences Flannigan et al's., (2021) argument that pathologising FASD leads to individuals being considered burdensome. In the classroom, Pei et al. (2015) postulate that the views which teachers hold of their students is significant in educating pupils with disabilities. They categorised educational professional's knowledge as ‘basic’ or ‘advanced’. A basic understanding meant recognising FASD as relating to prenatal alcohol exposure (PAE) but not identifying primary (e.g. difficulties with executive functioning) and associated needs (e.g. low self-esteem), for which an ‘advanced’ understanding accounted. They found ‘basic’ knowledge to be equal across elementary and secondary school staff, however, ‘advanced’ knowledge was lesser amongst high school teachers. Furthermore, they identified a relationship between Canadian teachers’ knowledge and their conceptions of students with FASD, including that they had low intelligence and were deliberately oppositional. Teachers from elementary school were better able to recognise the influence of school factors. Secondary school professionals were most likely to attribute behavioural difficulties as relating to within-child factors being ‘fixed,’ and viewed the pupils’ behaviour as a choice. As recognised by Corrigan et al., (2019) it is important that future research establishes education professionals’ views of individuals with FASD and strives to shift this narrative. From the perspective of students with FASD, when they felt understood by their teachers, they reported more positive experiences of school (Duquette et al., 2006; Duquette et al., 2007; Hammond, 2021). This related particularly to the recognition that behaviour for these individuals is not a choice. Indeed, Malbin (2004), advocates for a shift amongst education professionals away from seeing a student with FASD as someone who ‘won’t’, and towards understanding the pupil as someone who ‘can’t’. Where teachers have not yet reframed their narrative, research suggests that parents and students feel that inappropriate strategies are implemented in class, which perpetuate feelings of being different and humiliation (Duquette et al., 2006). Conversely, where students consider teachers to be kind and understanding, a sense of belonging is fostered (Hammond, 2021). Fundamentally, the above provides further evidence for the need to consider FASD within a systemic perspective, as within the school system, the individual does not operate in isolation.

The Family System

The family system for individuals with FASD is multifaceted, often including relationships with biological, foster, and adoptive parents or caregivers (Blackburn et al., 2009). Consequently, nuanced experiences exist within the literature dependent on what role the caregiver has in caring for their child. To better understand the parent experience within a ‘home-school’ context, this section explores research findings based on the experiences of those who continue to have an active role in raising an individual with FASD.

Raising an Individual with FASD. Parents of those with FASD share similarities with parents of those with other additional needs, particularly at the time of diagnosis (Balcaen et al., 2021; Brown & Brown, 2014; Whitehurst, 2011). The research base, however, suggests that this is where the shared experience ends. Upon receipt of diagnosis, parents naturally seek to acquire further knowledge of the condition (Opini, 2019; Balcaen et al., 2021). For adoptive parents, diagnosis is often a surprise because they were either not made aware or were ill informed of the possible effects of PAE on functioning during the adoption process (Sanders & Buck, 2010; Mukherjee et al., 2013). The 2014 research completed by Petrenko et al., found that parents reported having to educate themselves due to a perceived lack of knowledge across professionals. They expressed frustration at how this differed to other diagnoses, such as ASD and Down’s Syndrome. Duquette et al., (2012) found that parents’ primary sources of information were books, television, newspapers, and the internet, from which they pieced together the ‘bits and pieces’ available to them. This is of concern given that individuals with FASD are not homogeneous, nor do they follow a linear or predictable trajectory (Blackburn & Whitehurst, 2010). Raising an individual with FASD is described as a “different” and a “unique experience” (Mukherjee et al., 2013, p.48), which is both difficult and exhausting (Balcaen et al., 2021). However, there remains deficient recognition and support for these individuals (Mukherjee et al., 2013; Petrenko et al., 2014; Whitehurst, 2011). This is consistent with teachers’ experiences of educating this population (Van Schalkwyk & Marais, 2017).

Whitehurst (2011) identified a distinct lack of provision for families and their children, owing to a lack of services who understood the condition. One caregiver in Job et al’s., (2013) research, described being unsure of where to go or who to talk to, and happened upon support by chance from a knowledgeable professional. Petrenko et al’s (2014) research highlighted that support groups were fundamental for parents in spreading awareness of support pathways via word of mouth. This highlights the extent to which caregivers amongst this population are required to go beyond but do so independently. As Corrigan et al., (2019) write, this relates to structural discrimination, where services are better resourced to support children and their families who have other diagnoses, despite the prevalence of FASD being higher (Westrup, 2013).

Caregivers within Balcaen et al’s (2021) research shared times of ‘crisis’ when their children experience dysregulated behaviour in their homes. A sentiment echoed in Sanders & Buck’s (2010) findings where parents describe ‘living in a war zone’. Despite the best intentions of this review to reframe behaviour in the context of FASD, the fact remains that living with, and coping with, certain behaviours is difficult (Sanders & Buck, 2010). Parents perceive that these behaviours have consequences for the entire family. This is most difficult for biological parents once their child learns more about the aetiology of their condition (Thomas & Mukherjee, 2019). Research suggests that tension can occur as the stress strains relations throughout the family system including parent-child, sibling and marital relationships (Balcaen et al., 2021). For instance, marital relationships are affected by disaccord within approaches to behaviour management, there is a need for consistency between parents to best support one another (Sanders & Buck. 2010; Balcaen et al., 2021). Research suggests that raising an individual with FASD is a learning curve (Balcaen et al., 2021). Traditional parenting strategies are often ineffective owing to the complexity of need (Sanders & Buck, 2010). For instance, behaviourist approaches of praise, reward, and consequences are less effective for individuals with FASD due to memory difficulties (Sanders & Buck, 2010). Similarly, telling a child not to lie is futile for those with FASD who confabulate due to memory difficulties (McCarthy et al., 2022). Instead, parenting involves a trial-and-error approach, which develops over time so that they become well-versed in what works for their child (Balcaen et al., 2021; Sanders & Buck, 2010). These findings illustrate how important it is that parental expertise is recognised.

In research, CYP have consistently recognised and expressed their appreciation of the emotional and academic support their parents provide (Duquette et al., 2006; Hammond, 2021; Knorr & McIntyre, 2016). Parents are aware that the need for their assistance and input will likely be lifelong (Balcaen et al., 2021; Sanders & Buck, 2010). However, as parenting demands simply alter, rather than decrease, there are ongoing implications for parental autonomy, including loss of identity (Swart et al., 2014). Parents report feeling isolated from their communities because of their child’s behaviour (Corrigan et al., 2019; Mukherjee et al., 2013; Petrenko et al., 2014). Social inclusion is an important part of parental wellbeing, yet the characteristics of FASD are more difficult to navigate outside of the home environment, which can be controlled and adapted (Balcaen et al., 2021). Beyond those four walls, parents and their children are exposed to the attitudes and beliefs of others. This further pressurises parents (Mukherjee et al., 2013), leaving them longing for affirmation yet instead feeling inadequate (Brown, 2015; Swart et al., 2014). Research by Balcaen et al., (2021) suggests that there exists a 'negative feedback loop', where the constant cycle of receiving negative responses from society, school, and other family members results in feelings of self-doubt and challenges parental wellbeing. Parents report the need to explain or justify their situation to protect themselves and their family from judgement, that the child's difficulties relate to the quality of their parenting (Balcaen et al., 2021). This was supported by Pei et al., (2015) who found that secondary school teachers especially were likely to attribute student's difficulties to poor parenting. Research indicates this to be a shared experience for biological and adoptive parents alike (Mukherjee et al., 2013). A lack of understanding is greatest for those whose children present without physical features, whereby they 'seem alright on the outside' (Balcaen et al., 2021). All who fulfil the role of 'parent' report experiencing blame for their child's presentation (Balcaen et al., 2021; Cleversey et al., 2017; Sanders & Buck, 2010; Swart et al., 2014), although biological mothers often also blamed themselves (Swart et al., 2014). On occasions adoptive parents felt compelled to share that their child was adopted to avoid assumptions being made about them, despite not wanting to reveal the way in which they came to be parents (Whitehurst, 2011). This relates to Corrigan et al's., (2019) findings that birth mothers are stereotypically viewed as 'child abusers' and 'addicts' who were deserving of harsh judgements. Their interactions with others were often characterised by anger and disapproval directed towards them. This provides further evidence of a lack of public knowledge of FASD and stigmas surrounding the condition, particularly around the demographic of 'who' may be affected by FASD (Balcaen et al., 2021; Mukherjee et al., 2015). A seeming us (public) and them ('child abusers'/ 'addicts'). Although, adoptive parents have expressed these opinions of biological mothers also (Sanders & Buck, 2010).

Given the longevity of the parental role, it is unsurprising that apprehension about the future is a particular concern (Mukherjee et al., 2013; Adoption UK, 2020). However, education specifically is a recurring topic within this. Balcaen et al., (2021) found that school success was a high priority for parents and a perceived marker of overall parenting achievement. Brown and Brown (2014) suggest that formal education provides an opportunity for parents to compare a child with FASD to those following a typical developmental trajectory. It is possible that parental concerns are at least partly related to noticing the extent of difficulties their child experiences. Further support for this comes from Mukherjee et al., (2013), who found that regardless of the age of CYP, parental anxiety existed around how their child would cope in primary school or later during the transition to secondary school. This is reflective of the ever-changing profile of CYP with FASD, which occurs over time, resulting in subtle differences at various stages of their educational journeys (Blackburn et al, 2009). However, it may also relate to Opini's (2019) finding whereby parents feel great responsibility around decision making and identifying a setting which is the right fit for their child. A role which this review has highlighted certainly has its challenges. Despite this, research is primarily positioned within a health perspective and leaves education unexplored.

The Parent/ Caregiver Voice. The SEND CoP stipulates that we should consider the "views, wishes and feelings" of parents (DfE, 2015, p.19). However, research exploring the parental perspective of FASD is limited in the UK, and even in countries with an advanced understanding, parents remain unheard, (Job et al., 2013; Poth et al., 2014). Job et al., (2013) found that a fear of being judged leads some to remain silent and not share their perspectives. Thus, highlighting the need to empower parents and caregivers. Where they are given a voice, parents' language is highly emotive. They speak of "struggles" (Whitehurst, 2011, p.190), "fight" (Whitehurst, 2011, p.189), "feeling isolated" (Brown, 2015, p.24); and repetitive participation in a "tennis game of help" (Brown & Brown, 2014, p. 65). Research which simply presents these concerns alone is insufficient, as it does not provide space for parents to express their views about what could be done to support their children. In research thus far, the inclusion of parents and caregivers was often not the overall research aim (Duquette & Stodel, 2005; Duquette et al., 2006). Instead, they facilitated their child's contributions, as youth with FASD may not have the cognitive capabilities, knowledge. or insight into their condition to participate completely (Cleversey et al., 2017). Despite this, these studies identified that parents play a vital role in their children's lives. Duquette and Stodel (2005) identified that caregiver support is the most crucial factor contributing to perceived educational success. They also found that caregivers' perceptions of educational success were correlated with actual educational persistence, meaning pupils were less likely to drop out of school. In other research, their representation is unequitable compared to other stakeholders (Corrigan et al., 2019; Job et al., 2013; Pei et al., 2013; Poth et al., 2014), so questions are raised around their participation being tokenistic in providing triangulation for the views of others. Issues too exist within recruitment where caregivers were recruited via support groups and therefore findings are not necessarily reflective of those who are not yet accessing such provision (Thomas & Mukherjee, 2019). Where parents have been prioritised, small participant pools have been used including a case study methodology (Opini, 2019), which raises concerns around generalisability of findings. In others, this nature of the sample suited the study's phenomenological methodology (Balcaen et al., 2021; Whitehurst, 2011; Sanders & Buck, 2010), however, this approach is concerned with the individual experience and is a position adopted by much of the current research. It does not seek to make recommendations for positive change which might be achieved through a pragmatic or critical realist stance. As Flannigan et al., (2021) note, more research is needed to consider how the individual and systemic factors work together to best support positive outcomes. This highlights a seeming gap in the field.

The Family-School System Interaction

Joint Working. Green (2007) emphasised the importance of a multi-systemic approach to supporting individuals with FASD; specifically, school professionals and family members working alongside other services as a 'team'. More recent research highlighted that this has not yet been achieved. Cleversey et al., (2017) sought to identify caregivers' needs to support their child to be successful in school. A multitude of experiences were collated as part of the largest study exploring the interaction between the family and school system specifically. However, the use of concept mapping methodology resulted in qualitative data becoming quantitative. Thus, clarification or in-depth exploration of the concepts, from participants' perspectives, are not presented within their findings. Nevertheless, of relevance to joint working, Cleversey et al., (2017) identified frustrations around knowledge and understanding of FASD within education, and the importance of collaboration and communication.

Insufficient knowledge across systems has been reiterated throughout this review (e.g. Petrenko et al., 2014), thus supporting Cleversey et al's., (2017) findings. Green (2007) also argued that caregivers, health, and education professionals require equitable skills and knowledge to address the complexity of need amongst this group of students. However, in the UK, a recent survey conducted by Adoption UK (2020), found that 70% of parents whose child had a diagnosis of FASD felt that their child's school did not understand the condition. This is a troubling statistic and one that is triangulated by Blackburn and Whitehurst's (2010), and Blackburn's (2010a) research, which highlighted limited awareness amongst teaching staff. However, as with Cleversey et al., (2017), further qualitative research is required to better understand the experiences behind the numbers and ascertain why this finding reoccurs. This is particularly important as Job et al., (2013) found that a lack of knowledge impedes collaborative working with families, something which caregivers deemed necessary in Cleversey et al's., (2017) research.

Collaboration supports students to achieve their goals (Green, 2007), and enables supportive learning environments which increase the likelihood of pupils graduating from high school (Duquette et al., 2007). With collaboration comes a relationship, the strength of which is important in facilitating success (Poth et al., 2014). Job et al., (2013) focused particularly on collaboration and communication, and identified inconsistencies between caregivers' and school professionals' stances. Parents recognised the need to build relationships which value and respect the parental contribution to their child's educational experience, a finding corroborated by Cleversey et al., (2017). Whereas members of school leadership and teachers emphasised the need for caregivers to recognise their expertise, show willingness to form relationships, and cooperate in maintaining consistency, particularly with behaviour management. This is interesting when one considers the lack of knowledge around FASD, which is self-reported by teachers (Blackburn & Whitehurst, 2010; Blackburn, 2010a). Additionally, it provides further evidence of misattributions around behaviour, a consequence of poor knowledge (Duquette et al., 2007; Knorr & McIntyre, 2016). However, the participant in Opini's (2019) case study suggested there is no expectation on teachers to have the answers, instead it is important that they admit what they do not know and commit to finding the answers. Job et al's., (2013) findings may relate to the hierarchy of the school as an organisation. Dowling and Osbourne (2018) suggest that leadership shapes whether schools are open or closed systems and consequently resist change or acknowledge alternatives, such as those offered by parents. Indeed, 'resistance' has emerged within the literature (Poth et al., 2014), with one parent recently describing her experience of getting acknowledgment from school of her child's difficulties as "a brick wall" (McCarthy et al., 2022, p. 48). However, the school organisation argument suggests there will be distinctions between schools on a case-by-case basis. Whilst educational professionals in this study may not have felt supported by caregivers, this is inconsistent with research thus far which has demonstrated that parents are very much present but are not heard or listened to. Caregivers within Poth et al's., (2014) research felt dismissed, and others have reported that their perspectives were not sought at all (Job et al, 2013). This highlights an issue which exists both within and beyond the school organisation itself. One would hope this had been remedied by the emphasis on parental voice in the SEND CoP (DfE, 2015), however, this has not yet been considered by recent research. Within Adoption UK's (2018, p.10) report, Dr Sarah Brown, a Community Paediatrician, noted that a diagnosis is primarily not to inform parents but to encourage schools to listen and take parental concerns on board. The author acknowledges that debate around the significance of diagnostic labelling is well documented (e.g. Lauchlan & Boyle, 2007) and the aim of this review is certainly not to present an argument for either side of the debate. However, the author cannot help but consider the implications of the above for those who may not yet have received a diagnosis, especially given the complexities associated with obtaining one. These findings suggest that many individuals will remain unsupported and provide support for a shift away from the reliance on a medical model within the context of FASD.

When one considers the importance of listening to parents, the role of communication for effective collaboration becomes increasingly clear (Cleversey et al., 2017). Parents and teachers alike have emphasised the importance of this being early and frequent (Job et al., 2013). However, the need to manage this sensitively has been raised by caregivers who attribute daily negative feedback from school as being detrimental to their stress levels (Balcaen et al., 2021; Job et al., 2013; Poth et al., 2014). This relates to the ‘feedback loop’ within systems and reinforces the application of systems theory to FASD. Another recurring problem with communication between the family and school systems in this context, is trust (Poth et al., 2014). Job et al., (2013) first identified this in their findings, in which calls were made for greater transparency, including openness and honesty from education settings. Whilst resistance of this kind may relate to the dynamics of the school organisation discussed previously, the issue of trust has presented itself subsequently in research by Cleversey et al., (2017) and most recently McCarthy et al (2022). The latter study occurred during the COVID-19 pandemic, whereby school closures resulted in a need for home learning. One parent shared that they came to better understand their child’s academic needs, compared to their peers and felt there was evidence to suggest her child was significantly behind, which was at odds with communication from school (McCarthy et al., 2022). However, a criticism of this study is that this is one person’s perspective, i.e. there is a lack of triangulation, and as Frederickson and Cline (2015) note, school professionals are the experts of education, whereas parents are experts of their own child. Nevertheless, it will be interesting for future research to explore the implications for the interaction between family and school systems within the COVID-19 pandemic, given that the distinct roles of the two systems were blurred.

Advocacy. Whilst joint working is the ‘ideal’, research suggests that the reality for parents is a “battle” (Whitehurst, 2011, p.190) with the school system. So much so that parents adopting the role of ‘advocate’ is one of the most consistent and well-established findings in the field (Cleversey et al., 2017; Duquette et al., 2007; Duquette et al., 2012; Hammond, 2021; Petrenko et al. 2014; Opini, 2019). Duquette et al., (2007) found that every parent had experience of advocating for their child. This informed their subsequent research which explored this exclusively (Duquette et al., 2012). For most parents, advocating had become a way of life (Duquette et al., 2012). They found that the reasons behind parents advocating were diverse. In part the role involved a need to educate the educators. This included talking about FASD, signposting to other sources of information, talking to individual teachers about how FASD affects their child, and what accommodations are required (Duquette et al., 2012), a finding consistent with others (e.g. Duquette et al., 2007; Petrenko et al., 2014). This was a source of frustration for parents (Petrenko et al., 2014); as the need to ‘retrain’ teachers occurs annually at the beginning of a school year (Duquette et al., 2012).

Duquette et al., (2012) concluded that parental advocacy was overwhelmingly about lobbying for recognition and support for their children. A lack of recognition likely stems from limited awareness of the condition and its effects. McCarthy et al., (2022) also found that parents experienced considerable difficulties sharing their concerns around their child's needs, leading them to advocate for formal assessment or external support. This was most prominent for children who did not present with disruptive, externalised behaviours. The need for validation and support from external sources was also found in Duquette et al., (2012), where some parents spoke of a need to be accompanied by a lawyer, social worker, or professional advocate to ensure their expertise was respected. Balcaen et al., (2021) also highlighted feelings of helplessness and lack of control for parents around what happens in school. This demonstrates the unequal distribution of power in this interaction. This was explicitly recognised in research by Opini (2019), whereby the parent shared the importance of cooperating with the school leadership team, as they were perceived to have more power to influence outcomes than teachers.

The issue of trust within the family-school interaction certainly fuels parents' drive for advocacy. Duquette et al., (2012) found that parents felt they had to advocate for accommodations in school because these were often not being provided as they should. They emphasised the importance of 'monitoring' throughout the school year to ensure actions on their child's individual education plan (IEP) were implemented. However, to achieve this, parents first had to seek information for themselves and learn how the school system worked, including relevant documentation and what options were available to their child legally. Monitoring was often achieved through regular communication between home and school (Duquette et al., 2012), reiterating the importance of clear communication pathways. However, parents have reported that this is challenging, as asking critical questions damages teachers' perceptions, resulting in them being viewed as 'pushy' (Opinni, 2019).

Duquette et al., (2012) summarised advocacy as a tiring and stressful contribution that parents make towards their child's education. Similar conclusions were drawn by Balcaen et al., (2021) who emphasised that advocacy, educating school staff, and maintaining effective communication and collaboration with school, requires significant additional effort from parents. What is clear from the research base is that parents are achieving this on their own. Whilst parents cited the internet as helpful in establishing peer support avenues (Duquette et al., 2012), more recent research indicates that further parental support is still required to facilitate the interaction between home and school (Cleversey at al., 2017). It should be noted that the difficulties within this interaction have been overwhelmingly framed within Duquette et al's (2012) research. The children of interviewees had either already graduated from high school or were on course to do so. Therefore, as Duquette et al., (2012) acknowledge themselves, there are likely additional challenges for families who are not 'the success stories'. Although, despite their successes, the findings do not highlight what worked or facilitated success, just that they had overcome related challenges. This warrants consideration by future research.

The Role of EPs

As Roffey et al., (2018) write, EPs' knowledge base is situated between health and education. The needs of CYP with a diagnosis of FASD tentatively balance across the two domains. Roberts (2015) optimistically reflected on the potential impact that the updated SEND CoP (DfE, 2015) might bring to CYP with FASD. Namely, he hoped for a "stronger, more integrated approach" to providing support (Roberts, 2015, p. 242). This is furthered by several researchers who also noted the benefits of a collaborative, multi-disciplinary approach (Balcaen et al., 2021; Blackburn et al., 2012). When one considers the role and skillset of EPs, one could certainly argue that there is a place for them within this context. Whilst their inclusion in the newly published diagnostic guidelines is noteworthy (SIGN 156, 2019), as part of an extensive literature review, Westrup (2013) found no research which specifically examined FASD and educational psychology practice together. Westrup (2013) concluded that EPs are likely to be involved with individuals who have been affected by PAE during their careers, particularly in their support of CYP who have experienced the care system. Several key recommendations were made for a potential EP role in supporting this population. Notably supporting schools to identify suitable provision, evaluate their policies, develop appropriate learning environments, and reframe schools' beliefs and perceptions, especially around behaviour. However, Westrup (2013) acknowledged that a clearer picture of the level of involvement EPs have in the context of FASD, and what this might look like was needed.

Since Westrup's (2013) reflections, to the author's knowledge, only one Canadian study (Pei et al., 2013), and one unpublished thesis (Campbell, 2019), has further explored the role of EPs in supporting this group specifically. Pei et al., (2013) studied the role of school psychologists in supporting assessment and intervention for students with FASD. The research focused entirely on psychological assessment and how it was experienced, alongside stakeholders' attitudes towards it. Curran et al., (2003) argue that EPs work at the individual, organisation and system level. The former was the only aspect considered by Pei et al's (2013) research. Similarly, transferability of the findings to the UK context is limited, because in Canada the school psychologist's role in assessment relates partly to diagnosis. As such, this study is not discussed further. Campbell's research began as a small-scale preliminary study (Campbell, 2016 as cited in Campbell, 2019; Campbell, 2019). When examining the practice of three UK EPs, Campbell (2016) as cited in 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. The latter is consistent with recommendations by Balcaen et al., (2021), that the disconnect between knowledge and action in school can be addressed by developing strong relationships. Similarly, Job et al. (2013) suggested that future research should consider what facilitates effective collaboration and positive relationships. This captures the rationale for future research which considers the role for EPs within this.

Campbell (2019) sought to answer Westrup's (2013) call by surveying thirty-one EPs, fifteen of which had previously worked with CYP who had a diagnosis of FASD. It is important to note that the parameters of the study meant that only experiences involving primary school aged children were captured, and EPs worked within one area of the UK. Experiences may have differed had the entire educational spectrum been studied, or the practices of EPs working in different services been explored. Nevertheless, the aim was to identify how EPs were involved in identification and assessment of FASD, how they contributed to intervention and support strategies, what factors influenced their practice, to what extent EPs engaged in multi-disciplinary practice, and what their distinct contribution was. One prominent barrier to EP involvement, was their self-disclosed limited working knowledge of FASD (Campbell, 2019). This is echoed in parental experiences also. As part of Blackburn's (2010a) project, parental perspectives of professional support services they accessed were explored. Three of the nine parents had received EP support, but only one of these felt that this support was beneficial. One parent shared that their experience of EP involvement had not provided reassurance because the EP had explained that “you know more than me about FASD” (Blackburn, 2010a, p.30). A similar lack of knowledge amongst EPs was noted by a parent within a report by NOFAS-UK (2018, p.7) who was told that “they’ll catch up”. Perhaps then this highlights the need to further explore parental experiences of EP involvement and offer recommendations for EP practice.

Campbell (2019) noted that EP practice did not differ greatly whether involvement was FASD related or not. For instance, EPs reported recommending generic interventions and using frameworks for practice and consultation as they typically would for any other work. Whilst this may reflect EPs’ limited knowledge base, this may also offer explanation as to why recipients of EP support have been left feeling underwhelmed. Indeed, as emphasised throughout this review, it is well documented that a ‘universal’ approach is not appropriate for this population. Campbell (2019) also found that EPs considered their unique contribution to be ‘advocating for the child’ as they are highly skilled in ascertaining pupil views and holding those centrally. This is supported by Roffey et al., (2018) who argue that EPs have an awareness of contextual factors affecting child development and are well placed to ‘shout louder’ about the impact these may have. However, this is also interesting as this is a role which previous research indicates is more often adopted by caregivers of those with FASD (Cleversey et al., 2017; Duquette et al., 2007; Duquette et al., 2012; Hammond, 2021; Opini, 2019; Petrenko et al. 2014). In Campbell et al’s., (2019) research, the second highest ranking role for EPs related to providing a ‘holistic perspective’ which identified both strengths and needs. It is important that this is contextualised within other findings, such as Blackburn and Whitehurst (2010), who suggest that a diagnosis of FASD acts as a protective factor for both parents and CYP. However, members of school leadership in Job et al's., (2013) research contradicted this by suggesting that the label caused staff to place a glass ceiling on what may be possible for these students. Corrigan et al., (2019) echoes this by finding that expectations are often reduced for pupils with FASD. Further support for this comes from Poth et al., (2014), whereby participants attribute external professionals' reports which are deficit-focused as the cause of this. This is therefore a consideration for EP practice. Given the heavily medicalised underpinnings of the FASD literature base and the significance of strengths-based approaches (Cleversey et al, 2017; Job et al., 2013; Pei et al., 2013; Poth et al., 2014), it seems appropriate to suggest that EPs may be well placed to utilise solution seeking approaches, which could redirect focus away from deficits and towards resources (Franklin et al., 2012). This highlights that EPs have the potential to address the difficulties parents have discussed in previous research. However, Campbell's (2019) findings shine light on one perspective, and demonstrate what EPs consider to be 'best practice'. It will be important for future research to capture stakeholders' experiences of EP involvement and whether their views on their 'unique contribution' align.

When one reflects more widely on considering FASD within a systemic perspective, there is credibility in an argument which suggests that EPs may be skilled to develop and facilitate effective interactions between systems. Dowling and Osbourne (2018) and Beaver (2011), argue that EPs are appropriately positioned as 'meta' to both the school and family systems within which a CYP belongs. Consequently, they are one step removed and are better able to gather multiple perspectives and provide validation to all stakeholders. This is pertinent to Balcaen et al's., (2021) conclusion that the integration of numerous views helps inform a clear understanding of the whole individual with FASD. However, research suggests that parents are the 'bridge' between home and school (Hammond, 2021), and this is not yet working well. Indeed, this has the potential to blur the boundaries of the parental role and has significant consequences for parental wellbeing. Balcaen et al., (2021) argued that moving forwards, a family-centred approach with a focus on minimising collateral impacts is essential for those affected by PAE and their families. This seems pertinent to the EP role. However, major gaps exist in the necessary services. For instance, EP services are increasingly inaccessible to families (Peake, 1999). McGuiggan (2021) found that schools function as gatekeeper to EPs, particularly in services which use a traded model of delivery. Involvement with parents was variable, although no services were found to have structures in place to protect families and none were offering intervention to families. Given the literature which highlights the often-fractious interaction between systems in the context of FASD (e.g. Cleversey et al., 2017; Job et al., 2013), and the distribution of power alongside minimal parental support, the opportunities for change appear limitless, despite currently being underutilised. EPs may not yet be maximising the possibilities of their role.

Conclusions

This review has articulated the difficulties experienced by those with a diagnosis of FASD. and members of the systems within which they belong, namely their families and school. Whilst the implications of FASD have been broadly discussed, the author has illustrated that the issue of education is overwhelmingly neglected, despite being an area of significant need. The current research base is primarily positioned outside of the UK and is outdated when considered alongside current policies such as the SEND CoP (DfE, 2015). Whilst published findings barely scratch the surface, they make for uncomfortable reading. As can be seen throughout this review, the author has identified and highlighted several recommendations for future research. Research which has gathered the parent perspective thus far has uncovered numerous experiences of minimal support, isolation and being voiceless. Yet given difficulties identifying accurate prevalence rates, there are likely many other parents whose voices have not been captured. Moreover, the author concludes that previous research has not gone far enough in trying to remedy and seek solutions to the unsettling findings. Thus, the author suggests that further exploration considering the role of EPs in supporting this group must be prioritised.

Chapter Two: Empirical Paper

Abstract

This study gathered the voice of adoptive parents and foster carers who parent a child with a confirmed diagnosis of foetal alcohol spectrum disorders (FASD). Their views were explored in relation to 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. The study was underpinned by a solution-oriented approach (O'Hanlon & Weiner-Davis, 2003), which enabled a range of experiences including difficult, positive and any nuances which are positioned in-between, to be captured. A qualitative study using semi-structured interviews was conducted with eight adoptive parents and one pair of foster carers. Braun and Clarke's (2006; 2022) six phases of reflexive thematic analysis (TA) was used inductively through which four themes were identified: 'Understanding the Individual', 'Sense of Belonging', 'Collaboration and Communication' and 'Knowledge and Awareness of FASD'. The findings highlighted that parents of children with FASD consider school to be overwhelmingly challenging for their children. This related in part to within-child factors linked to FASD, however, to a greater extent these difficulties were systemic. This study adds to the current evidence-base which indicates that parents play a crucial role in the educational lives of children with FASD, as well as the findings that barriers to the family-school interaction are plentiful. This research adds support to the importance of effective family-school communication which authentically accounts for parents' views and their expertise. The need for improved knowledge and understanding of FASD within the school system and amongst EPs is also emphasised. Moving forwards, recommendations for how EPs might undertake a more supportive role in this context are provided.

Introduction

FASD is an umbrella term which describes complex physical and neurological difficulties resulting from prenatal alcohol exposure (PAE) (Blackburn & Whitehurst, 2010; Millar, et al., 2017). Neither the profile nor developmental trajectory of those with FASD is heterogeneous (Blackburn & Whitehurst, 2010). Instead, it is dependent upon several details relating to the individual context of alcohol use, including volume of consumption and occurrence of exposure in line with the foetus' developmental timeline (Blackburn et al., 2012). Research has drawn a clear link between FASD and developmental differences, including cognitive functioning (e.g. Price, 2019), meaning the effects of FASD are not always visible (e.g. Blackburn & Whitehurst, 2010; Streissguth & O'Malley. 2000). This is one of many obstacles to obtaining a diagnosis, as individuals are "clinical masquerades" (O'Malley, 2007, p.185) and share similarities with more widely recognised neurodiverse conditions (Bruer-Thompson, 2016; Petrenko et al., 2014). However, the prevalence of FASD is believed to be greater than other neurodevelopmental disorders (McCarthy et al., 2022; Schölin et al., 2021; Westrup, 2013), particularly amongst adoptees and looked after children (LAC) (Adoption UK, 2018). Yet FASD internationally, but particularly in the United Kingdom (UK), remains under-researched, especially within the context of education.

FASD in Education: A Systemic Shift Towards Solutions

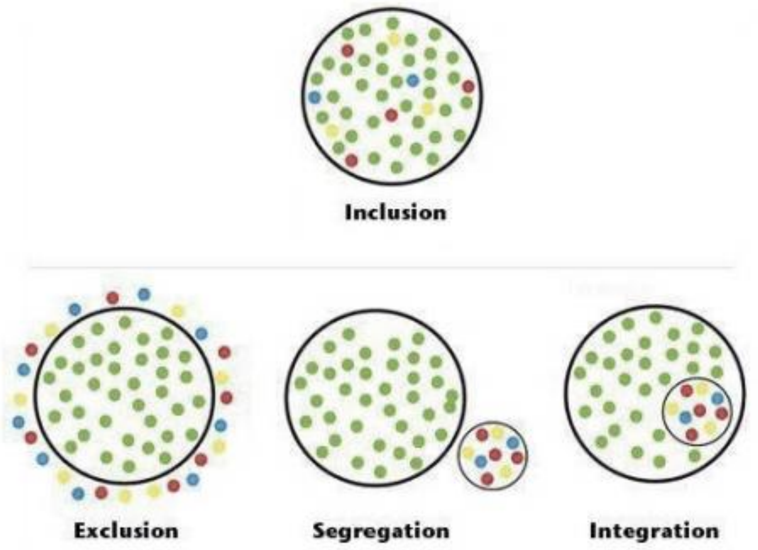
For individuals with FASD, experiences in the womb as their first 'classroom' into life (Treisman, 2018), shape those experienced later in the physical classroom. It is implied in the literature that FASD has considerable life-long connotations, not least for education, yet FASD internationally, but particularly in the United Kingdom (UK), remains under-researched, especially within the context of education.

Fundamentally FASD is a ‘within-child’ condition, the physical effects of which are irreversible (Blackburn & Whitehurst, 2010). It is a well-established medicalised term and researchers thus far have sought to identify what is ‘wrong’ within a medical, deficit model. Research has illustrated how the damage caused by PAE across brain domains affects education, particularly in relation to academic achievement (Millar et al., 2017) and behaviour (Blackburn et al., 2009) including, but not limited to, confabulation (McCarthy et al., 2022) and dysregulation (Duquette et al., 2007). This translates into high incidences of associated difficulties, such as a negative spiral of low self-esteem, mental health difficulties, and ultimately an increased likelihood of dropping out of school (Duquette et al. 2007; Duquette et al., 2012; Edmonds & Crichton, 2008; Kelly, 2009). However, research is now beginning to implicate the role of systemic factors, and a shift away from the ‘within-child’ narrative is emerging since a critical review by Flannigan et al., (2021). This is important due to the diverse and complex nature of systems that individuals with FASD sit within (Coggins et al., 2017). The review highlighted how the current literature base pathologizes FASD as an ‘abnormality’ which should be fixed, and concluded that a dearth of literature currently exists which explores a strengths-based perspective of individuals with the condition

The current understanding of ‘permanence’ surrounding FASD gives little hope for change. The Social Model of Disability (Oliver, 1983) may offer a positive reframing of FASD by highlighting how seeming ‘within child’ barriers may be overcome or reduced by adaptations made around the individual, an idea closely related to the ‘context’ concept of systems theory (Dowling & Osbourne, 2018). This is pertinent to education, as the school system has been found to be inconducive to learning for pupils with FASD (Price, 2019), and the school environment is better able to meet the needs of those with alternative diagnoses (Corrigan et al., 2019). This is evident in previous findings which provide insight into the difficulties which those with FASD face within education. For instance, despite research accentuating the importance of adaptations and differentiation within the curriculum (Carpenter, 2011, Millar et al., 2017), schools are consistently failing to provide inclusive opportunities for these students. Duquette et al., (2012) expressed this as an issue of ‘non-readiness’ to include them. Participants in Knorr and McIntyre’s (2016) research reported that because of this, coupled with their diagnosis of FASD, they saw themselves as different to their peers, which ultimately led them to resist engagement with the very learning support they required. More recently, and within the UK context, Hammond (2021) also found mixed feelings towards receiving specialist support, where even young pupils were concerned by stigmatisation of being ‘different’ if they were supported outside of the classroom. This pertains to the illustration in Figure 8, whereby differences exist between inclusion, exclusion, segregation, and integration. This highlights an important implication for teachers’ practice because peer relationships have been identified as being central to the overall experience of school for those with FASD (Duquette et al., 2006; 2007; Hammond, 2021). A desire to ‘fit in’ leaves these individuals susceptible to peer pressure, resulting in higher incidences of ostracism and bullying (Duquette et al., 2007; Duquette & Orders, 2013; Knorr & McIntyre, 2016; Sanders & Buck, 2010). Indeed, Corrigan et al (2019) recognised ‘social exclusion’ as one form of discrimination that children with FASD experience.

Figure 8

A visual representation of the concept of Inclusion. Think Inclusive (Villegas, 2017)



The educational experiences of those with FASD are also shaped by poor knowledge of the condition amongst education professionals, this is both self-disclosed (e.g. Blackburn & Whitehurst, 2010; Pei et al., 2013) and derived from parents' perspectives (e.g. Cleversey et al., 2017; Duquette et al., 2006; Duquette et al., 2007; Price, 2019). This correlates with issues of assumptions, prejudice, stereotypes and unrealistic expectations around behaviour (Corrigan et al., 2019; Flannigan et al., 2021, Price, 2019). Consequently, these pupils are often blamed, punished, and falsely labelled as deviant (Brown, 2015; Duquette et al., 2007; Knorr & McIntyre, 2016; Sanders & Buck, 2010). Whilst there is an emerging literature base arguing for a move towards recognising behaviour as a 'symptom' of FASD, and means of expression, not a choice (Malbin, 2004), it is not yet embedded. Taken together, the above results in the shared experience of 'structural discrimination' and 'educational jeopardy' amongst this population (Carpenter, 2011; Corrigan et al., 2019). Despite this, literature considering FASD and education within a systemic perspective is limited and in its infancy. To date, Poth et al.,, (2014) adopted Bronfenbrenner's (1979) Bioecological Model to better understand positive classroom experiences of individuals with FASD, and Flannigan et al., (2021) also advocated for recognition of the relevance of a systemic perspective. Similar conclusions were drawn by Price (2019) who 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. No research combines consideration of FASD within a systemic perspective with efforts to ascertain what works well. This empirical paper will therefore be structured by applying the principles of systems theory using the model presented previously in Figure 4 (see Literature Review).

FASD and the Family-School Interaction

Research which has prioritised capturing school experiences of pupils with FASD, has consistently highlighted education as arduous for students and parents alike (Duquette et al., 2007; Duquette & Orders, 2013; Edmonds & Crichton, 2008; Knorr & McIntyre, 2016). However, parental involvement has been found to be both highly valued by their offspring (Duquette et al., 2006; Hammond, 2021; Knorr & McIntyre, 2016) and facilitates positive educational outcomes (Duquette & Stodel, 2005). For instance, Duquette et al., (2006) found that parental support with homework and extra tuition enabled pupils to feel more academically integrated in school. This demonstrates how ‘involved’ the parental role is (Cleversey et al., 2017), and how it extends beyond the remit of ‘home’. It is therefore unsurprising that parents have described this as a significant undertaking which is hugely effortful (Balcaen et al., 2021; Duquette et al., 2012). Issues discussed previously, present an overwhelming basis for why parents unequivocally embrace a supportive role for their child (Balcaen et al., 2021; Sanders & Buck, 2010). Duquette et al., (2012) found that parents’ advocacy stemmed from a belief that their child was not receiving the support or recognition to which they were entitled. This pertains to findings which are indicative of dwindling parental confidence and trust, in the assurances school provide, that they can meet their child's needs and do action their promises of adaptations (Duquette et al., 2012; Job et al., 2013; Poth et al., 2014).

The importance of partnership working, specifically collaboration and effective communication between family and school systems, is emphasised throughout previous research (Cleversey et al., 2017; Green, 2007; Job et al., 2013; Poth et al., 2014). And yet, research also illustrates that parents feel unheard, their views and expertise are unacknowledged, and they experience a lack of authentic participation (Duquette et al., 2012; Job et al., 2013; Whitehurst, 2011). This poses a cause for concern given that schools' practice should be governed by the SEND CoP, which specifies the requirement to consider the "views, wishes and feelings" of parents (DfE, 2015, p.19). Research indicates that parents may not be listened to by educational professionals because they are instead positioned as being responsible for their child's difficulties in school. Indeed, parents have consistently expressed feelings of judgement and blame directed towards them (Balcaen et al., 2021; Cleversey et al., 2017 etc.). Cleversey et al., (2017) found that issues for parents were characterised by arguments from education professionals around superiority of their own professional knowledge. This is furthered by other studies also illustrating resistance from schools to acknowledge parental contributions and recommendations (McCarthy et al., 2022; Poth et al., 2014), resulting in parents inviting more powerful professionals to support their efforts (Duquette et al., 2012). At present, a lack of reciprocity and equality between systems persists. It is therefore ironic that the parental perspective within research is consistently supplementary to that of other stakeholders, despite their role being so pivotal. For instance, caregivers' voices so far have been underrepresented compared to teachers, members of senior leadership, and other allied professionals (Job et al., 2013). Similarly, parental views have been sought to achieve the researcher’s primary aim of obtaining pupil voice (Duquette et al., 2006; Duquette et al., 2007).

Parents continue to cite school as one of the biggest family stressors and the source of much aggravation (Balcaen et al., 2021; Corrigan et al., 2019). And yet, Opini (2019) concluded that in the context of FASD, there exists a dearth of literature which explores the relationship between the family and school systems, particularly from a parental perspective. Research studying the relationship thus far, has prioritised advocacy as one strand of the family-school interaction (Duquette et al., 2012; Opini, 2019), despite the parental role in education being multifaceted. Additionally, whilst researchers such as Cleversey et al., (2017), sought to explore how caregivers could be supported in this partnership, the use of concept mapping methodology meant that the detail of experiences gathered from qualitative based research was not captured. To the authors knowledge, no research exists which explores the parent-school interaction, exclusively in the context of FASD within the UK. Moreover, research thus far has done very little beyond identifying a significant problem. Persistent exploration of what works and opportunities to initiate positive change for individuals and their families have been missed by previous researchers (e.g. Duquette et al., 2012). This may be addressed by exploration of a breadth of parental perspectives across both primary and secondary schools. Previous researchers have opted to study one or the other, however, the collation of the entire educational experience may provide greater scope to identify times of strength. Consequently, a clear avenue for further research exists.

FASD and the Role of EPs

Whilst a multi-systemic approach is recommended by the current research base (Green, 2007), this has not yet been maximised to recognise the role of EPs in this context (Westrup, 2013). This is a significant oversight given that their knowledge base is situated between health and education (Roffey et al., 2018), thus mirroring the position of FASD. Moreover, their role is ‘meta’ to the family and school systems (Beaver, 2011; Dowling & Osbourne, 2018).

A literature review by Westrup (2013) identified that there was no research which has 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. Campbell’s research identified that EPs can, and do, make a valuable contribution to supporting individuals with FASD, particularly by being person-centred and adopting a holistic lens. However, it was also highlighted that this practice was variable, owing to individual characteristics of EPs, such as confidence and knowledge surrounding FASD. It was acknowledged that drawing upon the perspectives of other key stakeholders, such as parents, is necessary in future research to advance the understanding of the EP contribution in this context. So far, this has been addressed only on a small scale, in research funded by non-profit organisations, where methodology is not clearly articulated. Indeed, this formed one discrete element of a much larger project into FASD from the perspectives of multiple stakeholders, in which participants mentioned EPs’ knowledge of FASD in passing, when asked more broadly about their experiences of collaborating with professionals (Blackburn, 2010a). Nevertheless, parental views were not complimentary, thus confirming a need for future research to answer Westrup’s (2013) call to identify whether EPs are working with these families and if so, how?

Methodology and Method

Aims of the Current Study

This study aims to investigate parental perceptions of their child's school experience alongside parents' own experiences of engaging with their child's education. The second objective is to identify the parental perspective of EPs supporting the educational experiences of children and young people (CYP) with FASD, and what role EPs can take moving forwards. The purpose of the study was to use solution-oriented questioning with participants (O'Hanlon & Weiner-Davis, 2003). Unlike solution-focused approaches, which unanimously prioritise exploration of a positive future, a solution-oriented stance allows for discussion of less positive experiences in the past, as well as more hopeful futures. Thus, providing an opportunity to capture the range of experiences, including difficult, positive, and any nuances which are positioned in-between. This balances the narrative by acknowledging the mixed reality of FASD, as recommended by Flannigan et al., (2021). The overarching aim is to raise awareness of FASD and the associated realities, enrich the literature, and add to the research base within a UK context. It is hoped that it will help inform the direction of future research, and the development of effective practice within the family and school systems, and educational psychology profession more widely. The current study is guided by 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?

Design

Ontologically and epistemologically this research aligns with the beliefs of critical realism (CR). A position of CR recognises that a knowable world exists, however, this is shrouded by socially located knowledge (Braun & Clarke, 2013). Braun and Clarke (2013) liken the ‘knowable world’ to a prism, whereby how we see reality is nuanced by each ‘prism face’. Prism faces in the context of CR consist of elements of the social context, e.g. culture and history. Without the prism, we would have a clear view of ‘reality’, however, CR posits that to better understand participants’ ‘truth’, we must acknowledge the ‘prism faces’ through which their perspective is shaped.

The researcher’s primary hope in the current study is to gather the parental experience as a ‘reality’ to be explored, that is an ontological position of realism (Willig, 2013). However, within CR, the ways the individuals make meaning of their experience, the time and broader social context is also acknowledged, i.e. ‘prism faces’ (Bhaskar, 1978; Braun & Clarke, 2013; Willig, 2013), thus adopting a subjective epistemological position. This is integrated in the overall premise of CR, whereby the researchers aim is to gain a better understanding of what is happening in the world, whilst accepting that their findings may not provide direct access to this reality (Braun & Clarke, 2013). Nevertheless, as Kelly (2017, p.22) argues, a CR stance “guides and facilitates highly reasoned, reflective and coherent actions in bringing about positive change”, making it of upmost relevance to practice based professions, including educational psychology. CR provides a scientific basis for action and relies upon a social and interpretative evidence base for professional action (Kelly & Woolfson, 2017). As such, it is pertinent to the intended outcomes of this study and offers scope to consider implications for school and EP practice.

The above is compatible with a qualitative research design.

Participants

A purposive, criterion sampling strategy was used to recruit the participants for this study. The selection criteria were:

- Adopters or foster carers of individuals who have a confirmed diagnosis of FASD.
- Their child should also be between the ages of 5 and 16 years old and access educational provision within one particular region of England.

Participants were recruited through a regional centre which provides assessment, diagnosis, and post-diagnostic support for families. It operates locally and nationally. The centre distributed a recruitment poster inviting prospective participants to take part and make initial contact with the researcher (see Appendix B). After accounting for the inclusion criteria, participants were sent a participant information sheet (see Appendix C) and consent form (see Appendix D). This resulted in the recruitment of nine participants: eight adopters and one foster carer. However, whilst one adopter primarily attended interviews, on two occasions both adoptive parents and foster carers participated (participants 8 and 9). Similarly, one adopter (participant 6) had two children who met the selection criteria and wished to discuss experiences which related to both children. Therefore, nine interviews were conducted with eleven participants, who discussed ten CYP, who met the selection criteria.

At the time of the interviews, the children of participants were aged between 9 and 16 years old, with an average age of 12.7 years. They included seven males and three females. All adopters had adopted their child in early childhood; before the age of two. The only exception to this were the foster carers who began fostering their child at the age of five. Eight of the ten children had previously had at least one additional foster or adoption placement prior to residing with their current caregivers.

Of those, three had experienced more than two previous placements. Within this sample of children, the average age for obtaining a diagnosis was 8.8 years old. This is consistent with data suggesting that diagnosis typically occurs in the later years of primary school (Novick Brown, 2011, as cited in Blackburn et al., 2012). 70% of the participant's children had one confirmed, or ongoing, diagnosis alongside FASD, whilst 40% had multiple additional diagnoses. The most prevalent was attention deficit hyperactivity disorder (ADHD), however, other diagnoses included autism spectrum disorder (ASD), sensory processing disorder (SPD), attachment disorder (AD) and oppositional defiant disorder (ODD).

In respect of education, health and care plans (EHCPs), five of the ten children had one, two were actively engaged in preceding assessment processes, and two did not have one, nor were they yet involved in the process of obtaining one. One participant's child previously held an EHCP, however, this had been ceased owing to recommendations from their education setting. All but one of the participant's children had received EP involvement. This included both statutory involvement within the education, health and care needs assessment (EHCNA) process, and non-statutory involvement within traded and non-traded service delivery models. An overview of participant characteristics can be found in Tables 3 and 4.

Table 3

Participant Characteristics of Each Participant and Their Child(ren)

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 4

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

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	✓

Data Collection

Semi-structured interviews were used to explore how participants perceived their child to experience school, how they themselves experience the family-school interaction and EP support. Interviews were structured using an interview schedule (see Appendix E) which was informed by a solution-oriented approach (O'Hanlon & Weiner-Davis, 2003). This resulted in the inclusion of questions which were both positively and less positively framed to elicit parents' views on FASD and education. A solution-oriented interview schedule ensured that a breadth of experiences was captured, including nuances of more challenging times and glimmers of light. This included exploring exceptions and best hopes for a preferred future. The content of the questions was guided by those used previously by Duquette et al., (2012) as these facilitated wide coverage of 'educational experiences' in the context of FASD and adoptive parents. Whilst the interview was flexible to ensure fluid use dependant on the course of each interview, both the content and proposed order shown in Appendix E were refined following discussion with a key professional and adoptive parent in the field of FASD. Thought was especially given to the initial and final questions within the interview (Kvale, 2006). In the spirit of being person-centred, an introductory question which sought to gain insight into the family context of the participant was used. This enabled the gathering of rich developmental history, supporting the understanding of the individual context of FASD (Carpenter, 2011; Streissguth & O'Malley, 2000). Similarly, at the end of the interview, a closing question provided participants with an opportunity to share any additional information which they had not yet felt able to. It was hoped that this may mitigate the impact of researcher-driven interview questions and mirrored my practice in consultations.

Interviews were conducted during the spring and summer terms of 2021; a time where ongoing uncertainty remained due to the global COVID-19 pandemic. Consequently, all interviews took place remotely using Microsoft Teams. It was anticipated that the duration of interviews would be approximately 60 minutes, however, these varied in length between 48 and 82 minutes. The interviews were transcribed verbatim following each one.

Data Analysis

Qualitative interview transcripts were analysed using Braun and Clarke's (2006; 2022) six phases of reflexive TA (see Table 5). Braun and Clarke (2022) stipulate that TA is compatible with a range of ontologies, including CR.

Table 5

Six Phases of TA (Braun and Clarke, 2006; 2022)

Phase of Analysis	Action	Purpose
1. Familiarisation with the data	• Transcription of video recordings (see Appendix F for sample). • Checking transcripts against original recordings. • Immersion in the data by reading and re-reading the data set. • Familiarisation notes including initial thoughts, notes and reflections noted in the margins (see Appendix G for sample).	• To ensure transcripts captured accurate representations of discussions. • To become familiar with the content of the data and develop initial thoughts about meanings within the data. • To support the application of reflexivity including consideration of the researcher's position and noticing thoughts, feelings and reflections which may influence analysis.

2. Coding the data	• Systematic and inductive coding of the data set using a ‘what/how’ system (Watts, 2014) (see Appendix H for example). This produced semantic codes which reflect the overt meanings of data (Braun and Clarke, 2022). • Codes were reviewed and refined. Codes across the dataset were collated alongside relevant extracts as part of this process (see Appendix I for example). A total of 176 codes were collated. • Upon considering the relevance to each research question, a total of 162 final codes were produced (see Appendix J for list).	• Identifying “any meaning that is potentially relevant” to the research question (Braun and Clarke, 2022, p.53). • To ensure that the codes were rooted in the voices of participants, rather than the researcher’s interpretations at this stage. • To ensure code labels were relevant, clear and able to stand alone from the dataset whilst conveying meaning. This included a process of collapsing and fine-graining broader codes (Braun and Clarke, 2022).
3. Generating initial themes	• Active examination and sorting of codes into groups of ‘shared meaning’ by hand to develop provisional subthemes/ themes (Braun and Clarke, 2022) (see Appendix K for example).	• Shifting analytic attention away from smaller meaning units (codes) to larger meaning patterns (themes) (Braun and Clarke, 2022). • Identifying patterns of ‘shared meaning’ across the dataset and exploring relationships

		between codes, subthemes and themes to ensure they fit together within the overall analysis.
4. Developing and reviewing and themes	• Review of the coded extracts relating to each theme. • Data extracts moved or themes reworked when data did not fit coherently within a theme. • Review of the themes alongside the entire dataset(see Appendix K). • Creation of final thematic map following a process of discarding multiple alternatives. • Discussions with research supervisors.	• Checking there is enough meaningful data to support each theme. • Ensure each theme does not simply present a ‘topic summary’ and instead has a central organising concept which provides a core point and nuance from the dataset (Braun and Clarke, 2022). • Ensure the themes capture the meaning of the entire dataset and complement one another to provide a holistic understanding.
5. Refining, defining and naming themes	• Each theme defined. • Names chosen to reflect the core concept and reviewed with research supervisors.	• Clarify and illustrate what each theme is about, including the ‘key take-away’ from it (Braun and Clarke, 2022).
6. Writing the analysis	• Written presentation of data, under themes within the finding and discussion sections. • Careful selection of data extracts for each theme which are pertinent to	• Present the narrative and the interpretation of the data. • Ensure all participant voices were

	the meaning contained within the theme. These examples were taken across participants.	represented.

Ethical Considerations

This research was granted ethical approval by the University of East Anglia (UEA) Ethics Committee (see Appendix L) and was conducted in accordance with the British Psychological Society (BPS) Codes of Ethics and Conduct (2018) and Human Research Ethics (2021). Prior to arranging the interview, additional information about the study was shared with participants via an electronic participant information sheet and consent form (Appendices C and D). Within this, additional considerations around remote working, including the use of audio/video recordings were highlighted. This ensured participants were able to make an informed decision about whether to participate. At this time, it was reiterated that their participation was not obligatory, and participants were offered the choice to review their interview transcript to ensure that it captured an accurate representation of the discussion. This opportunity was taken up by five of the participants.

At the start of each interview, participants were reminded of their right to anonymity, and the boundaries of this were shared in respect of safeguarding concerns or the risk of harm. Additional consent around use of video recordings was sought verbally, and the right to withdraw or terminate the use of their video and/or audio was repeated. At the end of each interview, participants were again offered the opportunity to review their transcript. In addition, a follow up email was sent to participants which contained the researcher’s and research supervisor’s contact details should they have required a debrief or experience any concerns, or psychological distress, following their participation in the research. They were also signposted to relevant FASD charities and support networks which could assist with issues outside of the specific context of interview.

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

Findings

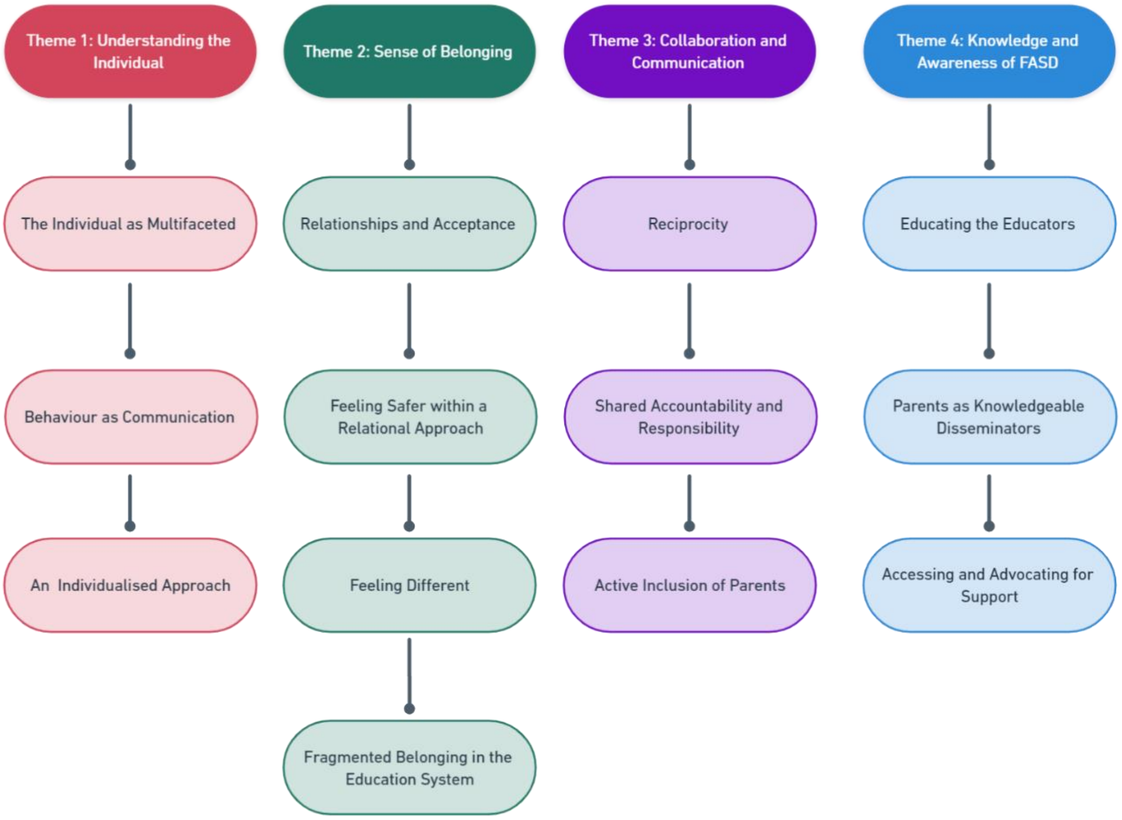
Four themes were identified through reflexive TA:

1. ‘Understanding the Individual’
2. ‘Sense of Belonging’
3. ‘Collaboration and Communication’
4. ‘Knowledge and Awareness of FASD’.

Themes 1, 3 and 4, comprise three related subthemes, and theme 2 has a further four subthemes nested within. These are shown within a thematic map in Figure 9. Whilst themes have been separated as part of this analysis, it is important to appreciate their interconnectedness throughout the parent/caregiver’s narratives and the subsequent overlapping relationships amongst all themes. Within this section each theme will be defined and discussed alongside the corresponding subthemes in turn.

Figure 9

Thematic Map Illustrating Themes and Subthemes



Theme 1: Understanding the Individual

The theme ‘Understanding the Individual’ reflected parents’ feelings that their child needed to be understood both as an individual, and as an individual with FASD. Parents emphasised their child’s unique, complex, and compounding strengths and difficulties, as captured within the sub-theme ‘The Individual as Multifaceted’. Parents spoke of the means through which their child expressed their needs within the school context. This is captured within the subtheme ‘Behaviour as Communication’. Parents stressed the value of adopting ‘An Individualised Approach’ to viewing and supporting their child, which is represented in the final subtheme.

The Individual as Multifaceted. Parents described their children’s needs as being multifaceted and compounding into an “*amalgamation*”, resulting in “*one big* *explosion of a boy*" (AP 4). AP 8 noted how a diagnosis of FASD established a golden thread of connections between the varying needs: "*there's lots of little different things that you're trying to deal with in different ways… you've got like behavioural things, compliance things and then like the ability not to pay attention… but it's all a bit fragmented… with the FASD thing it kind of brings it all together*". For this parent, the multifaceted nature of need did not necessarily become easier to manage following diagnosis, but the unique profile did become easier to understand. This extract also reflects how participants considered their child's needs to be wide-ranging (behavioural, emotional, social, cognitive etc.). Each parent described their child as having a unique developmental profile and no two individuals were the same. This is most clearly presented in Table 6. This table provides the reader with a visual representation of how for these parents, the variability in profile of primary difficulties for each individual with FASD is wide-ranging. Parents often spoke of their child's needs in a matter-of-fact manner. For example, in relation to attention difficulties, parents simply stated that their children "*can't concentrate for long*" (AP 6) and "*finds it difficult to sit still*" (AP 7). This is suggestive of a familiarity with their child's needs and acceptance that their child is as they are. Participants overwhelmingly explained their child's needs relating to FASD within the context of the impact for education and how their difficulties presented challenges for learning:

> *"It's his memory really…you know he would never remember what he's got to do for his homework, so you know teachers would let him take a screenshot of what the homework was, but then he'd come home, and you'd ask well what is it that you've got to do, and he just had no clue, he had no idea where to start"* (AP 7).

This extract illustrates how parents recognised that educational adaptations were required to support their child's needs. Academic attainment was cited by numerous parents as being problematic. They spoke about how their children "*really struggled*" with learning (AP 1), resulting in them being "*quite low and quite behind*" (AP 2). The extent of this was explained by AP3, who shared that their daughter was "*on a year 1 curriculum but she's in year 6*". This was reflective of most participants' descriptions of their child being several years behind same-aged peers, and consequently requiring access to a different curriculum. Contrastingly, AP 6 highlighted how their daughter "*is a bright girl*" who has "*got a normal IQ*". This demonstrates the distinct developmental profile of FASD, whilst also indicating that in this parent's view, further difficulties, discussed in upcoming themes, cannot necessarily be fully explained by issues contained 'within' the child. Instead, they felt they could achieve successful outcomes "*given the right support*". Nevertheless, FASD was recognised as a within-child condition, with parents describing it as an "*organic impairment*" (AP 5) and an "*invisible disability*" (AP 7). Although, this was often raised in the context of frustrations of others' understanding of FASD, discussed further in 'Theme 4: Knowledge and Awareness of FASD':

> *"They can't understand the concept of the brain being deformed and not grown properly, and I think they also think that if they keep doing the same thing over and over again then it'll get better, they'll learn, it'll go away, they don't understand that it's permanent damage and it will not change"* (FC 9).

In recognising that the primary effects of FASD are "*permanent*", this extract is also reminiscent of the parental acceptance discussed earlier.

As the below extract illustrates, participants acknowledged the presence of layers of intersectionality in relation to their children's previous life experiences:

> *"Yeah I think everyone knows that when they arrive young that that's a good thing and certainly they arrived younger than a lot of kids do, but when you think about it*

> *ultimately, the reason they are where they are is because their mum drank all the way through their pregnancies”* (AP 8).

However, as AP 8 described, parents considered FASD to be their child’s primary diagnosis with difficulties “*very much related to FASD*” (AP 7), compared to other impacts within their life experiences. For instance AP 3 explained that they “*don’t think that makes as much difference*” when comparing their child’s status as an adopted child with the effects of FASD.

Table 6

Participant Information Relating to Primary Difficulties

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										✓

Behaviour as Communication. Analysis of the data highlighted that parents saw school as an overwhelmingly challenging experience for their children. This is illustrated by parents' descriptions of how their child would describe school as "*awful in a word"* (AP 6). Even participants who overall had a more positive narrative, felt that their child would suggest school is "*something to be endured"* (AP 8). Moreover, this subtheme reflected the shared conclusion that these difficulties were expressed through their child's behaviour.

> *"Primary school was ok for X, I mean I think we were aware something wasn't quite right, but we couldn't quite figure out what it was…the year 2 teacher was saying I think he needs a hearing test; you know have you had his eyes tested? You know, he's a bit boisterous in the playground, we'd get those kind of things from the teachers and I think in hindsight perhaps that was their kind way of saying you know he's a little sod"* (AP 7).

As the above extract highlights, parents were often aware of their child's needs, but FASD specifically was often uncovered by the school environment. This participant described how school provided scope for noticing difference compared to same-aged peers, although "*boisterous*" behaviour was interpreted negatively as him being "*a little sod*", as opposed to a means of communicating the difficulties he was experiencing in the constraints of the school environment. Many parents shared examples of times when their child experienced school non-attendance, these occurred throughout schooling. This was often the climax of behavioural escalation, a last resort "*in the end*" (AP 2), when their child simply could not communicate just how "*distressed*" (AP 5) they were, through any other means:

> *“He just didn't want to go into school. He would, you know, be clinging to the railings outside the school gates crying, not wanting to go in. And that's, you know, it was heart-breaking for me, it was heart-breaking for him”* (AP 4).

> *“I couldn’t get her in. 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”* (AP 6).

As these participants suggest, this was challenging for parents and students alike and highlighted the extent to which school was not a place that their child felt able to be. Parents cited varied reasons for the occurrence of school non-attendance. This included their child feeling trapped so “*trying to flee*” (AP 5) and experiencing sensory sensitivities around noise particularly due to “*much bigger classes*” (AP 2). Although not always in the context of school non-attendance, parents consistently highlighted difficulties with curriculum ‘pinch points’ and increasing expectations:

> *“There comes a point in school where you come out of reception into year 1, where it was a little less demanding, a little more free…and it starts to get a little more serious and you have to do stuff at certain times, and you know the curriculum really kicks in, I would say both of those were really difficult points for the boys”* (AP 8).

Parents emphasised that this only worsened as their children grew older and progressed further through school. Besides school non-attendance, parents suggested that these difficulties presented within their child’s behaviour in other ways, namely masking and the adoption of coping mechanisms:

> *“Y masks the way she is feeling by her whole aggressive stance. Whereby X shuts down and becomes a little mouse… if I shrink small enough then they won’t notice me”* (AP 6).

> *“He’s quite clever in how he gets around things, he would be in registration and he would know what his next lesson was, and 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 because he had nobody to follow" (FC 9).*

As these extracts demonstrate, parents reported considerable variations in how individuals concealed their difficulties, but in both instances, behaviours such as masking, communicated an underlying need which they are "*trying to tell me, without telling me*" (FC 9), i.e. they do not wish to, or may not be able to, explicitly communicate. It was noted by several parents that masking had consequences for the recognition of their child's needs. For instance, those who internalised rather than exhibited externalised behaviours were at risk of "*slipping through the net"* (AP 6). Others highlighted the impact of discrepancies between how their child presented at home compared to at school:

> *"I don't think there's been a time where anything has gone particularly well for him because academically he struggles, and that's why we just saw a such an increase of his meltdowns at home because he tried so hard to focus during the day, soon as he was home, it all came out. You know, his behaviour would go through the wall, you know it's umm, because he was just at home in his safe space, but school has been hard* (AP 4).

This extract illustrates the exaggerated difference and reflects the experiences of most participants, however, one participant noted that their child's presentation was opposite to this, thus reiterating the individualised nature of FASD:

> *"We don't recognise that boy in school, that's always been the way. A lot of children I think mask it at school and bring it home. X is who he is at school, and then he's just chilled at home"* (AP 1).

An Individualised Approach. Fundamentally, parents felt that what worked well to support their child was unique to the individual, and this permeated throughout multiple contexts. For instance, parents described their experience of external professional involvement as more positive when said professional adopted an individualised approach, and viewed their child through such a lens, as this prevented the occurrence of assumptions:

> *"I think we've identified the fact that each child is unique, and they don't present, necessarily similarly, you know, like the executive function and all that sort of thing. But first of all, make a relationship with the child, don't go in there with preconceived ideas that oh, this is what I know about FASD, therefore, he's going to present like this"* (AP 1).

Most emphasised in the school context was the importance of an individualised approach to behaviour management. Parents reported variations of strategies which were, and were not, effective and distinctions existed particularly in relation to the use of rewards and the timings of such:

> *"I remember the teacher saying they did a sticker chart with her, and they said, "oh she just wants all the stickers to stick on the chart there and then", and I said, "well yeah she doesn't get it does she, she doesn't understand the whole oh I have to do this for so many days to get that", it's now, and that's something that people don't understand.. either she needs a reward there and then or she needs whatever consequence there and then…I remember she got an award in an assembly for doing a piece of work or something at the beginning of the week and by Friday when they do the awards assembly, she didn't have a clue what it was for…they live in the moment, yesterday and tomorrow don't mean anything…the only thing that means anything, is now"* (AP 6).

This example illustrates how this pupil’s behaviour was understood as a choice because she “*just wants all the stickers*”. Instead, the meaning behind it, which in this case was that “*she doesn’t understand*”, highlights how parents felt that ‘typical’, behaviour management strategies which might work for the majority, were not necessarily appropriate for use with students who have FASD. Contrastingly, other participants felt that their children thrived off similar incentives. These parents felt that it was about knowing the child well to ascertain what would and would not work for them, thus reiterating the need for an individualised approach. However, nearly all parents described occasions where their child’s behaviour had been addressed in school through universally punitive approaches:

> *“They expected her to follow all the behavioural policies which she didn’t understand, and she didn’t know how to do,… to sit quietly, wait your turn to speak, stay on your chair, and then you had to do the activities that the teacher was going through, and she didn’t know how to”* (AP 3).

> *“They're definitely switched on now into what works for X, what makes him tick, what's benefiting him and what’s…well they're getting the best out of him I think in the classroom. They, as I say, he can still have times where he’s just slumped on the desk, and they will read that and they will go come on X, let's go and have a little walk. But they're taking the time to do that, as opposed to just making him like every other neurotypical child in the class. He's not neurotypical, which they now realise. Whereas before they go, you gotta sit up, you've gotta try harder, you've gotta try harder, you know he couldn't try harder…that was the problem, and they're realising that now”* (AP 4).

As the above extracts demonstrate, participants shared 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 unsuccessful. This was a battle experienced by most participants. Where participants felt approaches were successful, it was around developing an understanding of how the individual's *"tick"* which facilitated *"getting the best out of him",* as the second extract shows.

An individualised approach was often advocated for by parents in relation to provision and adaptations required in school. One parent reiterated the importance of *"not just standard measures in, but the measures to support him as an individual which we're starting to see benefit from"* (AP 4). The role of teacher's considering both "*how they teach and what they teach"* (AP 2) was emphasised. For instance, parents talked about success as being when teachers recognised the need for "*thinking outside the box*" (AP 5), avoiding abstract concepts in favour of concrete resources, "*micro-managing and breaking things right down*" (AP 6) and "*hovering over, around him*" (AP 2) to check whether they require help. AP 2 also described how their child's emotional literacy was supported by using "*different colour cubes so that he could show how he was feeling"* and *"a table space where he could take 5 minutes every now and again".* Another caregiver positioned this care and attention as being central to their overall experience, so much so that this was their rationale for participating in the research study:

> *"I think part of the reason I want to do this, as an aside, I think with the right stuff in place, children with difficulties really can make it work, it's not a lost cause, and although there's obviously a lot of bad things as well, but a lot about this is positive and I think that shows that actually they can make it work, and what the school has done is kind of testimony to the fact that if you put that right, then school can be a goer for them"* (AP 8).

Parents attributed the implementation of highly personalised strategies as being significant for their child's experience of school:

> *"The school has been giving him a weekly time slot with the maintenance guys, like the caretakers of the, of the school. He absolutely loves that because he's being practical, he's allowed to help them at gardening or doing some jobs around the school and it really boosts him. I mean, that's his favourite part of the week at school, so that's going great* (AP 4).

As this extract illustrates, parents highlighted the benefit of provision which allowed the child to experience being successful. One parent described how this was achieved for their child by reducing the amount of work they were expected to complete at a given time, thus aligning with what was achievable for that individual. They explained how this "*makes him feel better because he's achieved, finished his work and he's achieved it"* (AP 2). However, this was something which parents felt their child did not experience often. One parent described the rigidity of education as a barrier to this and felt that the 'one size fits all' approach to learning meant that their child's strengths in other areas, namely more practical skills, over and above academic skills, were not acknowledged. Practical skills were overwhelmingly represented in parents' narratives around their child's interests, particularly science, sport, art and cooking. Interest led learning was raised by parents within discussions of an individualised approach:

> *"It is that planning, and you know sequencing that he finds difficult, or found difficult. But now…he runs a boxing, umm a fitness class, on a Monday night which he plans, he prepares, he sets it all out and then he delivers it, so he's got it if it's quite short and it's something he's interested in"* (AP 7)*.*

As this extract illustrates, interest-based learning enabled greater engagement with learning and enhanced opportunities to be successful. This parent felt that interest-based learning mitigated the effects of their child's difficulties. This was something that parents consistently reported as being facilitated by COVID-19 lockdowns, whereby smaller class sizes facilitated greater opportunities to explore their child's unique interests. This was recalled as a positive lesson learned from the pandemic.

Theme 2: Sense of Belonging

The theme 'Sense of Belonging' captured parents' reflections of their child's experience of school as a place which both fostered and severed their belief that they belonged. This was supported by 'Relationships and Acceptance' and 'Feeling Safer within a Relational Approach'. Yet parents perceived that their child was left 'Feeling Different' and did not have an obvious 'place' or 'fit' within the wider school systems, resulting in a 'Fragmented Belonging with the Education System'. These components comprised the four underpinning subthemes of this theme.

Relationships and Acceptance. Analysis of the data clearly illustrated the importance that parents placed on relationships for ensuring pupils felt integrated within school, this incorporated relationships with peers and adults alike. Parents overwhelmingly deemed peer relationships and friendships as being one of the few aspects of school which their child valued. They spoke about their children enjoying "*socialising*" (AP 7), "*hanging out*" (AP 8) and how they "*relied on these friendships*" (FC 9) as being "*pretty much*" (FC 9) the only positive aspect of school from their child's perspective. One participant suggested that this had previously informed their decision not to move their child to another school and was a concern for upcoming transitions:

> *"He'll struggle if, well when, because it will change, when that circle changes, because obviously they've been in school together from year 7 to year 11, and it has changed a little in that time but those people have been around for that time, now they're going to college, some of them are going to different places, some of them are going to do apprenticeships, and he'll meet new people at college so that will change and he will be all over the place for a while until he's found his group"* (FC 9).

Whilst considered important for their child, parents also held numerous worries relating to peer relationships, particularly their child's vulnerability to issues such as bullying, which was raised as a regular occurrence. Nearly all parents described their concerns relating to their child being misled by a strong desire to be accepted by others:

> *"I do worry about the future for him. I worry about him turning, you know, in his teen years and the kind of boy he is...he's got a real love of danger. He's a bit of a people pleaser, so he loves to impress other kids, so, impressing other kids, 'cause it, you know, can lead him down the wrong path, in the wrong crowd" (AP 4).*

As this extract highlights, parental concerns extended into the future but was also very much a present issue, with parents sharing times when a longing for friendships had resulted in their child being coerced into doing certain things. These behaviours were wide-ranging, from swearing to drug taking, and sometimes included sexualised behaviours. Parents reported that this often resulted in their child getting into trouble at school and sometimes with the law. Parents reflected that these challenges also related to their child's awareness of social skills and boundaries:

> *"Friendships are really hard because X certainly wants to be very easy to please but a lot of the kids are a lot more savvy about what that means, he doesn't necessarily have as many filters, so he's more likely to get into trouble and more likely to be led*

> *into trouble, and that's not me excusing his behaviour because obviously he's responsible you know, but the other kids know when to pack it in and it's too much, but X struggles to know when they come in, so friendships both in terms of interactions with those friendship groups which is often, it can be quite fractious, but also then how that then gets behaviourally into trouble with teachers and that is quite a struggle for him"* (AP 8).

As illustrated by the above extract, parents felt that friendships, whilst important, were often difficult for their child to maintain. Similarly, where other children were aware of boundaries and "*when to pack it in"*, parents reflected that their children were often not. Consequently, parents recognised that their child would need ongoing support in this area, particularly "*to filter out friends, so-called friends*" (AP 3). One participant shared that psychoeducation had supported their child to feel accepted in a more pro-social way:

> "*One of X's teachers, I had a phone call with her, going back a couple of months, and she wanted to do a lesson within class about different disabilities and bring up about FASD, and X was happy to take part of that. So, I printed loads of information off that I could, for her, and sent her a couple of the YouTube videos from the website so that she could, they could see, and understand a bit better and that apparently, within the school, the children actually were quite receptive of all of that, and their outlook or how they see X and you know what he's like, they can understand it a little better. It's now a case of, if he has one of his meltdowns at school, it's not just because he's misbehaving or just doesn't want to do his work, they, sort of, know now that this is, sort of, what it is. One of his class friends, the following day, apparently went on to the website and had a look and had a read*

> *about it…I think that helped a great deal with X, that he feels more accepted now because everybody is, you know, understanding a bit more"* (AP 2).

As evidenced by the above extract, this parent felt that the school's approach had been supportive for their child's sense of belonging, particularly amongst their peers. This extract also demonstrates that beyond relationships with peers, parents emphasised the importance of, and the difference, that teachers and other education professionals could make for their child's experience of school. Parents spoke particularly highly of special educational needs coordinators (SENCOs) stating that "*I will never forget, you know, he made all the difference for X. And yeah, that's when I become a bit tearful*" (AP 1). Another felt that the SENCO was there to "*fight her corner"* in school (AP 5), which demonstrates the importance that parents placed on there being an adult in school championing their child.

> *"I think they do know him very well, certainly his TA (teaching assistant) because she's been with him for such a while, she really knows how he ticks and how to help him navigate stuff"* (AP 8).

Parents felt it was important for their child to have key adult relationships in school, whereby their child had a point of call who understood and was supportive. This pertained to school staff assisting them to manage potential barriers in the school environment. They recognised that this took time to establish, but nearly all parents highlighted the importance of that 1:1 relationship. Parents shared that secondary school was particularly challenging for achieving this as teachers changed each year and there were multiple relationships for their child to manage. When teachers have "*remained the same*" this has been helpful because this provides some stability (FC 9).

Feeling Safer within a Relational Approach. Parents emphasised that beyond having key relationships with adults in school, their approach, particularly when relational, was hugely beneficial for their child:

> *"I think he feels very safe with them … it was a lot about forming the relationship and the trust first of all"* (AP 5).

> *"it's kind of an empathetic approach, like with X, if you approach him with that empathy and that understanding and that calm, kindness, all those other things instantly get much easier…"* (AP 8).

As these extracts illustrate, a relational approach was built upon trust, empathy, respect, and was supported by teachers who had "*a hell of a lot of patience*" (AP 6) as this promoted feelings of safety and security in school. One parent described how the use of this approach by the entire teaching staff was hugely successful in ensuring their child belonged in the entire school, not just with one adult. Many participants discussed the need for a relational approach specifically in the context of behaviour management:

> *"He does like a more nurturing teacher…it was the sterner teachers that he struggled more with. So, his teacher this year can be, she's been quite stern, and he's really struggled with that. Uh, we know at home as parents, any kind of shouting or raising voices doesn't work at all, it doesn't do him any favours; he just crumbles under that. He just needs a real, soft, gentle approach"* (AP 4).

As illustrated above, parents consistently noted that less open and nurturing approaches did not work well to support their child. Instead, parents reflected that teachers who took the time to talk, listen, approach things sideways and be more hands off, worked well.

Parents stressed the importance of a relational approach extending to all interactions with their child, including those with external professionals:

> *"She needed to get to know her first so she knows she can trust you, before she'll talk to you, at that point she didn't really trust anybody. That was difficult. And for it to be helpful she would've had to have started to build that relationship up to be able to, to get useful strategies to help her, to move forward"* (AP 3).

This parent explained that EP involvement would have been more purposeful and have achieved better outcomes had a relational approach been adopted. This echoed feelings of others who felt that one off visits were insufficient to get to know the child and vice versa. Where efforts were not made to form relationships, or build trust, parents reported feeling that the EP "*struggled*" to work with their child, with one participant explaining how this "*didn't give me much confidence*" (AP 1). Contrastingly, EP involvement was described as successful and useful when such an approach was used, as parents reported feeling that the EP had made a connection and enabled the child to engage fully and "*really pour her heart out*" (AP 6).

Feeling Different. It was clear that parents were aware of their child feeling different in school. Parents described their child's frustrations around receiving support in school which made them stand out from the crowd:

> *"What he didn't like was being made to feel different, and you know having his name called out, and then being taken to do his exams elsewhere, so again I just worked with the school and said don't do that, he knows he's got his exam, so he'll come over to the room, so please don't call his name out and make him feel different"* (AP 7).

As evidenced above, parents reflected that often it was learning accommodations that perpetuated these feelings of being different. This occurred particularly in the contexts of exams which took place in a different location or within which an adult accompanied them to read or scribe. Parents also described scenarios when their child was taken out of class for interventions as being difficult. One parent described how the attention of being singled out as different had a noticeable change on their child, particularly their self-esteem:

> *"she used to be so, quite outgoing, she used to perform, she used to be part of the '—' performing arts academy, performed on stage, she's put on singing competitions… you know performing arts was really her thing and now she won't sing, she won't get on stage, she, she's like a little mouse now and she just shrinks from any kind of attention, she just, it's like it's been knocked out of her, like the saying knocked the stuffing out of you, and that's what it's like really"* (AP 6).

Within their narratives, parents explained that practices which left their child feeling different also infiltrated throughout school's approaches to behaviour management and had similar effects as that described before:

> *"They triggered her, and they put her in isolation. Every time she did anything wrong, they blamed her for it, but she couldn't help it. They'd put her back into the isolation and they made her feel really alone. That affected her self-esteem and her learning. They really weren't very helpful"* (AP 3).

Parents often spoke of the negative impact of behaviour policies, including the use of isolation rooms and other 'public' strategies, such as moving their child's name up or down, dependant on their behaviour. As described in the above extract, parents were particularly concerned by the effect of this on their child's emotional wellbeing and sense of self, specifically feeling isolated and having reduced self-esteem. In addition, shame was an emotion described by parents as one that their child experienced intensely:

> *“I think schools are set up to make kids feel ashamed. That's kind of their behaviour technique isn't it…I think they need to avoid things that are very punitive and very public. I think they do need to be really aware that shame is such a powerful emotion when these kids are already feeling quite ashamed”* (AP 5).

As this parent suggested, participants felt that current school behaviour practices were not yet conducive to minimising feelings of shame, which parents associated with the profile of FASD, and instead often did the opposite.

Parents raised that issues relating to feeling different were mitigated when their child worked with others who had similar needs, such as in ability groups. For some this was based on experiences thus far and for others it related to what they imagined would be helpful, in a preferred future. As the following extract shows, this opportunity occurred most often outside of mainstream settings:

> *“Through the SENCO and the ‘—’ services, they got him involved in ‘—'. So he really enjoys that and that breaks it down that, even though he’s still learning, it's a different side of the curriculum that he's learning, it’s more to do with how he behaves, you know, making friendships being open and talking about how he is, and there are other children, the other children there are all similar, with different, sort of, disabilities, but they can all not feel just on their own, they all sort of have something to talk about, which is great for him, that he doesn't feel that he's the only one or just him that has these difficulties”* (AP 2).

This parent perceived that working with similar peers supported difficulties with peer relationships and helped their child better understand themselves, thus developing an improved sense of self and belonging as they no longer felt different in that environment.

Fragmented Belonging within the Education System. As shown in Tables 3 and 4, participants' children in the study were currently, or had previously, been educated in a variety of educational settings including mainstream and specialist institutions, such as pupil referral units (PRUs), and home tuition via EOTAS. Others had dual placements where they attended alternative provisions such as forest schools on a part-time basis. Parents held conflicting views around whether mainstream or specialist settings were most appropriate for their child. Many described having experiences of both and the flexibility that different educational settings offered was celebrated. For instance, AP 7 described how remote online teaching as well as placement-based tutoring "*suits*" their child and was a "*really good way of learning"* for them. Multiple participants spoke about learning in the community, including a placement in a gym for a YP who aspired to be a personal trainer and another at a horse racing yard for a YP who hoped to become a jockey. Again, as highlighted in 'Theme 1: Understanding the Individual', the emphasis was not on the universal but the individualised suitability of education which tapped into individual interests. Parents also highlighted the multitude of school transitions that their child had experienced. One parent described being "*lucky*" that their child had had a stable experience, despite feeling that it was "*possibly not the best school environment*" (FC 9). They attributed the importance of friendships, and belonging as the reasoning behind this:

> *"It is really difficult; I mean maybe we should've tried harder to get an EHCP and maybe look at a specialist school, but because his friendships were so important and we knew he struggled emotionally, we sort of went with the flow and let him stay*

> *with his friends, and the harder he found it, the more he relied on these friendships, so the harder it was to take him away from that"* (FC 9).

It was clear that parents felt learning was a complex process for their children owing to their multifaceted profile as highlighted previously, however, this extended beyond 'within-child', neurological differences:

> *"She can learn you know, she can but you know she couldn't, it's a combination of all the sensory problems and attachment disorder and the whole FASD, she couldn't go, she couldn't' cope in a classroom with that many other children"* (AP 6).

As evidenced by the previous extract, parents consistently reiterated the importance of the school and classroom environments as a condition necessary to support their child's learning. Importance was placed upon the need for a quiet, calm and nurturing environment. Many parents shared examples of times when their child had intentionally found themselves in isolation or refused to leave 'THRIVE' classrooms because these environments were better able to meet their needs. Individuals "*enjoyed being there*" (AP 1) and felt "*relieved"* (FC 9) in these environments. It was this understanding that informed many reasons for choosing one education setting over another. These included greater flexibility around formal examinations (taking fewer options, foundation level etc.), creative curriculums (forest school, practice-based learning, life skills etc.) and smaller class sizes within specialist settings. The latter was most consistently referenced in parents' narratives. Nearly all spoke about a time when their child attended a small school as being the most positive educational experience, Parents felt this provided their child with space to go "*if it gets too much*" (AP 6), and less demand on teacher's time from others. Those who did not share this experience often expressed an ongoing desire to find a smaller placement with fewer children. However, AP 8 reflected that whilst a small school may appeal to parents, with many "*thinking you want a small school*", but "*that makes the effect of him actually quite dramatic*". They felt that larger schools had greater access to resources, including more staff which provided greater flexibility than smaller settings could offer.

What was unanimously clear from parents' experiences, was that they did not know where, or even if, their child belonged within the broad education system:

> *"Nobody knew what to do with her and that's what we've found all the way along…we then tried another school which, they've got a specialist support class, but at that time she couldn't go in that class because she didn't meet the need. She didn't meet the criteria because she'd got a normal IQ"*
>
> *"there just isn't anywhere and they do keep coming back and I keep phoning up '—', who are supposedly finding her somewhere to go with school and you know they keep saying, oh we've had another meeting and we're thinking this school, and then that school, and then it'll go to another meeting, and either the school will say no, we can't meet her needs, or umm at the moment they're talking about '—' which is the social, emotional, mental health school which has just opened, and they've said they can meet her needs, but they don't know if there is a place there because there are so many children who need to go there and there's only 60 places, its now, you know who needs it most. It's a nightmare, there is just nowhere. You see there are quite a few ASD schools around now, but she doesn't fit the profile of any of the provisions that are there at the moment"* (AP 6).

As this parent noted, parents did not feel that anybody knew where their child belonged educationally. This parents' description reflected that of others who named a distinct lack of availability of specialist provision as a barrier, and as this extract shows, parents felt there was more availability for those with other neurodevelopmental conditions compared to FASD. What participants did agree on was that some experiences were better than others, there was no one ‘perfect fit’:

> *“Then they put her in this special support class which she did seem to settle better in there, but she didn’t learn anything…*
>
> *…so, although she attended that school and they gradually got her up to a normal timetable, she really didn’t learn anything, it was more like a babysitting service. It sounds awful…it’s not really the fault of the staff because they did try”* (AP 6).

As this extract illustrates, the complexity and variation of their child’s needs meant that whilst some components of a particular setting were supportive, others were not. This parent suggested that the issue was wider than the school itself, or staff within it, but instead related to a systemic problem. Parents overwhelmingly described the decision of where to educate their child as a huge responsibility and yet, as the first extract also demonstrates, one that is often out of their hands, particularly when placements failed:

> *“We had lots of meetings 'cause basically, obviously the local authority just wanted to move him to another school, 'cause that's what they do. We were pretty adamant that wasn't going to happen because we knew the problem wasn't the school, it was that any environment like that was not the right environment for X” (*AP 5).

One parent felt that identifying a ‘best fit’ school was an area where parents could be better supported, whether that be by an EP or other professional:

> *“I think the only thing and it might not be within the scope of what you do, I don’t know, but the EHCP was actually fine for us in a lot of ways, we know that a lot of people really struggle to get one…but I think the thing that we found really difficult was that you kind of get all of this stuff and they kind of list all of the things that they*

> *need, and they say to the parents now go and find a school that kind of fits all of that…*
>
> **P2 nods in agreement**
>
> *P1: And you kind of go ummm I don't know, I guess it was worse in lockdown when we tried to do this because we couldn't visit schools and maybe that would've been easier but that's the bit that flummoxed us, you're left to make this big decision about where to put your children but it's like we're not the experts in what all of these schools are about and that kind of thing and that was the thing that we struggled in"* (AP 8).

Theme 3: Collaboration and Communication

The theme 'Collaboration and Communication' reflected parents desires to have a collaborative working relationship with their child's educational setting, which was underpinned by effective communication. The extent to which parents felt this had been achieved was variable. Analysis of the data provided an insight into parents' experiences of 'Collaboration and Communication' within the family-school interaction. It was found to be facilitated and hindered by the presence of and dearth of, 'Reciprocity', 'Shared Accountability and Responsibility' and 'Active Inclusion of Parents' respectfully, thus formulating the three related sub-themes.

Reciprocity. Participants described undertaking an active role in supporting their child's school, yet their efforts were not necessarily matched by those within the school system. Different attributions were made around the purpose of this, including nuanced distinctions between whether their involvement was assumed or voluntary.

> *"Yeah well I was going to say, you know I think what has really helped, and I don't mean this in any way that we are bigging ourselves up, you know we've just done what parents do, but I think it is about having that relationship with the school and*

> *being available to be part of that, so when they've called and had problems with them I've gone in, I've dealt with it, helped them and actually so that they see that there isn't an expectation that we just expect them to deal with our children and you sort it out, you know, they're at school with you, we've always been a part of that, and I think you're taken a bit more seriously if you do that, if you are part of it and you acknowledge it, you know what's going on at school and you try and be useful…*" (AP 8).

Whilst a role upheld willingly for this parent, this extract demonstrates that there exists an assumption that parents should be "*available*" to support school. This extract highlights that parental support often meant having a physical presence. The need to be physically available is also reiterated within the following extract which suggests that parental support is required not only to support their child's experience of school, but also that of educators who needed to be relieved:

> *"I would be picking him up at lunchtime 'cause he couldn't cope or when they couldn't cope"* (AP 5*).*

As demonstrated by the first extract, often parents themselves did not recognise the extent of their efforts in providing support to schools, instead this was minimised to "*what parents do*". For others, offerings of support stemmed from expressions of empathy given their own experiences of parenting. Indeed, parents who cited good working relationships with schools acknowledged the challenges faced by educators.

> *"I think we'd always tried to be really, you know, we always had a very civilised relationship with them because we were living with him, so we knew how difficult he was. We were very worried about him at school, which is why when they were talking about, you know, the head there was trying to get him moved to another local*

> *primary school, you know, we didn't feel it was the school's fault, I mean, they weren't particularly understanding or enlightened, but actually it's hard to manage a child like that in a mainstream classroom. We didn't really know how else they could"* (AP 5).

This extract further highlights the conscious efforts made by parents to secure a collaborative relationship with schools. Parents maintained politeness in "*civilised*" relationships despite the challenges they were experiencing within those partnerships and the growing concerns they held for their child. A central part of the collaboration for this parent was that they themselves did not necessarily have an identified 'solution' which they could offer as a means of support to the school. Again, it was about being "*available*" to schools.

The first extract illustrates that some participants saw returns in that they were "*taken a bit more seriously*", suggesting that parents perceived that their active contributions furthered effective collaboration. However, other parents described inequalities in the reciprocity of support they received from school, and this was the primary narrative. This was most evident when parents were driving collaboration with the aim of seeking support for their child, often to no prevail, an experience expressed by one participant as "*like banging my head against a brick wall"* (AP 6). Two-way communication was a mediating variable that was particularly valued by parents, but not consistently reciprocated:

> *"The communication with a child who's got additional needs is so key because I think if your parent and teacher are on board and you're doing the same stuff at home and at school, it works, you know? You're working for the child, but when there's a lack of communication, it's so hard and we found that really difficult this year"* (AP 4).

Within this extract, the need for consistency across the family and school systems is emphasised as being both important and achieved through collaboration. This point was furthered by other parents who shared that schools were more likely to see the value of implementing support if they could see it was reciprocated within the family system also. For example, AP 7 shared how they asked "*if he's got homework set then please can you email us, tell us what the homework is as well and we will make sure he does it and we'll be his external brain*". Consequently, "*as the school year progressed he got less negative points because he had got those support strategies in place*". AP 4 reflected that within effective collaboration '*the child'* is positioned centrally, but that communication is important to achieve this. Other participants reflected on teachers as sources of support for them, however, meeting them was a challenge posed by the COVID-19 pandemic, where parents were not permitted to enter the school buildings. Other parents reported appreciating teachers giving their time through clear and accessible communication avenues. AP 8 shared that communication was an area that EPs could provide support:

> *"Ed psychs could probably be maybe looking at supporting parents and educating them about how to deal with a school, because teachers are human, and if you go in and you're rude or angry or you're defensive, then it's hard for teachers not to be offended by that, whereas if you're going in and saying you know I'm with you, we want to support you, we think you're a great school but what can we do to help from home? You get a better response, there's no doubt about it, so I think that'll be another thing for the ed psych, for them to talk to parents about how to communicate and how to support effectively from home, to support the school basically"* (AP 8).

They stressed that the manner of communication was important to ensure reciprocity from school. However, this differed from the experiences of others who had fewer positive interactions with the school system and had therefore felt it necessary to adopt a "*defensiv*e" stance to ensure their voice was heard.

Shared Accountability and Responsibility. Parents described home-school collaboration as being halted by issues relating to responsibility and accountability. Parents shared experiences where responsibilities were weighted towards parents, despite in some instances shifting from what were clear school remits. This included refusal to have the child on school premises without parental accompaniment and advising parents to cease EHCPs so that their child could attend. For many participants, this resulted in them advocating for their child's school to accept accountability, as demonstrated by the following extract:

> *"It is really difficult, very frustrating. It it's made me and my husband very angry and our relationship, as we've said, with the, with the founder of '—', is very, very tense. It is, because we have, I think, made him accountable for the first time, I think he's not had to be accountable"* (AP 1).

As this extract highlights, pursuing issues of accountability for many parents was perceived as a barrier to maintaining collaborative relationships with schools. Other participants described that this perpetuated feelings of distrust. Parents felt that often their child's school did not implement actions following on from their words, resulting in parents taking the responsibility of managing and holding people to account:

> *"I keep a… I've got a lot of folders, but I keep a book and I record every meeting, who's there, you know vaguely what is said, what are the action plans, what are the time frames and things like that. I think people think it's a bit intimidating, but it's almost like I've felt like I've had to chair a lot of the meetings that we've had over the*

> *years, and so can I just clarify who's doing what I mean, I've just got used to that"* (AP 5).

Issues of trust extended into communication also, including information sharing:

> *"There was one day I remember having real difficulties getting her in and she ran away. She ran up the road and I went to get her and it took about, I don't know, twenty minutes to half an hour to get her into school and then when I spoke to the head teacher then she said "oh you know she was fine, you know five to nine and she was in class and sitting down" and I said well I don't know how because I didn't leave until twenty past nine because I was trying to get her into school. So, you know that just made me think, you know they're just not being truthful" (*AP 6).

Other parents shared that reports produced from external professionals were the first time they gathered a clear understanding of how their child was, or was not, managing in school because information shared previously was not coherent. One parent described how "*you see it written down on a report then you just think oh my god you know why hasn't anybody told us this?*" (AP 7).

Issues relating to accountability for parents were two-fold. Not only did they explain the need for schools to be held to account, but they felt that they too were held to account as part of this interaction.

> *"I'd often have to pick him up and I remember the SENCO, it was a small school to be fair, but a quite elderly SENCO said are you going to take his computer away when he gets home? And this was 10 years ago, and we genuinely didn't have a computer at that time, 'cause we're not particularly people like that, and I said we don't have a computer and I wouldn't have my 4-year-old on a computer. I just thought that summed up their attitude that his problems were all because we were rubbish parents"* (AP 5).

As this extract illustrates, parents overwhelmingly felt blamed by schools, and that their parenting was both responsible for their child's presentation, and consequently they should accept accountability for this. This infiltrated into issues of trust also as one participant explained "*they were saying oh it's all at home, you know she's fine when she gets here, after you've gone, she's fine"* (AP 6). Experiences of blame extended beyond the family-school relationship into interactions with professionals and the wider community.

> *"My experience is that people blame me, and I can't do any better. So rather than point the finger, you need to offer help. 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*" (AP 3).

AP 3 echoed the reflections of many others who felt that blaming parents was unhelpful. Parents shared that it would be more beneficial for alternatives such as support to be offered instead of judgement. The above extract also demonstrates the efforts to which parents felt they must go to avoid being blamed. Similarly, it evidences misunderstandings associated with the aetiology of FASD.

Active Inclusion of Parents. Analysis of the data revealed that parents did not feel authentically included in the interaction with school. As one participant explained "*they say I'm the parent and I know her best, but then you put your views to the school, and they don't really take any notice"* (AP 6). This illustrates how parents deemed their participation to be tokenistic in nature and did not feel listened to. Other participants shared that they did not feel heard, and teachers were disinterested in what they had to say:

> *"I did most of the parent's evenings because they only want one of the parents to go most of the time, and you'd start talking to these teachers and it was almost as if*

> *what you were suggesting to them was so foreign, so alienated, that you might as well have been speaking in another language because you could see them switch off, I've got four minutes left and then this person who is really testing me will be gone. Not all of the teachers were like that but some of them definitely, 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* (FC 9).

Parents perceived themselves as sometimes being an annoyance to education professionals and that what they were sharing was either irrelevant to the teacher's role or did not fit with their understanding. This occurred even at times which ordinarily welcomed parent-school communication, such as parents evening. The previous extract demonstrates that variability existed in the extent to which participants felt ignored and experiences differed between teachers. Where parents did feel respectfully included, their experiences of collaboration were more positive. Perhaps where this participants' experience differed most was in the school's receptiveness towards their input:

> *"Yeah absolutely, we'll come in and we kind of give them information about how they are at home and stuff we've found that works for them or might antagonise them and stuff so yeah that's a lot of backwards and forwards between us and the school. We kind of chat that through, often the SENCO, TA and teacher, not always the teacher but always the TA will be there to kind of discuss, I think they call it team about the family…"* (AP 8).

Where parents did not feel listened to or included, they spoke of feeling removed and watching on as situations arose around them:

> *“We knew in reception that we were having issues, we could see what was coming but nobody stopped it, they just carried on until there was nothing they could do, so the school just kicked her out”* (AP 3).

These feelings of powerlessness reverberated through others’ experiences whereby parents witnessed school staff using physical restraint instead of alternative, more nurturing approaches that they had suggested. Parents described battles with those in positions of power including senior leadership members and the LA to secure EP assessments and school placements. At other times, parents described inviting others, whose opinions they deemed to hold more weight, including social workers or counsellors, along to support the parent to be heard. One parent described how meetings with multiple stakeholders were a regular occurrence to secure a placement for their child, and yet they were not consulted, included or updated on the outcomes. This was a repeated experience for this parent and highlights the lack of participation or power that parents felt they had despite their willingness to be involved:

> *“Towards the end of Year 6, in fact, about this time last year, we still didn’t have a placement for the September, they didn’t know where to put her basically. They didn’t like my suggestions, so she left in year 6 without knowing which high school she was going to, so, you know, and in her EHCP it said she needs a robust hand over, really robust transition into high school and she didn’t have any. In fact, she’s in an alternative provision because they didn’t identify a high school for her, and she’s supposed to leave there at the end of July and yet again we don’t know where she’s going in September”* (AP 6).

Not feeling heard and unequitable power distributions were also reiterated in parental interactions with EPs. Despite all but one parent experiencing EP involvement, they often spoke of not being included in meetings. A lack of physical inclusion with EPs was captured by one parent as "*just a done deal*" (AP 7), as no space was offered for them to share their views. Other parents shared that this was a concern for them because they were unclear of how that professional understood their child or their needs, something which parents would have liked to clarify upon meeting. Another parent reflected that despite being physically included; they did not feel their views were valued. After describing the experience as "*hierarchical*", they expanded to say "*she was the professional, do you know what I mean? And it didn't really matter what we felt*" (AP 1). Conversely, others had a dissimilar experience and felt listened to and heard by their EP:

> *"I think it's just, part of it is feeling listened to, somebody is actually listening to me, listening to X, umm. She's putting forwards suggestions that I've thought for a long time…having a professional say it, it holds more. Like I've been trying to push for an EHCP for so long and they've been like oh no no she doesn't need one but suddenly the psychologist says she needs one and then it's like oh ok then. You know it's just being heard again I guess, it's just you know, having someone in your corner kind of thing"* (AP 6).

However, for this parent, like those who invited other professionals to support their battle to be heard, they felt that EPs were better listened to, and their views held more weighting.

Theme 4: Knowledge and Awareness of FASD

The theme 'Knowledge and Awareness of FASD' encompassed parents' reiterations of the need for improved knowledge and awareness of FASD across systems. Parents emphasised a profound need for improved knowledge amongst education professionals particularly. Parents' reflections around the presence of and the resulting the impact of poor understanding of FASD on their child's experience of school, is captured within the subtheme 'Educating the Educators'. The subtheme 'Parents as Knowledgeable Disseminators' reflected parents' learning journey as they acquired knowledge of FASD and subsequently became fountains of knowledge who distribute this information to wider audiences. This included educational professionals as part of an advocacy role. Finally, the wider implications of limited awareness of FASD, within the context of education, both for families, children and educators are highlighted within the subtheme 'Accessing and Advocating for Support'.

Educating the Educators. Analysis of the data clearly showed that all parents considered education professionals to have a poor level of knowledge and awareness of FASD. As one parent succinctly explained they found the understanding of FASD in school to be "*pretty much nothing*" (AP 3). This was prevalent throughout parents' narratives regardless of whether their child attended mainstream or specialist settings. Parents noted that limited understanding of FASD had considerable implications for their child's experience of school, particularly teachers' interactions with their child. Parents reflected that schools did not consider their child holistically and as they had a better understanding of adoption in the context of trauma and attachment, they made assumptions that their child's difficulties related to that over and above FASD, yet this was not consistent with parents' understanding of their child. The idea that school's knowledge was better in other areas compared to FASD was reiterated throughout narratives:

> *"I tried to explain to them 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 isn't as large, doesn't function properly, to understand what you're telling them"* (FC 9).

One parent suggested that *"they discriminate against invisible disabilities"* (AP 6). The above extract offers one of several examples where parents highlighted inconsistencies between practice which schools would not deem acceptable for those with other difficulties.

> "*They just thought he was a naughty boy, they genuinely just thought he was naughty"* (AP 5).

Parents raised frustrations that a lack of knowledge of FASD often resulted in teachers misinterpreting their child's behaviour:

> *"it's like, that old phrase you get a sledgehammer to crack a nut, they just keep going at it from a its behavioural and that's what that they, even when we got the diagnosis and you know we said no it's organic brain damage, they can't separate the two"* (AP 6).

> *"The school seemed to think it was because of the behaviour, the learning difficulties would come first, she couldn't do it, she couldn't do anything about it, but they'd just keep telling her off and punishing her for it because she just wasn't capable of doing any better, she was doing the best she could"* (AP 3).

As the above extracts illustrate, for some, incorrect assumptions and attributions led to their child being blamed or punished. Indeed, nearly all parents reported times when their child's school had viewed behavioural difficulties as a deliberate choice made by the child. Parents stressed their concern in relation to the impact this had on their child's sense of self:

> *"I think probably over the last year or so he's definitely got a huge complex that basically, a lot of the time his opinion is that a lot of the teachers hate me, and I think he genuinely believes that"* (FC 9).

As this extract shows, parents felt that their child was acutely aware of how others viewed them. One participant expressed how diagnosis had mitigated this and shifted their child's sense of self which they felt had been formed based upon their experiences of education:

> *"X has talked about how, I don't know if you might come on to diagnosis, he finds it really helpful… *participant cries*… 'cause he thought he was bad, sorry…you know it's brain damage, there's no, it's not that he's bad. He's been told for years that he was bad boy"* (AP 5).

However, others felt that diagnosis alone had negligible impact, particularly on teachers' understanding, and thus their child's sense of self continued to be negatively affected:

> *"They say it to her, they tell her she's childish, they tell her she's lazy, they've told her that she's not doing enough work but even though they're well aware of her diagnosis"* (AP 6).

One parent explained their experience of EP involvement as being supportive of these difficulties:

> *"I think some of the teachers hadn't really experienced a child with FASD, so I think for them it was really useful to have that feedback, so kind of a validation of why he behaves the way he does, I think for some teachers, I mean they've all been excellent but 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 you know, there's a valid reason so I think that's really useful from that point of view"* (AP 8).

As this extract shows, parents felt that EPs involvement was helpful when they provided explanation as to why their child presented as they did within the school environment. Parents reported noticing that EPs were considered experts who had the power to instigate change:

> *"Although that was all in the report from the clinical psychologist, I think having it from somebody who is in education, coming into the school and physically saying yes this is what is needed is really good because I think teachers will listen to that if that makes sense…It's kind of credible isn't it"* (AP 8).

This participant felt that the EP's unique knowledge of education was what facilitated this over and above other professionals.

The following extract reflected parents' view that there exists a need to improve school's knowledge, and training was consistently highlighted as one means of achieving this:

> *"I think there should be somewhere, training available for schools so that if they have a child with a diagnosis of FASD, all teachers attend the training so that they understand what it is and how it affects that individual"* (AP 7).

As this extract suggests, parents felt strongly that all teaching staff should attend training where possible. Participants cited the prevalence of FASD, the physical effects of the condition as brain damage, and the variation in presentation across individuals with a diagnosis as key rationales for why training in this area should be prioritised. Parents also raised this as one avenue of support that EPs could offer, however, this was a future consideration as none had experience of this thus far. Whilst some considered the school SENCO to have greater knowledge than other staff members, many still felt this was insufficient. Where the SENCO's knowledge was considered to be better, the SENCO's role was described as being both a gatekeeper and information distributor within the school system:

> *“The SENCO is very very clued up about all things and they’re very good at, I’m not sure specifically what training they’ve been on but they’re very good at putting their teaching assistants and teachers through the training they need, whether that’s face to face I don’t know, but certainly kind of having fact files and that kind of thing on all of these things and how you need to adjust how you approach children I guess in light of that”* (AP 8).

However, other participants highlighted several barriers to the reality of this, including difficulties engaging teachers and their receptiveness:

> *“She said you know they’re struggling to get the teachers to do it, to take up the offer, she said because “we can’t force them, its optional” and I’m thinking well it shouldn’t be. They should just do it you know, all of the teachers, it’s not just X you know there are more children out there…so why shouldn’t they all just have to do the training, it’s only a couple of hours out of their day” (AP 6).*

> *“I’ve sent every report that we’ve had, it’s gone into school, and again ‘—’ she said, “well the teachers don’t read the reports because they’re too lengthy, we go through them, pull out bullet points and send them and hope they read them””* (AP 6).

One parent particularly noted the discrepancy between their experience of knowledge and action:

> *“There was a lot of talk and when it came to it there wasn’t a great deal of action, you know, it’s one thing that SENCO knowing about it but it’s something else getting the lecturers etc to know about it”* (AP 7).

As this extract highlights, parents felt that simply an understanding of FASD was not enough, ‘who’ had that knowledge was also important and the proximity with which they worked with their child. This is referenced within the earlier extract from AP 8 whereby they noted the value of teachers considering the implications of what this means for their practice. One parent shared examples of when this had not yet been fulfilled, despite the best of intentions:

> *"In one or two lessons where they obviously have tried to listen, or looked at it but not quite got it, they've, oh she said my science teacher is really annoying now because she keeps coming up to me and saying, "are you concentrating?" So, where we've said she needs a prompt to bring her back to task, you know, what are you doing? or how are you getting on? the teacher has just gone every few minutes and said, "are you concentrating?" and I thought well you know, they're still not getting what she actually needs"* (AP 6).

This extract captured parents' views that a distinction exists between knowledge of the condition and knowledge of how to support that child within the classroom, for instance what strategies or approach to take. Parents highlighted this as an important contribution of EPs:

> *"I think it was really helpful, I think yeah validating and backing up our feelings about how things were and then giving that useful help within school of how the school could move the children forwards"* (AP 8).

As this extract highlights, some had positive experiences of this. Others felt that EP involvement did not go far enough in supporting schools to implement their recommendations:

> *"More than just that one of assessment and off you go, I think it is that follow up and supporting schools 'cause actually if you think '---' was a special school with all children on the EHCPs, I think they did struggle to understand what the recommendations were and implement them, and that's… I think it is hard for a professional to admit that you know"* (AP 5).

It was clear from the data that parents 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 well developed. The following extract demonstrates one parent's view that EPs first need to improve their knowledge to better support schools in turn:

> *"Get a really good understanding of what FASD is, what it looks like, what the difficulties are and ways that schools can manage it, or educators can manage it. That's what needs to happen isn't it"* (AP 7).

Parents as Knowledgeable Disseminators. Parents described their understanding of FASD as a learning journey whereby they initially had minimal knowledge of the condition, but this developed over time. Parents discussed the early days as being particularly challenging and that a lack of guidance and information was available to them. Receiving the diagnosis of FASD was cited as being particularly helpful in expanding their knowledge as it provided a clear explanation of the aetiology of their child's condition:

> *I think the diagnosis was really helpful because then that could make you understand why he did certain things or acted certain ways"* (AP 2).

Parents often described this as being the beginning of their journey to become more knowledgeable because following the diagnosis they went on to research and gather more information as they knew what information they needed to access:

> *"We you know, we've read books as well since that diagnosis to help understand what's going on with his brain and how best we can help him"* (AP 4).

Parents described being driven to pursue and acquire additional knowledge to better understand the condition more broadly and what that meant for their child. One parent emphasised that gaining knowledge extended to include specialist knowledge as well:

> *“You shouldn’t have to fight, to be a parent of a child with special education needs you need to know all the laws, all the rules about how you can get places, or you don’t get it”* (AP 3).

As this extract illustrates, it was apparent that parents felt they needed as much information as possible to ensure they were able to advocate for their child to be adequately and appropriately supported. This included advocating for improved knowledge and awareness of FASD amongst education professionals through various means. For some participants this involved encouraging schools to attend training, for others it was about voicing their concerns around school practice and offering alternatives.

> *“When he was in year 7, he got, I can’t remember, something like 100 negative points and so by the time he got to year 8 it was his aim to go for the whole year and get no negative behaviour points… what we used to do was we used to say for every 100 positive behaviour points you can have a treat or a day out so, his teachers were doing something similar. His teachers put a report card, or a behaviour card I think they called it umm, so he had to get it signed in every lesson if he’d been a good boy, I’m trying to remember what they called it but anyway, they’d done it a certain way so that if he was naughty, he got a mark on this card and that didn’t go down very well with mum. So mum was straight onto the school and said no we’re not doing that, what we’re doing is we’re going to put a mark on X’s card every time he… I just swapped it around for the school and said no we’re not focusing on the negative stuff, reward the positive and don’t punish him… I mean I think the teachers*

> *probably thought holy moly what have we got here with this parent, but you know I know more about FASD than they do* (AP 7).

Fundamentally, this extract captures the parents' views that they had an overwhelmingly greater knowledge and understanding of FASD compared to members of staff in school. Consequently, participants consistently adopted a role whereby they strove to better inform teachers, and this informed a considerable part of their interaction with education professionals. This extract touches on the points elaborated upon in theme 3 that barriers to collaboration certainly existed in parents sharing their knowledge. However, their efforts took many forms including disseminating knowledge about strategies, 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 or social services reports. This role varied and parents described multiple barriers as this undertaking was extensive, time-consuming and extremely challenging:

> *"When he was at school, I would spend on average four hours a week emailing teachers of an evening about things that he'd, you know why he'd done things and what they needed to do to accommodate his special needs"* (AP 7).

> *"I'm trying to educate the educators on how to educate and it is just like a constant battle and its exhausting because you're constantly having to fight their corner"* (AP 6).

Accessing and Advocating for Support. Parents attributed lack of knowledge and awareness of FASD across systems as resulting in significant difficulties accessing support in a multitude of contexts. Consequently, parents found themselves advocating for support, particularly for their child. Parents emphasised that both parenting and educating their children with FASD was difficult, and yet the availability of clear support pathways was also lacking. Whilst obtaining a diagnosis had helped shape parents' understanding, parents did not feel that this unlocked access to any support as it was simply not available:

> *"I've got the report, but that's it. I've not had anything else, and I think that's the real struggle, is the fact that you're sort of given a report, but then, you know, it's where do I go now with this report?...You're not really given much information as to where to go or who you can call or contact to find anything out"* (AP 2).

> *"The diagnosis isn't very helpful, it's not something that you can use, it doesn't get you support"* (AP 3).

Parents felt that lack of understanding, specifically in school, presented a barrier to gaining support. This was described especially in the context of EHCPs and seeking support from external professionals, including EPs. Many parents described obtaining an EHCP as a complicated process and they considered schools' knowledge and understanding as halting this because they were gatekeepers:

> *"It's something we've tried to get but we haven't succeeded…I think it's basically because he functions at a level at which school thinks, that's not an issue…in their opinion"* (FC 9).

This extract illustrates that discrepancies often existed between how parents perceived their child's needs and how schools understood this. As this quote highlights, distinctions often centred around cognitive functioning, such as IQ, which disguised other difficulties, more widely seen by parents. Parents described driving the EHCNA process and felt that they did most of it independent of school. They spoke of being better placed to advise what support their child needed as their knowledge and understanding of their child and FASD was greater. This process was often highlighted as a means of preventing repetition of inadequate support in future schools, parents particularly highlighted the transition to secondary school as a concern in relation to knowledge and understanding. One parent explained this as necessary so that "*when she goes to a new school, they know exactly what needs to be done and when*" (AP 3). Similar concerns were raised in relation to accessing EP involvement. Parents talked of battles in trying to convince the school that their child would benefit from external support and sought to persuade schools to agree to updated assessments. One parent explained how they had "*tried and tried, and they just won't"* (AP 6). It is worth noting that other reasons were also given besides education professionals' knowledge including funding streams and service models (time allocation and traded models).

Once parents had overcome difficulties in accessing support, they often described further difficulties when the support they had advocated for fell short of their expectations. For instance, despite battling to obtain it, one parent described the EHCP as a *"rubber stamp"* which was *"pretty meaningless"* (AP 5). Another felt that the EHCP placed a glass ceiling on expectations for their child on two separate occasions:

> *"X was put on a level 3 course and accepted onto a level 3 course because all of his grades were estimated, then they caught sight of his EHCP and said he couldn't do the level 3 and they put him down to the level 2 which meant he had to do an additional year. He was doing brilliantly on his course, absolutely fantastic, he was top of his class and helping to teach the other students, so he was clearly capable probably of doing the level 3… I think they just looked at him and thought you know we can't facilitate this in a mainstream, he needs to be put with those who*

> *struggle a little bit more. It kind of felt a little bit discriminatory and I did use that word"*
>
> *"It was all because of the EHCP which we had had written, so there's mum feeling like there's this amazing opportunity for my boy and now because of something we've done he's not going to be able to do his apprenticeship"* (AP 7).

For this parent, the intention of trying to obtain support for their child had posed further barriers because education settings were unsure and unconfident of how to meet the individual's needs, despite them managing well. Conversely, when EHCPs were viewed as being most helpful, it was in relation to the contributions that EPs made. Parents highlighted their support in securing additional funding and recommending whether the child would be able to manage within a mainstream setting or not.

Discussion

This study aimed to explore 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). This was achieved using reflexive TA to analyse the transcripts of nine parent/caregivers. Four themes, 'Understanding the Individual', 'Sense of Belonging', 'Collaboration and Communication' and 'Knowledge and Awareness of FASD' were identified in relation to the RQs. These findings will be discussed using a psychological lens and within the context of existing literature, organised under sub-headings relating to each research question. The inductive nature of this research coupled with the scarcity of existing literature means that when considering these findings, previously undiscussed findings within pre-existing literature will be drawn upon alongside those discussed previously.

To the researcher’s knowledge, this is the first UK-based study looking at the entirety of the parent-school interaction, solely from a caregiver’s perspective. Similarly, this research is the first of its kind to explore parents’ perspectives of EP support specifically. This study is also unique in capturing a holistic perspective to address all research questions owing to the solution-oriented underpinnings. As such, distinct findings from the current study will be discussed alongside limitations and recommendations for future research. Conclusions will be drawn, within which implications for schools and EP practice will be contained.

RQ1: How do parents perceive their child’s experience of school?

For parents in this study, the overall narrative was suggestive of an educational journey that is fragmented and challenging for students with FASD. This is consistent with parental experiences shared previously (e.g. Duquette et al., 2007; Poth et al., 2014). Taken together, the findings are indicative of the developmental profile of FASD being diverse and heterogeneous (Blackburn & Whitehurst, 2010). This was illustrated in Table 6 whereby the variability of primary difficulties between each individual is clear. As is consistent with previous findings (e.g., Price, 2019), parents emphasised the impact of PAE on their child’s cognitive and behavioural functioning particularly. However, it is important to note that this is the parents’ perspectives of their child’s difficulties, and this may not necessarily be reflective of how the children themselves view their primary difficulties in school. Parents felt that FASD meant their child experienced school differently and as more arduous than their peers. Parents positioned the effects of FASD to be greater than other factors relating to the individual’s ‘makeup’, specifically attachment, thus providing support for conclusions drawn previously that the effects of PAE are distinct (Mukherjee et al., 2019; Price, 2019). However, parents perceived their child’s experience of school to be shaped by ‘within-child’ factors minimally compared to the emphasis placed upon systemic factors within the school system. Consequently, this provides weighting to emerging arguments for consideration of FASD within a systemic perspective (Flannigan et al., 2021; Poth et al., 2014; Price, 2019). Moreover, it seemingly illustrates that parents feel that their child’s experience of school is malleable. This supports recommendations, which are also at an embryonic stage, for a move towards recognising that positive change is possible amongst a population whose difficulties have, up until now, consistently been perceived to be ‘fixed’ or situated within the individual only (Corrigan et al., 2019; Flannigan et al., 2021; Pei et al., 2015). This aligns closely with the principles of the Social Model of Disability (Oliver, 1983).

To experience school more positively, parents felt that their child needed to be understood as an individual, as well as an individual with FASD. In the current study this related to themes 1 and 2 particularly. Parents commented that their child benefited from educators adopting an individualised approach to support, including differentiation and provision which considered their personal interests. This is consistent with previous findings (e.g. Duquette et al., 2007; Edmonds & Crichton, 2008) and adds particularly to those of Poth et al (2014) who advocates for a holistic approach to support. Parents implicated that student-teacher relationships contributed strongly to a more positive school experience for their child. This has previously been identified in the context of FASD (eg., Duquette et al., 2006; 2007; Hammond, 2021; Knorr & McIntyre, 2016; Poth et al., 2015) but also has long been associated with positive school outcomes for students more widely (Hattie, n.d.). The above might be understood within self-determination theory (SDT), which stipulates that motivation is facilitated by competence, autonomy and relatedness (Ryan & Deci, 2000). It is possible that personal interests may relate to the need for choice, appropriate differentiation may enable the individual to feel competent, and student-teacher relationships may support the relatedness strand of motivation. However, given the prevalence of underlying attachment difficulties amongst adoptees and LAC (Bombèr, 2007), one cannot truly ascertain whether the importance of relationships with teachers met this need, rather than those relating to FASD specifically. Nevertheless, it highlights a useful consideration for schools when educating pupils amongst this population.

Parents commented that a teachers' approach, including tone of voice, openness and manner towards their child was particularly important. Displaying empathy and being understanding within a relational approach was reflected upon most positively (Hammond, 2021). As Duquette et al., (2006; 2007) and Pei et al., (2015) identified, in the current research this was mediated by parents' perceptions of educational professionals' knowledge of FASD, which in turn affected how the individual was viewed. Knowledge of the individual related particularly to the subtheme 'Behaviour as Communication' which captured parents' view that their child's behaviour was a means of expressing difficulties within school, particularly in relation to externalised behaviours (Duquette et al., 2007). For instance, parents emphasised their child's use of 'coping mechanisms' as strategies to manage and ensure self-preservation. Although this was noted by parents in Price's (2019) research, and adults have retrospectively described their use of masking to conceal learning difficulties (Knorr & McIntyre, 2016), it is not hugely prevalent within existing literature. Nevertheless, this seems to fit with parents' perceptions in the current study. And yet, parents felt their child was blamed and held accountable for their behaviours as though it were a choice, and consequently were punished (Duquette et al., 2007; Knorr & McIntyre, 2016; Kully-Martens et al., 2012; Pei et al., 2015). The lens through which children were viewed in school was detrimental to how parents perceived their child's experience. This resulted in reduced expectations of their child's capabilities and misattributions around behaviour. This conforms to broader stereotypes and misconceptions of children with FASD (Corrigan et al., 2019; Pei et al., 2015). As Stanbridge and Mercer (2019) advocate in the context of social, emotional and mental health (SEMH), language informs meaning. These findings relate to calls by Flannigan et al., (2021) to explore how education professionals view students with FASD and provides further clarity that parents perceive their child to be viewed unfavourably, particularly in relation to behaviour. This subscribes to Malbin's (2004) recommendation of the need to view behaviour as a symptom of FASD and suggests that this remains an area of development for schools.

Parents explained how routine use of conventional behaviour management approaches, such as isolation, perpetuated their child's feelings of being 'different' and alone in school, thus inhibiting how achievable 'social integration' was (Duquette et al., 2007). This finding is important given that belonging is a core psychological need (Maslow, 1943). It can be understood through consideration of the principles of attachment theory and trauma informed practice which would argue that physically isolating an individual disrupts connectedness with others (Bowlby, 1969). The experiences described pertain to an educational experience which is characterised by exclusionary, rather than inclusive practice (see Figure 8).

The issue of belonging was represented more explicitly in theme 2 and reflected integration both academically and socially, thus supporting Duquette et al's (2007) findings and addressing concerns around the inductivity of their results. Relationships with peers were particularly important for children's sense of belonging and feeling accepted in school, thus corroborating with Duquette et al., (2007) and

Hammond (2021). Conversely, they were a concern for parents given their child's susceptibility to peer pressure and bullying which negatively impacted upon school experiences (Duquette et al., 2007; Duquette & Orders, 2013; Knorr & McIntyre, 2016; Sanders & Buck, 2010). Parents noted that their child required considerable differentiation to access the curriculum. This aligns with previous research highlighting the importance of inclusive practice and academic integration (Carpenter, 2011, Duquette et al., 2007; Millar et al., 2017). Parents felt that the need for academic support became more acute as the demands of the curriculum increased, thus suggesting that the educational trajectory for these pupils becomes increasingly difficult as they move through the school system. However, professional knowledge was a concern for parents expressed within the context of the primary to secondary transition. It is therefore possible that this finding might be understood in the context of Poth et al's (2014) research, in which differences in conceptions of FASD between primary school and secondary school teachers were identified. However, it may also be explained by a 'vicious cycle' encompassing issues relating to academic integration (Duquette et al., 2007) and feeling different to peers (Petrenko et al., 2014). Academically, parents raised that support was not consistently provided by schools and so overcoming barriers to learning was challenging (Duquette et al., 2012). Parents echoed sentiments raised by Corrigan et al., (2019) that the physical learning environment was often ill prepared to facilitate their child's learning and thus discriminated towards students with FASD. Parents also held concerns at how support was implemented. This mirrored other findings (Knorr & McIntyre, 2016; Petrenko et al., 2014), as parents felt it attracted unwanted attention, leaving their children rejecting the support that they needed. As is expressed within theme 4, it seems probable that the above findings indicate a lack of support to be an implication of poor knowledge amongst education professionals (Duquette et al., 2007). As such, these findings sit alongside others which have previously highlighted a dearth of knowledge of FASD in schools and a need for FASD informed educators (Cleversey et al., 2017; Petrenko et al., 2014). Similarly, they provide further justification to ask critical questions around whether pupils with FASD are being appropriately and inclusively educated. Up until now these have been raised outside of the UK (Duquette et al., 2012; Poth et al., 2014), however, these findings suggest this issue exists within the UK context also.

RQ2: What are parents' experiences of the family-school interaction?

This research question is primarily addressed by themes 3 and 4. Parents' experiences of the family-school interaction were such that considerable efforts were required (Balcaen et al., 2021; Duquette et al., 2012). Parents were required to be present and available, although school did not necessarily reciprocate this. Parents of children with FASD have consistently been found to undertake an active role in supporting their child's education (Cleversey et al., 2017; Duquette et al., 2006), and current findings corroborate these. It was noted by parents that in doing so, their partnership was furthered, thus aligning with educational professionals' views gathered previously (Job et al., 2013). However, whilst parents valued the family-school partnership (Job et al., 2013; Cleversey et al., 2017), for many it was characterised by barriers. Parents' experience of their relationship with school was plagued by blame (Sanders & Buck, 2010; Swart et al., 2014) in which education professionals understood their child's needs as relating to poor parenting choices (Balcaen et al. 2021; Mukherjee et al., 2013). As previously found by Cleversey et al., (2017), this related to limited knowledge of FASD amongst education professionals. Consequently, parents assumed the role of educating the educators by distributing information, imparting their knowledge, and making suggestions for how schools could better meet their child’s needs (Blackburn, 2010a; Brown and Brown, 2014; Cleversey et al., 2017; Duquette et al., 2007; Duquette et al., 2012; Petrenko et al., 2014). This sits alongside previous literature which has highlighted parents’ role as advocates in the context of FASD and education (Duquette et al., 2012; Opini, 2019). For parents, the advocacy role was fuelled by mistrust of schools to action their promises and share information honestly and authentically. This adds to the current understanding that the family-school interaction in this context is riddled with issues relating to trust (Cleversey et al., 2017; Job et al., 2013; Poth et al., 2014; McCarthy, 2022).

Parents commented on the importance of effective communication pathways to ensure a collaborative working relationship (Cleversey et al., 2017) and achieve positive outcomes from their advocacy efforts. However, parents faced resistance from school in implementing their recommendations (McCarthy, 2022; Poth et al., 2014) and the parental contribution was often not well received (Opini, 2019). This related to imbalances within power dynamics where parents were viewed as non-expert and felt the need to call upon reinforcement to add weighting to their arguments (Duquette et al., 2012; Opini, 2019). Indeed, parents described feeling powerless within their interactions in school and shaping their child’s experiences in school (Balcaen et al., 2021), this included which school their child attended and what support their child received. This can be understood by systemic challenges posed by a closed school system (Dowling & Osbourne, 2018). However, it also pertains to the fact that parents did not feel listened to. This finding adds to an already compelling evidence base of the recurring phenomenon of parents remaining unheard in the context of FASD (Duquette et al., 2012; Job et al., 2013; Whitehurst, 2011).

RQ3: What are parents' experiences of EPs supporting the educational experiences of their child?

Parents' experiences of EP involvement were variable. All but one parent had received EP support, however, it was apparent that the involvement had not been hugely diverse or in-depth. This is consistent with Campbell's (2019) findings from EP's perspectives in the sense that EP involvement in the context of FASD was not distinct from any other. Consequently, several recommendations were made for how the EP contribution might evolve. For instance, parents commented that there was a role for EPs to offer training to schools (Campbell, 2019; Westrup, 2013), and support effective relationships and communication between home and school, thus aligning with the implication that EPs are in a "unique position to work with the immediate systems around the child" (Beaver, 2011, p.16). When working with their children, parents prioritised the need for EPs to build relationships. This is consistent with Treisman (2018) who argues, this relationship is the glue which makes activities meaningful and purposeful. Furthermore, Beaver (2011) advocates that EPs are uniquely skilled at building rapport which enhances the quality of relationship between the client and practitioner, which in turn increases the likelihood of goals being achieved.

Parents felt that EPs were powerful professionals in school, thus agreeing with the suggestion put forward by Frederickson and Cline (2015) that EPs are often positioned as experts. Parents felt that teachers respected their expertise around education, which enabled receptiveness. This aligns with Roffey et al., (2018) that EPs' knowledge falls within education and health. To this end, parents felt that EPs were helpful in shaping an improved understanding of FASD. This mirrored Campbell’s (2019) findings around EPs offering a ‘holistic perspective’ which accounts for strengths and needs. Similarly, EPs supported the knowledge of educators through their recommendations around suitable strategies that may support their pupils to overcome barriers to learning. Although parents felt this needed to go further to include implementation and evaluation to ensure accountability. This is supported by research which indicates that overall, pupil progress was evidenced when intervention was evaluated at review (Dunsmuir et al., 2009). Furthermore, ‘Implementation Science’ argues intervention and implementation must be evaluated to measure effectiveness (Kelly & Perkins, 2012).

Parents felt that the EP contribution related more to the fact that they were listened to in school, rather than them holding a secure understanding of FASD to advise appropriately. The above positions schools as agents for change and EPs as a ‘critical friend’ within these settings (Richards, 2017). However, this finding is inconsistent with educational professionals’ who felt that they too held expertise of equal value to school psychologists (Pei et al., 2013). Parents noted that EPs demonstrated a distinct lack of knowledge around FASD, which echoes parental reflections made previously (Blackburn, 2010a; National Organisation for FASD, 2018) and self-reported limited knowledge by EPs (Campbell, 2019).

A lack of knowledge amongst EPs was a frustration for parents who felt that they were not listened to or actively included in the EP involvement. This is a concerning finding given the emphasis placed upon gathering parental views through ‘person-centred approaches’ within the SEND CoP (DfE, 2015). As Newton (2000) argues, simply ‘having regard’ for the family voice, is insufficient. Consequently, parental expertise (Frederickson & Cline, 2015), was often not acknowledged. This perpetuated issues of unequitable power dynamics already experienced by families (Balcaen et al., 2021) and was furthered by difficulties accessing EP support. Parents commented that schools were resistant gatekeepers thus aligning with McGuiggan (2021) who questioned whether EPs meet the needs of schools over and above those of families.

Distinct Findings, Limitations and Future Research Directions

The present study tentatively offers insightful findings about how the behaviour of children with FASD may be an expression of their school experience. This was particularly in relation to masking and school-non-attendance. Thus far, ‘masking’ is more widely captured within research around ASD, particularly girls (McCarthy, 2022).The finding in the present study relates to individuals with varying demographic characteristics, suggesting its presence may be more widespread amongst individuals with FASD, although exists within the varied profile between individuals with the same diagnosis. However, to date, research in the field of FASD has primarily discussed ‘masking’ in relation to the ‘spikey profile’, whereby extreme areas of strength may disguise considerable difficulties (see Figure 6). This has resulted in the colloquial use of the term ‘invisible disability’ with reference to the absence of physical features (Blackburn & Whitehurst, 2010; Millar et al, 2017). It will be important to draw distinctions between how ‘masking’ differs in FASD and ASD and whether the term is appropriate for use within the FASD population. The term is included here as it mirrors the language used by the participants, however, it seems likely that use of the term ‘masking’ for the parents in this study related to the idea that their child engaged in efforts to maintain and preserve their self-image amongst peers. This perhaps differs from the understanding of masking in the field of ASD as a conscious or unconscious suppression of certain behaviours and deliberate performance of others which they perceive to be more desirable. Nevertheless, it is not possible to draw definitive conclusions using these findings alone and therefore there is a need for future research to explore. The recurrent issue of ‘school refusal’ was also framed differently by parents in this study. Up to now, research has raised issues relating to attendance in the context of disengaging with school altogether (Duquette et al., 2007) and as a ‘challenging behaviour’ that is simply prevalent amongst this population (Skorka et al., 2020). Conversely, in the current study parents described periods of school non-attendance as transient and related directly to challenging circumstances existing in school at a particular time, for instance a lack of support. This is instead consistent with existing literature around the role that school factors play more widely in school non-attendance (Havik et al., 2015). The above findings warrant further consideration by researchers.

Whilst research in the field of FASD has previously highlighted the issue of shame, until recently, this had been in relation to accounts from birthmothers only (Olson et al., 2009). Parents within McCarthy’s (2022) did raise shame as a difficulty for their child, however, this was described as a behavioural change relating to COVID-19 lockdowns. Whilst this context applies to the current study, caregivers in this research discussed shame more broadly as a powerful emotion which they considered their child experienced to a greater extent than others. Whilst parents felt that conventional behavioural approaches were ‘designed’ to shame pupils, they attributed this response as being distinct to the profile of FASD. It is important to consider this in relation to wider contextual factors. For instance, this might be understood as relating to their status as a looked after or adopted child given that these individuals often experience difficulties with identity and understanding themselves, resulting in feelings of shame (Neil, 2000; Cook et al., 2005). Bombèr

(2007) argued that a negative internal working model, i.e., low self-esteem, can perpetuate feelings of worthlessness and thus result in feelings of shame. As Maslow's Hierarchy of Needs (1943) indicates, belonging is fundamental to enhanced esteem. Yet, participants in the current study deemed fostering a sense of belonging in school as something which had not been met. Consequently, the relationship between shame, FASD and experiences of school at the current time remains tangled and intricate. This is an area for future research to explore further given the high prevalence amongst this population (Adoption UK, 2018), as the relationship with shame may be nuanced in the context of FASD.

One parent described the value that psychoeducation tools brought to their child's experience in school in relation to being accepted and better understood by peers. This offers support to Hammond's (2021) finding around peer advocacy. However, to the authors knowledge, intentional use of psychoeducation-based strategies in relation to FASD have only been researched within the context of training for parents (Petrenko & Alto, 2017). Whilst this was only one parent's experience, given that this study aimed to identify 'what works', it seems reasonable to consider the use of psychoeducation as an avenue for future researchers to build upon.

The study contributes to a limited UK research base around FASD and education, however, it is important to consider these within the limitations of the research. Firstly, as Braun and Clarke (2022) note, there is no one 'right' interpretation of data. Whilst efforts were made to remain close to the first-person perspective (Watts, 2014), another researcher, who holds an alternative ontological position, may have identified different themes and drawn other conclusions. Coding will likely have been influenced by the researcher's pre-existing values, assumptions and theoretical knowledge. Therefore, it is likely that there was an implicit, researcher-driven, deductive element to the coding process as the researcher cannot stand outside of the reality that they are observing through their research (Pilgrim, 2014). However, this is also the intention and a strength of effective reflexive TA. Braun and Clarke (2021a, p.334) argue that the “avoidance of bias is illogical” and instead reflexive TA emphasises the importance of the researcher’s subjectivity as an analytic resource. In a similar vein, the limitations of qualitative research should be noted. For instance, a small sample size may prohibit the generalisability of findings (Willig, 2013), although this, alongside seeking ‘saturation’, is most closely aligned with research which adopts a positivist position (Braun & Clarke, 2021b). Braun and Clarke (2021b) argue that these are ‘myth requirements’ in qualitative research and researchers should consider ‘information power’, aka quality over quantity. Similarly, a position of CR acknowledges ‘context’ (Braun & Clarke, 2013). It is important to consider how participants may have formed their understanding of the ’truth’. For instance, different views around the suitability of ‘mainstream’ vs ‘specialist’ provision are informed by experiences of one interaction with a particular school, and components within that unique system, and then applied to an overall narrative. It is therefore not appropriate to draw wider conclusions about the suitability of one or the other for the population of students with FASD, not least because of the heterogeneous nature of the condition (Blackburn & Whitehurst, 2010). Furthermore, the research questions were addressed only by obtaining the parental perspective. 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. Similarly, the inclusion criteria of the current research meant that the experiences of birth mothers 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 careers, theirs and their children's experiences are likely affected by issues relating to intersectionality. It was not possible, nor was it an aim of the current research, to tease these apart, however, as Mukherjee et al., (2019) highlights, this is an area for research to pursue to enhance the understanding of FASD explicitly. Finally, the current study aimed to gather parental perspectives through a solution-oriented lens, thus capturing a breadth of experiences. Whilst this was achieved to some extent, parental narratives were overwhelmingly suggestive of struggles. More positive experiences from which we can learn from were uncovered within the data analysis and these will be discussed in relation to implications and recommendations for schools and EPs. However, there remains a need for research to further elicit strengths and success stories.

Conclusions and Implications

This study offers an insight into how a sample of adopters' and foster carers perceive their child to experience school given their diagnosis of FASD (RQ1), how they experience the family-school working relationship (RQ2) and EP support (RQ3). Overall, it was identified that education is a challenging experience for children and their families and EP support in this context barely scratches the surface. This contributes to the first UK based study using reflexive TA to exclusively study the above, particularly through solution-oriented questioning and the lens of educational psychology. As such these findings help to extend understanding of FASD in educational contexts, and highlights implications for schools, EP practice and parents.

The complexities across systems were prominent in parents’ narratives and consequently the findings from this study provide real-life application of the principles of general systems theory (GST) in the context of FASD and education. The family-school interaction especially provides evidence for the idea of ‘circular causality’, as the actions and reactions of the family or school influenced that of the other. This was particularly evident in ‘Theme 3: Collaboration and Communication’ in which the relationship between parents and school staff might be likened to a magnet that attracted and repelled dependent upon the other party. The principle of homeostasis within GST was also pertinent to the findings of this research as parents frequently discussed experiencing resistance from education professionals in numerous forms. This can also be understood through Bronfenbrenner’s (1979) Bioecological Theory of Human Development (BTHD) as parents acknowledged the contribution of the exosystem with which neither the parent nor their child was directly involved. This included consideration of school leadership, availability of funding/resources and behaviour policies to name a few. GST’s feedback loop was prominent in the overall findings of this study, as parents repeatedly reported feeling blamed and judged by school professionals, likewise they felt this echoed their child’s experience of school. Similarly, the feedback loop of information exchange did not present as being transparent or reliable in parents’ experiences. Often feedback that was provided was not accurate or lacking sufficient detail for parents to ascertain just how difficult school was for their child. This translated into issues of trust and the need for parental advocacy. Figure 10 provides a visual representation of the application of GST when considering FASD within a systemic perspective. As was apparent throughout the data analysis, no one educational experience occurred in isolation. Whilst some additional implications are discussed in depth below, stakeholders should also refer to the relevant section of the handout in Appendix as this provides specific recommendations for their role in supporting individuals with FASD and families in the context of education. A key area for development identified in response to all three research questions is around knowledge and understanding of FASD amongst professionals, both within schools and amongst EPs. This consists of a need to improve early recognition of FASD in school to support diagnosis and intervention and prevent the development of associated difficulties (Petrenko et al., 2014). Furthermore, greater knowledge of FASD will support individuals and their families to be met with less stigma, prejudice, assumptions and unrealistic expectations (Corrigan et al., 2019) from those within and outside of the school system. At the current time, the extent to which EPs can practice ethically when supporting individuals and families within this population is questionable given that their competence within FASD is seemingly inadequate (BPS Code of Ethics and Conduct, 2018). Beal (2017) notes a contradiction between EPs positioning themselves as ‘non-expert’ in casework and adopting a position of expertise when striving to improve outcomes for young people. The sparse understanding of FASD offers an opportunity to rebalance power differentials and position the parent as an ‘expert’ and schools and EPs as equal, who may learn alongside one another. Although, the author acknowledges the societal challenges associated with achieving this given the historical positioning of EPs.

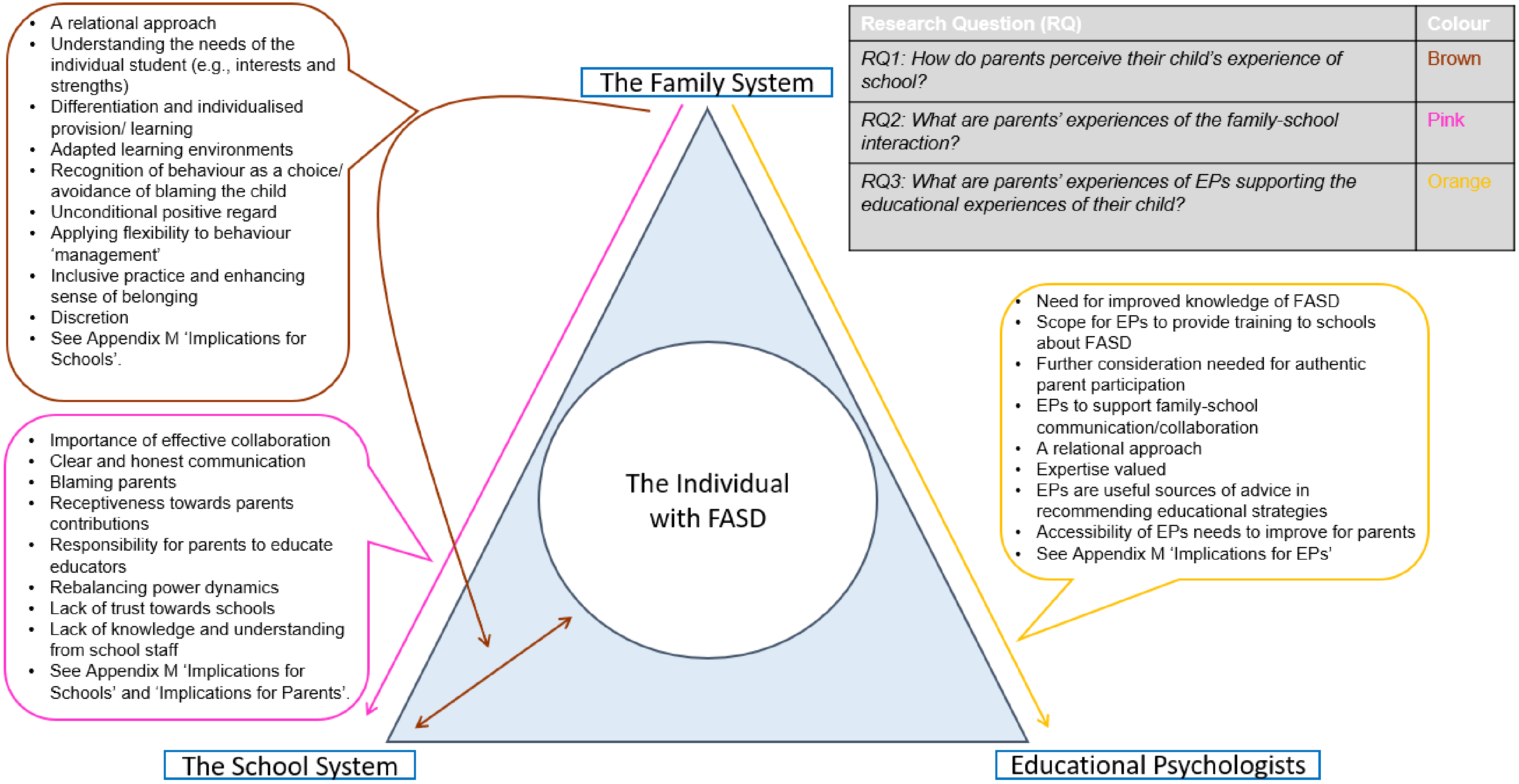
In time, understanding in school may be suitably supported by an EP for whom FASD is a specialism. As a minimum, it will be important for EPs with a specialist role in supporting adoptees and LAC to have a good working knowledge of FASD, but findings in this research also emphasise the need to understand FASD independently. As currently exists for other neurodiverse conditions, an EP who positions FASD first and foremost will likely be hugely beneficial to pupils and their families. This aligns with recommendations made previously by Campbell (2019).

Findings from this research highlight a need to emphasise the influence of systemic factors in relation to FASD and education. An FASD informed EP may most impactfully work beyond the individual and within the school organisation (Curran et al., 2003). They could reclaim the role that findings suggest parents currently are compelled to undertake, in educating the educators and advocating for the educational rights of the child. Thus, allowing parents to return as experts of their child. Furthermore, they may provide school staff with supervision, alongside training, to address concerns relating to knowledge of effective educational strategies and the legitimacy of implementation. They may also be well-placed to reframe conceptions of individuals with FASD, away from deficits and towards strengths and capacities through person-centred approaches, rooted in principles of positive psychology and solution-oriented work (Franklin et al., 2012. Newton et al., 2016). It would be beneficial for EPs to support schools to audit and evaluate their behaviour policies and inclusive ethos to account for the need for students with FASD to be taught within an individualised, relational approach. This might relate to an approach such as Gottman’s (1998) Emotion Coaching and use of Booth and Ainscow’s (2017) Inclusion Index. This adheres to the view that EPs are ‘agents of change’ (Dunsmuir & Kratochwill, 2013) and illustrates how they may facilitate organisational change.

Once EPs’ knowledge has been addressed, findings in this study support observations made beyond the context of FASD (McGuiggan, 2021), that there exists a need for EP involvement to move away from working within the school system only, and instead form a bridge between the family and school system. This is consistent with the notion that EPs are ‘meta’ and suitability positioned outside of the two systems to facilitate change (Beaver, 2011; Dowling & Osbourne, 2018). Given that findings raised important questions in relation to the stipulations of the SEND CoP (DfE, 2015), this could include supporting schools to authentically capture the views of parents and caregivers using Hart’s Ladder of Participation (1992) as a framework. Although, findings in the current research are also indicative of person-centred practice being an area of development for EPs. Fundamentally, the efforts, knowledge and invaluable contribution that parents make at present is inexcusably underacknowledged. It is of paramount importance that this changes to improve the overall experiences of students with FASD and their families.

Figure 10

Applied Model of GST in the context of FASD and education illustrating key findings/implications.



Research Question (RQ)	Colour
RQ1: How do parents perceive their child's experience of school?	Brown
RQ2: What are parents' experiences of the family-school interaction?	Pink
RQ3: What are parents' experiences of EPs supporting the educational experiences of their child?	Orange

- A relational approach
- Understanding the needs of the individual student (e.g., interests and strengths)
- Differentiation and individualised provision/ learning
- Adapted learning environments
- Recognition of behaviour as a choice/ avoidance of blaming the child
- Unconditional positive regard
- Applying flexibility to behaviour 'management'
- Inclusive practice and enhancing sense of belonging
- Discretion
- See Appendix M 'Implications for Schools'.

- Importance of effective collaboration
- Clear and honest communication
- Blaming parents
- Receptiveness towards parents contributions
- Responsibility for parents to educate educators
- Rebalancing power dynamics
- Lack of trust towards schools
- Lack of knowledge and understanding from school staff
- See Appendix M 'Implications for Schools' and 'Implications for Parents'.

- Need for improved knowledge of FASD
- Scope for EPs to provide training to schools about FASD
- Further consideration needed for authentic parent participation
- EPs to support family-school communication/collaboration
- A relational approach
- Expertise valued
- EPs are useful sources of advice in recommending educational strategies
- Accessibility of EPs needs to improve for parents
- See Appendix M 'Implications for EPs'

Chapter Three: Reflective Account

Introduction

Trainee educational psychologists (TEPs) and educational psychologists (EPs) fulfil a dual role as ‘scientist-practitioners’, in which they make contributions to research with application to the real world (Sedgewick, 2019). Reflection permeates both aspects. TEPs are required to demonstrate competence in self-awareness and reflection, enabling them to be reflective practitioners. Similarly, researchers have a social responsibility to be self-reflective (British Psychological Society (BPS) Code of Human Research Ethics, 2021). This chapter addresses these requirements by offering insight into ‘why’ decisions were taken at various timepoints throughout the development of this research. According to Schön’s (1983) model of reflection, this reflective chapter provides a ‘reflection-on-action’ account of the research process. This is retrospective, thus taking place after the event. Furthermore, the account is written in first person to allow for authentic reflections.

Researchers hold a responsibility towards the research audience and participants to be open and transparent about their position within the research process (Bell & Waters, 2018). Reflexivity addresses this by critically reflecting on the knowledge one produces and their role in producing that knowledge (Braun & Clarke, 2013; Willig 2013). Consequently, throughout my reflective offerings, the role of my values and beliefs are discussed with issues of bias interweaved. My reflections are guided by questions posed initially by Palmer et al., (1994) and subsequently adapted by Mellor (1998). This includes pre-flection around what happened before the research, celebrations of what went well, a description of how the research came to be, reflection around what I hoped to achieve and why I intervened as I did. Consideration is also given to influencing factors that will have shaped the research, learning opportunities which have arisen, and wider implications of the findings including dissemination and the furthering of my personal knowledge.

Identifying a Research Interest

My interest in supporting individuals with neurodiverse conditions began in my previous role as a primary school teacher, although my experience primarily involved working with children and young people (CYP) with diagnoses of autism spectrum disorder (ASD). The phrase ‘see the able, not the label’, has always resonated with my core beliefs. This shaped my classroom ethos which was underpinned by inclusivity. It was important to me that those I taught accepted individual difference and celebrated the strengths of their peers. This also related to my concern with issues of social justice which drove me to complete my teacher training with ‘Teach First’ initially and my doctoral EP training at the University of East Anglia (UEA), as social justice is a core value underpinning both courses.

Frederickson and Cline’s (2015) comment that parents are the experts of their children has remained with me since a pre-doctorate reading task. I reflected that as a teacher I had not always upheld this position, owing to the values, ethos and structure of the school system in which I was a part (Dowling & Osbourne, 2018). Conversely, through my development as a TEP, the importance of gathering parental voice to inform provision and intervention has become clearer. This relates to most of my training experiences being in a service which is heavily driven by person-centred ways of working. This approach recognises the importance of contributions from those close to the CYP that we are supporting. Undoubtedly this has shaped my metamorphosis from teacher to future EP (Anthony, 1999). Consequently, I knew that gathering experiences and exploring parental views would be an important tenet of my research.

My understanding of Foetal Alcohol Spectrum Disorder (FASD) as a teacher was almost non-existent. FASD first came to my attention as part of a multi-agency placement with the local authority (LA) post-adoption services, in my first year on the doctorate. I had chosen to work with this service as adoption was something I had close experience of within my family. Owing to the COVID-19 pandemic, this placement took place remotely, and therefore opportunities to shadow practice were extremely limited. Contrarily, the remote working context facilitated meetings and enabled me to have in-depth conversations with multiple social workers. As part of these discussions, I asked, “how could EPs support your work?” and the theme of FASD and ‘battles with education’ reoccurred. This sparked my curiosity and led me to read wider around the topic.

Reviewing the Literature

My initial searches began with ‘grey literature’ to gain a broader understanding. As part of this, issues of inequality and unfairness were well-documented, which struck a chord with my passion for addressing issues of social justice. I noted that where the research base around ASD was expanding and becoming more nuanced, the same could not be said for FASD, especially in the United Kingdom (UK). This was a concern particularly when I better understood the prevalence rates. Consequently, a clear avenue for my research began to take shape.

The process of conducting more rigorous literature searches was highly emotive. My response was multifaceted, but I primarily experienced feelings of frustration and at times, sadness. Primarily, FASD is entirely preventable. In my practice I consider all those whom I support with unconditional positive regard

(Rogers, 1957), and I hold the belief that everybody is doing the best that they can at the time. Having said that, I experienced cognitive dissonance (Festinger, 1957) on multiple occasions when in striving to view birth mothers in this light, I could not dismiss the intense empathy I held for the rights of an unborn foetus. Whilst I found the ‘FASD: UK Preferred Language Guide’ (National Organisation for FASD, 2020) particularly helpful in framing alcohol as the cause, I felt overwhelmed by the enormity of the issue. It appeared unjust that educating the public around use of other teratogens such as smoking is prioritised. For instance, I gained heightened awareness of the more visible attempts to spread awareness on cigarette packaging compared to bottles of wine. I also felt disappointed that the effects of prenatal alcohol exposure (PAE) are not widely known, not least amongst health professionals (Scottish Intercollegiate Guidelines Network (SIGN) 156, 2019).

Within the timeframe that my literature searches were conducted, the National Institute for Health and Care Excellence’s (NICE) (2022) proposed quality standards around recording maternal alcohol consumption progressed from consultation to publication. This was an interesting time to be conducting research into FASD because these were significant changes in its history. I was aware that the topic of PAE was being spoken about in the public domain more so than it had been previously. However, upon reading articles in the media I realised this was situated within a much wider debate and one which extended well beyond the remit of my research. I knew I needed to ascertain what was positive and possible and accept that my project was one exceedingly small component of a much bigger issue. This was complicated by the fact that the UK literature base around FASD was sparse, which was both helpful and unhelpful. Fundamentally it meant I had multiple avenues which I could explore, but this weighed down on me quite heavily.

A themed narrative literature review was chosen to pull together what is already known about the topic and develop appropriate research questions (RQs) (Baumeister & Leary, 1997). By presenting a broad overview of the literature I hoped my review may prove useful as a standalone resource to improve awareness of FASD. Throughout the process of reviewing the literature I was conscious of my own thoughts and feelings about the subject matter, indeed, using Johari's Window (Luft & Ingham, 1995), it could be said that my values and beliefs were known to me. However, efforts were made to minimise researcher bias through open and honest research supervision and reflexive discussions around adopting a position of neutrality as far as possible. I reflected upon my own knowledge and tried to remain objective in my literature searches also. This was supported by use of stringent search terms and immersion in the literature, rather than following lines of enquiry based on my views, thoughts or feelings. Although, the decision of whether to include research papers or not, and the extent to which findings were discussed, was a decision I made, and consequently this is one way in which the person of the researcher may be implicated in the research (Willig, 2013).

Theoretical Framework

As alluded to earlier, as a teacher I aligned with a strengths-based approach, whereby I looked beyond a child's 'label' and sought to recognise what was working well. As Goodley and Billington (2017) discuss, historically this has not necessarily been compatible with a medical model which seeks to diagnose. My position within the 'diagnosis debate' is a pragmatic one which considers the context of the individual. Upon reading the literature around FASD my position was challenged as the research base was largely positioned within a clinical perspective. Moreover, findings around diagnosis as being difficult to obtain but equally as important to individuals and their families, for a multitude of reasons, came through strongly (Balcaen et al., 2021; Brown, 2015; Petrenko et al., 2014; Sanders & Buck, 2010; Whitehurst, 2011). The very nature of damage to the brain and central nervous system (CNS) means that FASD is a ‘within-child’ condition, there is limited scope to challenge this. It seemed to me that the difficulties experienced by individuals and their families who have been affected by FASD were consistently perpetuated by multisystemic failures. As explained in previous chapters, a plethora of research which intentionally adopted a systemic perspective in relation to FASD did not exist. Therefore, providing research that did so, thus moving away from a deficit focus, informed part of my rationale.

I intended to frame my research within Bronfenbrenner’s (1979) Bioecological Model as this has been used before in this context by Poth et al., (2014) and was pertinent to my practice as a TEP. Flannigan et al., (2021) had also noted its relevance. However, during discussions in research supervision, I kept returning to Coggins et al’s (2017) comment that systems around individuals with FASD are extraordinarily complex. For example, I recognised the overrepresentation of looked after and adopted CYP amongst those with a diagnosis of FASD. I questioned how I might differentiate between that and the effects of attachment, trauma, and wider involvement in the social care system. I considered framing my research through a lens of intersectionality, however, publication of Price (2019) and Mukherjee et al., (2019) further into my research journey led me to reconsider. The possibilities for my research felt endless and adopting a bio-ecological perspective would have furthered these challenges. I recognised the need to streamline my research to focus on the central components of FASD and education. Doing so within systems theory (Dowling & Osbourne, 2018) minimised the risk of my research becoming unmanageable, supported a more compact research focus, and led to the development of Figure 4.

Participants

Framing my research within systems theory enabled me to identify four key groups involved in FASD and education: the individual with FASD, parents, education professionals and EPs. Initially I considered how I might gather the views of CYP with FASD, but I encountered two key issues. I could not be sure that CYP would necessarily be aware of their diagnosis and consequently may not be able to describe the impact of this. Secondly, I felt uneasy about discussing the difficulties they may experience because of PAE. I held ethical concerns in relation to preventing emotional distress amongst participants and the possibility for prolonged effects. At this time, I also became aware of Hammond's (2021) research which was already gathering pupil views in the UK context. Given the limited literature base overall, I decided to explore the parental perspective, although many additional reasons also contributed to this decision. Firstly, research had illustrated that in the context of FASD, parents held a significant role in supporting their child's education (Duquette & Stodel, 2005). Furthermore, the importance of the family-school relationship had been reiterated (e.g. Cleversey et al., 2017; Job et al., 2013; Poth et al., 2014), however, the school perspective of this relationship had been prioritised (Opini, 2019). I considered triangulating parents' views with those of relevant educational professionals. However, I did not feel comfortable pursuing this given previous research findings which had described the family-school interaction as being fractious (e.g. Job et al., 2013; Poth et al., 2014). This posed an ethical risk as further damage to relationships might ensue because of their participation. Similarly, as part of my literature review it was apparent that parental views were often secondary to others (e.g. Corrigan et al., 2019; Job et al., 2013; Pei et al., 2013; Poth et al., 2014). I did not wish to contribute further to parental views being subsidiary and therefore made the decision to explore their views independently. It should be noted that in the context of FASD the term parent/caregiver may relate to biological parents, adopters or foster carers. Given the context of my first encounter with FASD, I always intended to speak to adoptive rather than biological parents. This also seemed fitting given the high prevalence of FASD amongst adoptees. The choice to also include foster carers was made following feedback as part of an ‘early research development’ presentation. I had hoped to have a more equitable representation to explore whether experiences differed between the two roles, however, I was only able to recruit one pair of foster carers.

I wanted my research to produce actionable outcomes for change. I subscribe to the idea that EPs are ‘agents of change’ (Dunsmuir & Kratochwill, 2013) and so it felt important for their role to be considered in my research. However, I was also acutely aware of power differentials. I noted that findings in the literature indicated that parents are consistently unheard, do not feel listened to, and are ‘powerless’ (Job et al., 2013; Poth et al., 2014). I was aware that these were findings outside of the UK and even less was known about parents’ views in this country. Whilst literature exploring EPs in the context of FASD was extremely limited (Westrup, 2013) and was certainly a gap, I reflected upon my developing understanding of EPs being positioned as ‘experts’. My review of the literature consistently illustrated that parents were notably some of the most experienced and knowledgeable people about FASD, particularly in comparison to EPs (Campbell, 2019). Consequently, it did not feel appropriate to prioritise gathering experiences of EPs at a time when the literature base around FASD and education was so limited. I acknowledge however, that the exclusion of pupils', school professionals' and EPs' views could all be considered limitations of my findings.

Inclusion Criteria

During research supervision ongoing discussions were held around participant inclusion criteria. Owing to diagnostic challenges described in my literature review, I made the decision to only gather experiences of adopters or foster carers whose child had a confirmed diagnosis of FASD. Similar decisions were taken to boundary the geographical location of participants to one region of the UK. This was important given the recency with which the UEA doctorate programme had been developed and the lack of representation in research for those living in the area. It was intended that research might support issues in the locality and enhance actionability of implications for schools and EP practice which might arise from the research. Although had recruitment been unsuccessful the geographic inclusion criteria would have been widened. During the recruitment phase, I was contacted by several prospective participants outside of the chosen region of England and who had not yet obtained a diagnosis. This is a regret of mine as I feel the tight inclusion criteria may have furthered issues with social justice. I would reconsider these decisions if I were to begin the research journey again. Nevertheless, there were strengths within my participant pool. For instance, I did not enforce a narrow age limit. This allowed me to interview parents who had broad experiences of interacting with pre-school, primary, secondary and college staff. Although I do feel that I missed an opportunity to explicitly draw out nuances further. Additionally, my participants included a sample of both adoptive mothers and fathers. The inclusion of paternal views has been a consideration of my practice since I attended a seminar on the subject at the Division of Educational and Child Psychology (DECP) TEP conference in 2021. However, it should be noted that this occurred by chance and was not a deliberate choice made by myself as the researcher. Again, I feel that whilst an organically occurring strength, this was not drawn upon enough in my empirical paper.

Recruitment

I am incredibly grateful for the support from the regional based centre in my participant recruitment. They had access to adopters and foster carers who met the inclusion criteria for my project and had already provided consent to be contacted for future research opportunities. This meant that my recruitment was a straightforward process. On the other hand, this posed some limitations. My recruitment poster was circulated and shared with potential participants by a regional resource base for FASD. As the researcher I had no ownership over who was, or was not, sent information about my study. This may raise issues in relation to a selection bias. Similarly, participants had previously expressed an interest in participating in research. There was no scope to advertise my research to all who may have met the inclusion criteria. This meant there was no option for those who may subsequently have changed their minds or been interested specifically in the aims of my study. In addition, the resource base is a private clinic where adoption support funds (ASF) were used to facilitate FASD diagnosis. It is likely that not everyone was able to access this service, both in relation to issues with ASFs and the resources of the service itself. Upon reflection it would have been beneficial to advertise more elsewhere, alongside the chosen recruitment process, to ensure that the offer of participation was extended to a wider audience. Further consideration of how this might have been achieved would be required as I decided not to recruit through schools or EPs owing to similar concerns relating to selection bias.

I would like to take this opportunity to express my sadness upon hearing the news that the local centre which supports diagnosis for FASD is to close. I echo comments made by the National Organisation for FASD (2022), that the centre “filled a gaping hole in national capacity for FASD diagnosis” and the closure will be distressing for many families who spoke so fondly of the support they received. As a result, the relevance of recommendations and implications for EPs from this research could not be timelier, as a dearth of commissioned services for FASD exists (National Organisation for FASD, 2022).

Research Design

Developing Research Questions

Agee (2009) highlighted that effective RQs derive from researcher curiosity or a passion for a topic area. To address my concerns around a deficit focus of FASD, I knew that an aim of my research would be to seek solutions and explore exceptions, for instance times that were better. Initially this was an important consideration for my RQs. I contemplated the use of RQs which were framed within a solution focused approach, but as Flannigan et al., (2021) suggest, it did not seem appropriate to dismiss the difficulties which are seemingly a reality of parents’ experiences. Instead, I settled upon solution-oriented workings which keep one foot in pain and the other in possibility (O’Hanlon & Weiner-Davis, 2003). This informed the formulation of my initial RQs at the research proposal stage:

1. What difficulties do parents perceive their children experience in school when they have a diagnosis of FASD?
2. Which factors do parents perceive contribute to the positive educational experience of children with a diagnosis of FASD?

3. What are parents' experiences of EPs supporting the educational experiences of their children who have a diagnosis of FASD?

Following feedback from my research supervisors, I recognised that questions one and two might force responses into two opposing poles: positive and difficult experiences. They did not allow for nuanced experiences in between. Similarly, it was after some time that I realised that my proposed questions failed to capture parents' experiences at all. This was a significant oversight. As part of the review process, I broadened the questions and moved away from solution-oriented thinking. I decided this was better placed in the design of my interview schedule. Constructing RQs is a process of drafting and revisiting (Agee, 2009), and after several iterations the following RQs were finalised:

1. How do parents perceive their child's experience of school?
2. What are parents' experiences of the family-school interaction?
3. What are parents' experiences of EPs supporting the educational experiences of their child?

Upon reflection the first question was still too broad. The value and credibility in considering parents' perceptions of how their child experiences school can also be questioned. There may be nuances or more specific circumstances in their school lives which parents are simply not aware of and are therefore not represented in this research. Similarly, the understanding that parents have ascertained of their child's experience is second hand and will have been interpretated in accordance with their own values and beliefs. Their perception may therefore not necessarily align with how their child might describe their experience. For instance, if the parent had a particularly positive or negative experience of their own schooling, or the interaction with their child's school, it may be difficult to consider how their child's experience could be any different. It might have been better to refine it to focus on one specific aspect that parents are appropriately positioned to reflect on, not include it at all, or triangulate with additional interviews with CYP for whom it is a first-hand experience. The three RQs together meant that I had a large volume of wide-ranging findings and fewer questions might have allowed for more in-depth analysis and discussions. Having said that, I have offered actionable outcomes to address all three, and therefore the initial aims of my research were broadly met.

From Interviews to Transcription

I found the experience of conducting interviews thoroughly enjoyable, although initially nerve-wracking. I gave extensive time to preparing my interview schedule and as my confidence improved, my reliance on this reduced. Participants' experiences were gathered using semi-structured interviewing. I considered the possible limitation ofstructured interviews outlined by Smith et al., (2009) that analysis of the data may simply reflect key topics identified in the interview. However, in choosing semi-structured interviews I was able to follow participants' lead and ask additional follow-up questions, whilst ensuring that topics relevant to the RQs were covered (Robson & McCartan, 2016). Upon transcribing the interviews, I noticed a few occasions where additional follow up questions may have been beneficial. This in part related to 'being in the moment', whereas during transcription I was further removed and able to gather my thoughts more comfortably. As an inexperienced researcher I was particularly cautious of influencing the conversation too heavily. Additionally, I was aware of participants' time commitments and upon reflection what I was hoping to achieve in sixty minutes was perhaps not entirely manageable. This relates to my earlier comment around not including RQ1, however, if I were to complete this research again, I would also allocate more time. This may have been identified earlier had I conducted a pilot study; a point of learning for me.

Critique of the interview schedule was sought from research supervision, peers and key professionals in the field, one of which was also an adopter. This was a highly valuable experience which enabled me to refine and/or broaden questions where necessary. On the other hand, a pilot study may have facilitated further familiarisation with the interview process, particularly as I found it difficult to position myself as a researcher and not as a TEP who was facilitating consultation. EP consultation is recognised as a ‘collaborative’ process (Wagner, 2000); however, I was aware that in this context my role was to listen, not problem solve together or offer advice. This was particularly challenging at times when participants were visibly upset upon describing their experiences. This was perpetuated by the remote nature of the interviews, where the physical distance made efforts to provide comfort and reassurance much harder. I found myself exaggerating my body language to demonstrate that I had noticed their feelings and was actively listening with both empathy and concern. It was clear that parents faced many difficulties which ordinarily in our role as TEPs we might be encouraged to explore further. My practice very much aligns with solution-oriented approaches whereby we consider potential solutions that already exist, and yet as a researcher it was not appropriate for me to make recommendations at an individual level. This was especially tempting in interviews where parents described how the environment of isolation booths were better suited to their child’s needs than the classroom. As a TEP I would question what adaptations could be made to the classroom environment to bring it closer to that of isolation. For me there were clear, relatively ‘quick wins’ that might make a considerable difference, but I knew that I needed to resist this urge.

Reflexive Thematic Analysis (TA)

Data analysis was conducted using Braun and Clarke’s (2006; 2022) six phases of reflexive TA, this was a laborious process. Interpretative phenomenological analysis (IPA) was considered as an alternative; indeed, previous research in this context has adopted this methodology and/or used a phenomenological lens (e.g. Duquette et al., 2007; Duquette et al., 2012; Hammond, 2021). However, this qualitative approach seeks to provide in-depth examinations of personal lived experiences for each individual participant, prior to the move to recognise patterns of shared meaning (Willig, 2013). Instead, reflexive TA prioritises the identification of patterned meaning. This still offers the opportunity for an inductively oriented exploration to ensure that identified themes originated from participant’s experiences. This was achieved in the current research through data-derived coding; a bottom-up approach. IPA was not as conducive to achieving one of the central aims of the research, to broadly ascertain what works and offer actionable solutions. This was more suited to reflexive TA.

Familiarisation. Following transcription, I read and reviewed the transcripts and made initial familiarisation notes. At this time, similar emotions were invoked to those experienced during my initial literature searches. Watts (2014) emphasised the importance of reading the dataset to immerse and position oneself in the participants’ shoes. Before completing this research, I would never have believed that as a researcher you could experience participants emotions second-hand, but I did. I felt anger when parents expressed frustration and was nearly brought to tears when I re-read their experiences. At this time particularly I felt heavily invested in and connected to my participants.

Coding. I followed Watts' (2014) recommended 'what/how system' of coding to ensure that I engaged with the data from the first-person, or participant's perspective. I considered 'what' a participant was talking about and then 'how' they were talking about that subject matter. This ensured that the development of codes remained suitably close to the data (Watts, 2014). I made a conscious decision at this time not to revisit the literature and focus entirely on the coding process. This ensured that as far as possible my coding was inductive and not influenced by what I may or may not have read. At this stage I became acutely aware of my current role as a TEP and previous role as a teacher. It was difficult to adopt neutrality when data related to either role because I was personally close to that experience. For example, on occasion I felt defensive of views held towards teachers and EPs, as I am aware of perspectives from the other side. However, as Watts (2014) suggested, the researcher's job is not to always agree with your participants. Instead, what is important is that our analysis reflects the participants' views about a subject-matter and not our views of the participants. I found this comment helpful in providing peace of mind that I would not necessarily be assumed to hold the same viewpoints. To improve rigour and evidence confirmability it may be considered valuable to have multiple coders to check interpretation against the data. However, Braun and Clarke (2021a) are clear that this is not a requirement of reflexive TA, nor is it desirable. Equally, as this research is a requirement of qualifying to become an EP, it was necessary for us to be independent researchers. As is consistent with my chosen methodology, I noted my feelings in my reflective diary (see Appendix N) and refocused myself back into the 'what/how' coding system. This supported me to acknowledge my subjectivity whilst remaining close to the participants' views.

Braun and Clarke (2013) note that analysis of qualitative data tells one story amongst many. I battled with this as I felt an overwhelming responsibility towards my participants to ensure that their views were accurately represented. This fear became most prominent at the coding stage. Whilst more time consuming, the decision to code electronically was helpful as it was both systematic and methodical. On the other hand, I overcomplicated the process because I succumbed to my heightened anxiety at the possibility of making a mistake, despite there being no 'right answer'. Braun and Clarke (2022) highlight that there is no definitive time to move onto the next stage of analysis and I found it especially hard to draw the coding stage to a close. In truth, I was apprehensive about moving on to consider themes as I knew this involved 'zooming out' from individual interviews and considering the wider dataset. This fuelled my anxiety about missing something or misinterpreting a participant.

Developing Themes. My experience of data analysis, particularly stages three to five (see Table 5), can be likened to completing a puzzle without having a picture to follow. Braun and Clarke's (2022) recommendation encouraged me to step away from the data for short periods of time, however, I grappled with feelings of guilt at not proactively 'working'. At other times I did not feel able to settle into any one task. Through discussions with peers, I realised that I was physically working on one stage of analysis but thinking too far ahead. For instance, when generating initial themes, I was concerned with what the write up might look like. Upon reflection this was furthered by time pressures, as it was necessary for me to take some time away from my research to have a medical procedure. Although strangely having this time redirected my focus as I was better able to compartmentalise the thesis into smaller, more manageable chunks. It was from this point onwards that I stopped setting myself additional deadlines and instead planned in time periods of no more than two weeks.

In developing my themes, I held in mind two key points. Firstly, Braun and Clarke (2022) are clear that themes are distinct from topic summaries. Topic summaries report everything that was said about a subject, but in fact tell us little. For instance, in the current study ‘behaviour management’ was spoken about on numerous occasions, and I might have discussed everything in relation to this, but this does not provide the pattern of shared meaning that is required of themes. Instead, it tells us that behaviour management was discussed. As Watts (2014) questions, so what? A topic summary neglects meaning. This informed my decision to develop themes across the entire dataset, rather than in relation to RQs. For instance, presenting ‘Parents’ Perceptions’, ‘The EP Role’ and ‘The Family-School Interaction’ as themes, would have merely offered topic summaries of what was discussed in the interviews. Furthermore, these would have been discussed in the interviews because the interview schedule was designed to address specific RQs. Themes instead are more authentic and develop from interpretation of what was discussed. The second point of note was that I did not need to include every single nuance and individual perspective on a subject. Again, this related to the pattern of shared meaning, and as Braun and Clarke (2022) discuss, difficulties with ‘letting go’ of proposed codes and themes. I had initially coded all my data, and this may have contributed to the difficulties I experienced as the breadth of my findings were vast. There were no research questions that specifically related to parenting which, upon analysing the data, appeared to be concepts of some importance within the study. This is one of the weaknesses of a study which is exploratory in nature, however it does suggest a direction for future research, namely the family-community interaction and experiences of parenting an individual with FASD.

Writing the Analysis. To support the reader, I created a thematic map and presented my findings and discussion separately, choosing to frame my discussion under my RQs as subheadings. Watts (2014) argues that in integrating the two, analysis is otherwise too quickly moved away from the first-person perspective and towards previous literature. My decision goes against Braun and Clarke's (2013; 2022) recommendation of an integrated findings and discussion, however, this came from a consideration of practicalities such as a limited word count. Instead, I found Watts' (2014) suggestion that the findings and discussion serve two distinct purposes to be helpful, as an emerging researcher. It ensured that participants' accounts were presented first, before later drawing on a third person perspective that accounted for current understanding in the literature. Owing to the volume of findings I structured my discussion by initially considering findings in relation to existing literature. I felt that separating findings into those which corroborated with others and those which were novel or of particular interest for further consideration, highlighted the unique contribution of the study to the reader.

Dissemination and Wider Implications of Research

I certainly intend to publish and disseminate the findings of my research. Fundamentally, this is essential as a step to addressing one of the primary issues of limited knowledge and understanding of FASD that this research illustrated. In addition, without dissemination, actionable change, a key priority of this research, will not be possible. I feel this research may be most appropriately suited to publication in journals such as Educational Psychology in Practice (EPIP) and the Adoption and Fostering Quarterly Journal, owing to relevance to the RQs and participant profile. I also hope to share a summary of my findings with key organisations and charities such as Adoption UK and the National Organisation for FASD. Whilst parents and carers will receive an executive summary of the findings from this study, dissemination to the above organisations will be a particularly important step in sharing findings with parents and carers elsewhere, who did not participate. Similarly, this will be achieved via other stakeholders such as social workers and EPs. To raise further awareness amongst EPs I would also like to present at the Eastern Region Conference and the Division of Educational and Child Psychology (DECP) TEP Conference. It is hoped that in doing so, I may capture the interest of future researchers who may consider FASD in their theses. Furthermore, in raising the profile of FASD amongst TEPs particularly, it is hoped that conversations within the wider EP community such as supervisors, tutors, peers etc may be ignited. Indeed, TEPs are in a unique position to shape practice and share their learning with others.

As I come to the end of my training, opportunities for continuous professional development (CPD) and furthering my knowledge post-qualification is something I have become increasingly concerned by. This first came to my attention during a presentation on ‘Open Psychology’ at the DECP TEP conference in 2020. Issues of accessibility to research findings were raised, given that many require considerable subscription fees. I considered this in relation to my own research findings and realised that my recommendations for schools and EPs may never reach the intended audience. One positive of the COVID-19 pandemic is that the availability of online CPD is expanding. For instance, Dr Tim Cox’s ‘Agents of Hope’ podcast and Southend’s ‘Reach Out Webinar’ series have become particularly popular amongst EPs. In time I feel there would be a place for my research on these platforms also.

However, there exists a need for a FASD training package for EPs, both in terms of their own CPD and for them to deliver to schools. Historically in the chosen region for this research especially, the latter was offered by the resource base I used during participant recruitment, however, sadly the role may now be unfulfilled. Beyond training there is a need for a framework or resource that may support both schools and EPs in practice. This relates to the 'application' component of the 'scientist-practitioner' role. In time I would like to propose an adaptation to Moran's (2010; 2015) Coventry Grid. The Coventry Grid is a well-established tool which seeks to summarise and distinguish between CYP with ASD or attachment needs, two areas which have considerable overlapping features with FASD (Bruer-Thompson, 2016; Petrenko et al., 2014). I wonder whether the inclusion of a third strand might raise the profile of FASD amongst schools and EPs and alleviate misidentification. I recognise that owing to issues of generalisability, the adaptation cannot be based purely on the findings of this study. Having said that, one critique of the Coventry Grid is that it is not based upon research findings, rather clinical observation. Findings from this study, alongside others detailed in the literature review, may facilitate the development of an evidence based FASD column. Similarly, the Coventry Grid does not make recommendation of how best to support need. Again, in relation to FASD, this is directly addressed by the findings of this research, so some advice can be offered from this sample. Flackhill et al., (2017) modified the Coventry Grid to interview format, thus improving accessibility during conversations with parents. According to research by Campbell (2016), as cited in Campbell (2019), EPs hold mixed views around their role in gathering developmental histories with parents in the context of FASD. They were especially concerned by issues of stigma. Perhaps adaptation of the Coventry Grid Interview (Flackhill et al., 2017), to include appropriately and sensitively framed questions may support EPs to feel more comfortable to ask tough questions. This might improve identification and facilitate implementation of early intervention. In turn this provides scope to reduce the development of associated difficulties and improve the school experience for individuals and their families.

It is important to also consider the wider implications of my research findings which extend beyond stakeholders for whom this study is of direct relevance. Despite being initially cautious to name these, the emotive findings of my research highlight the need for change at a much broader level, namely prevention. After all, these experiences are entirely avoidable and engaging with my reflections as a researcher is in line with my methodological approach of reflexive TA. As the National Organisation for FASD (2020) argue, alcohol is the catalyst for FASD, and yet, in our society, alcohol remains a ‘treat’, something to assist us after a difficult day, a reward even. Newly published guidance books for expectant mothers such as ‘How to Give Birth Like a Feminist’ by Milli Hill are guilty of misinforming pregnant women that the recommendation to avoid alcohol during pregnancy is simply a result of the ‘patriarchy’. I would myself grapple to ‘fact check’ something which claims to be in the best interest of women. Many women continue to see abstinence as a limitation of pregnancy, something you just do, without fully comprehending why. The idea that we cannot have fun without a drink in hand is problematic yet accepted in our society. We need a societal shift like that which has been achieved with smoking, this can only be achieved through education. The narrative which argues that enquiring about maternal alcohol consumption is a breach of privacy is in my view, unhelpful. Health professionals should feel empowered, knowledgeable, and confident to ask difficult questions and advise on safe practice. Expectant mothers and those trying to conceive deserve to be better informed to enable them to make conscious decisions, with scientifically sound evidence. Consequently, as a field of research interest, this must continue to grow. Moreover, perhaps the notion that this affects 50% of the population again is the reason this does not gain traction. However, regardless of how a baby is conceived, biologically a male is involved. We must ask why this is therefore not of interest to prospective fathers too? The view that it doesn’t affect them seems unsubstantiated. As ambitious as it may seem, ultimately, I would be delighted if even one person read this research and as a result reconsidered their relationship with alcohol, resulting in a move away from abstinence during pregnancy being a sacrifice to a lifeline.

Contributions to Personal Development

The process of conducting this research has certainly not been linear and this is reflected in my personal feelings towards the journey. Having said that, I can look back and recognise that I have achieved something which I did not think possible at the start of the doctorate. The thought of research filled me with dread as I had not had a positive experience during my undergraduate degree. Upon reflection this relates to my aversion to number and statistics. My understanding of research until this project was situated within a quantitative approach. As one might expect given the doctoral level of qualification, the freedom to choose, explore my interests and learn about who I am as a researcher has contributed to a more successful experience. It is ironic how closely this mirrors my research findings.

Although self-confidence will likely remain a battle for me, I have certainly grown throughout this process and trusted my abilities more. This research has improved my research skills, particularly in relation to qualitative research methods and methodology, such as interviewing, data analysis and the significance of research paradigms. Now that I have been exposed to qualitative research, I have come to see the value and have greater respect for research than I had previously. Nevertheless, I am also content in my chosen career path as an EP. I am much more interested in actioning and supporting change on the ground than I am in making contributions via research. I must acknowledge how the opportunity to conduct this research has led to me find a subject that I am immensely passionate about. I am sure that this will continue to be pertinent in my work as an EP. Moreover, I have grown to better understand my value system around social justice, capturing voice and being person-centred. As a result, this research journey stands me in good stead to become the EP I want to be, and for that I am very appreciative.

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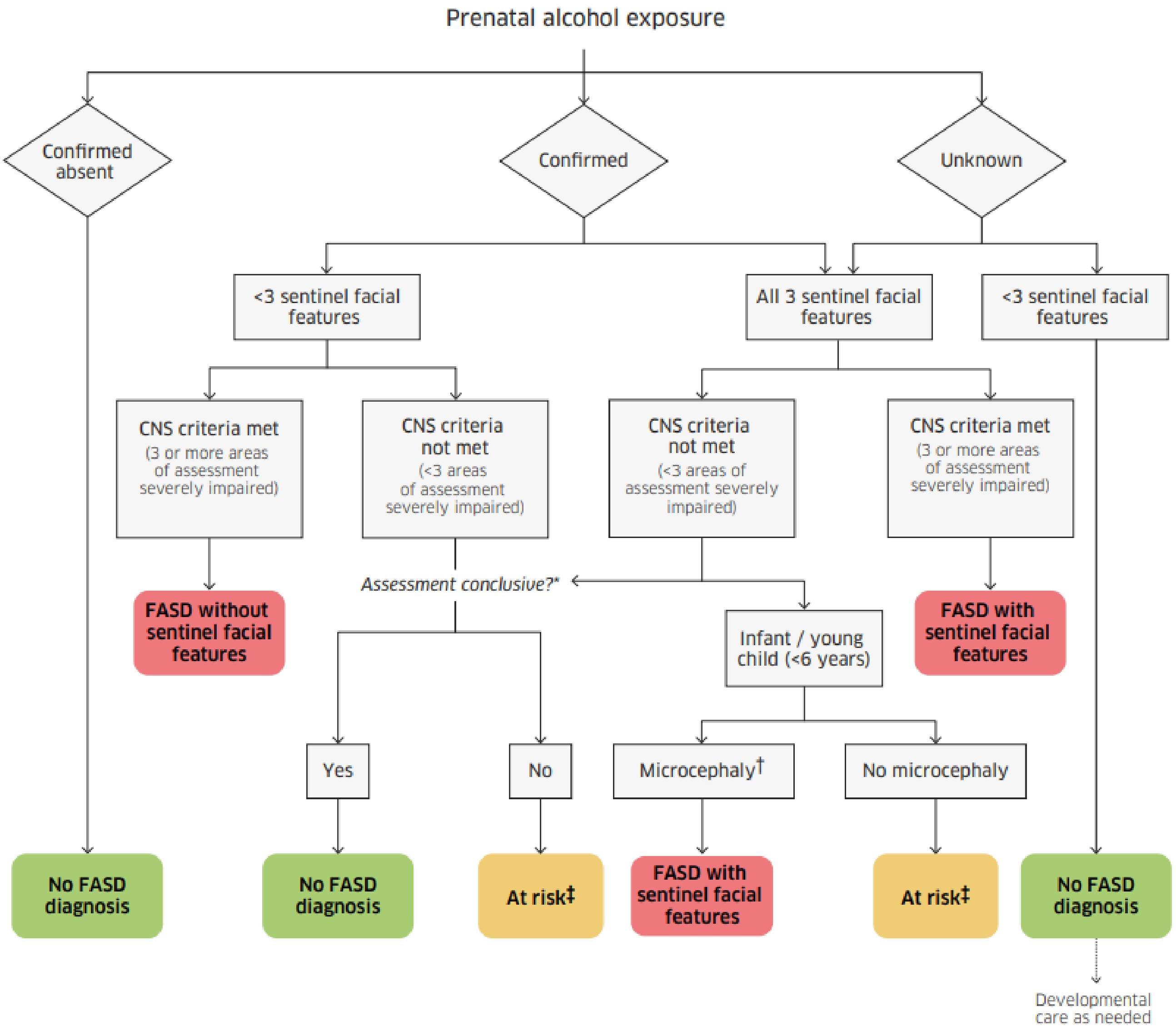
Appendix A

SIGN 156 Diagnostic Algorithm



Appendix B

Recruitment Poster

Are you an adoptive parent or foster carer with a child aged between 5 and 16 years old that has a diagnosis of Foetal Alcohol Spectrum Disorder (FASD)?

Do you live in [redacted]?

Would you be interested in talking to me about your thoughts on their experiences of education?

Project Title: Foetal Alcohol Spectrum Disorders (FASD): The Parent Perspective and The Role of Educational Psychologists (EPs).

My name is Rebecca Griffiths. I am a Trainee Educational Psychologist, training at the University of East Anglia, Norwich. For my doctoral research, I am interested in researching the educational experience for those with FASD. I am currently looking to recruit **adoptive parents or foster carers who have a child aged between 5 and 16 years old with a confirmed diagnosis of FASD.**

Why is this research important?

- Research suggests that FASD is more prevalent than we might expect.
- FASD disproportionally affects adopted and looked after children and young people.
- Currently, research in the UK is heavily medicalised. It does not necessarily explore the impact of FASD on education or gather the views of families.

What will I be asked to do?

You will be asked to take part in an interview with myself at a mutually convenient date and time between May and August 2021. This interview will take place online using Microsoft Teams and will last for approximately one hour.

How can I take part?

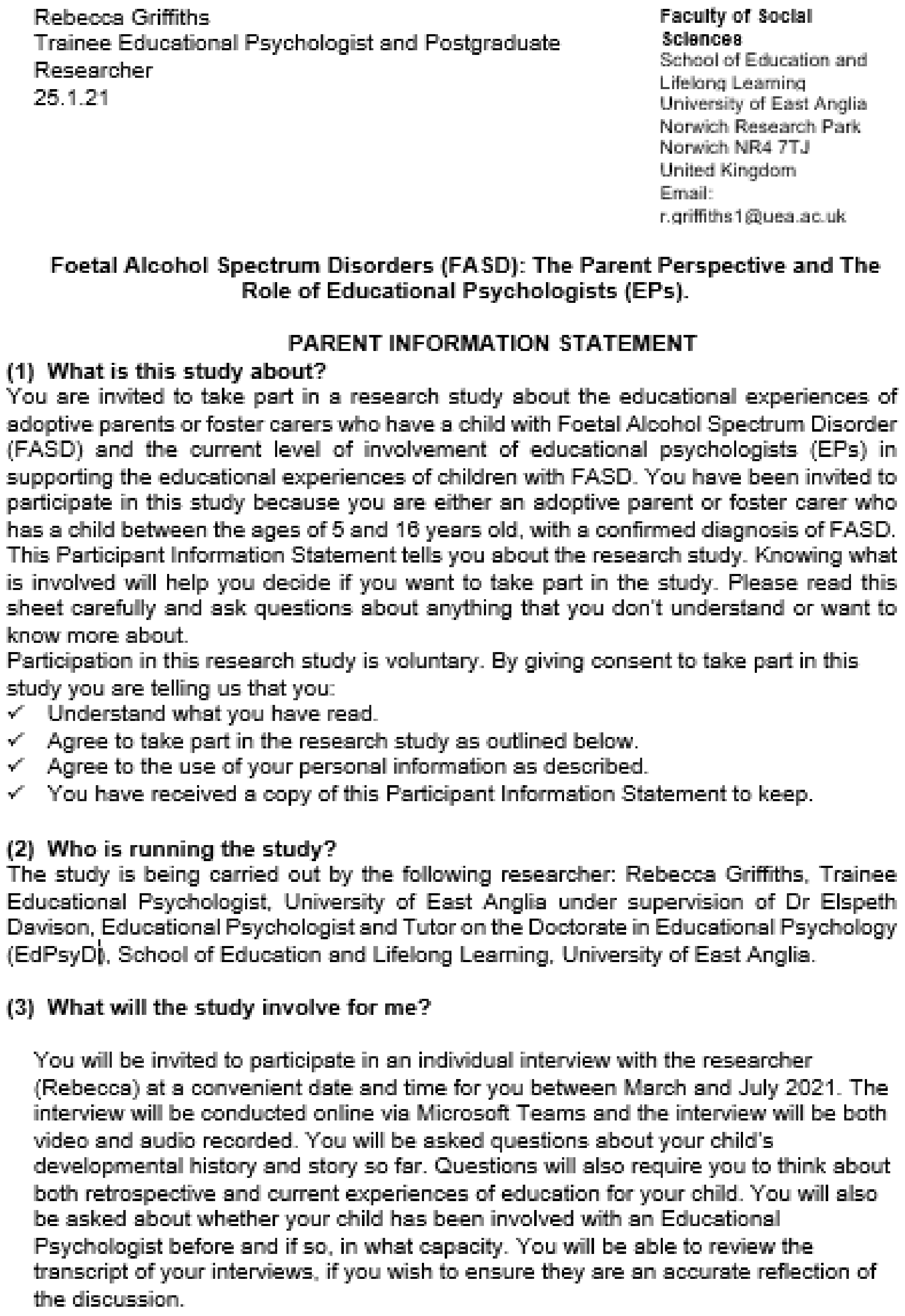
If you are interested in taking part, please email me- r.griffiths1@uea.ac.uk. I will then be able to send you more information about this research.

Thank you

UEA University of East Anglia

Appendix C

Participant Information Sheet



Rebecca Griffiths
Trainee Educational Psychologist and Postgraduate Researcher
25.1.21

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Foetal Alcohol Spectrum Disorders (FASD): The Parent Perspective and The Role of Educational Psychologists (EPs).

PARENT INFORMATION STATEMENT

(1) What is this study about?

You are invited to take part in a research study about the educational experiences of adoptive parents or foster carers who have a child with Foetal Alcohol Spectrum Disorder (FASD) and the current level of involvement of educational psychologists (EPs) in supporting the educational experiences of children with FASD. You have been invited to participate in this study because you are either an adoptive parent or foster carer who has a child between the ages of 5 and 16 years old, with a confirmed diagnosis of FASD. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary. By giving consent to take part in this study you are telling us that you:

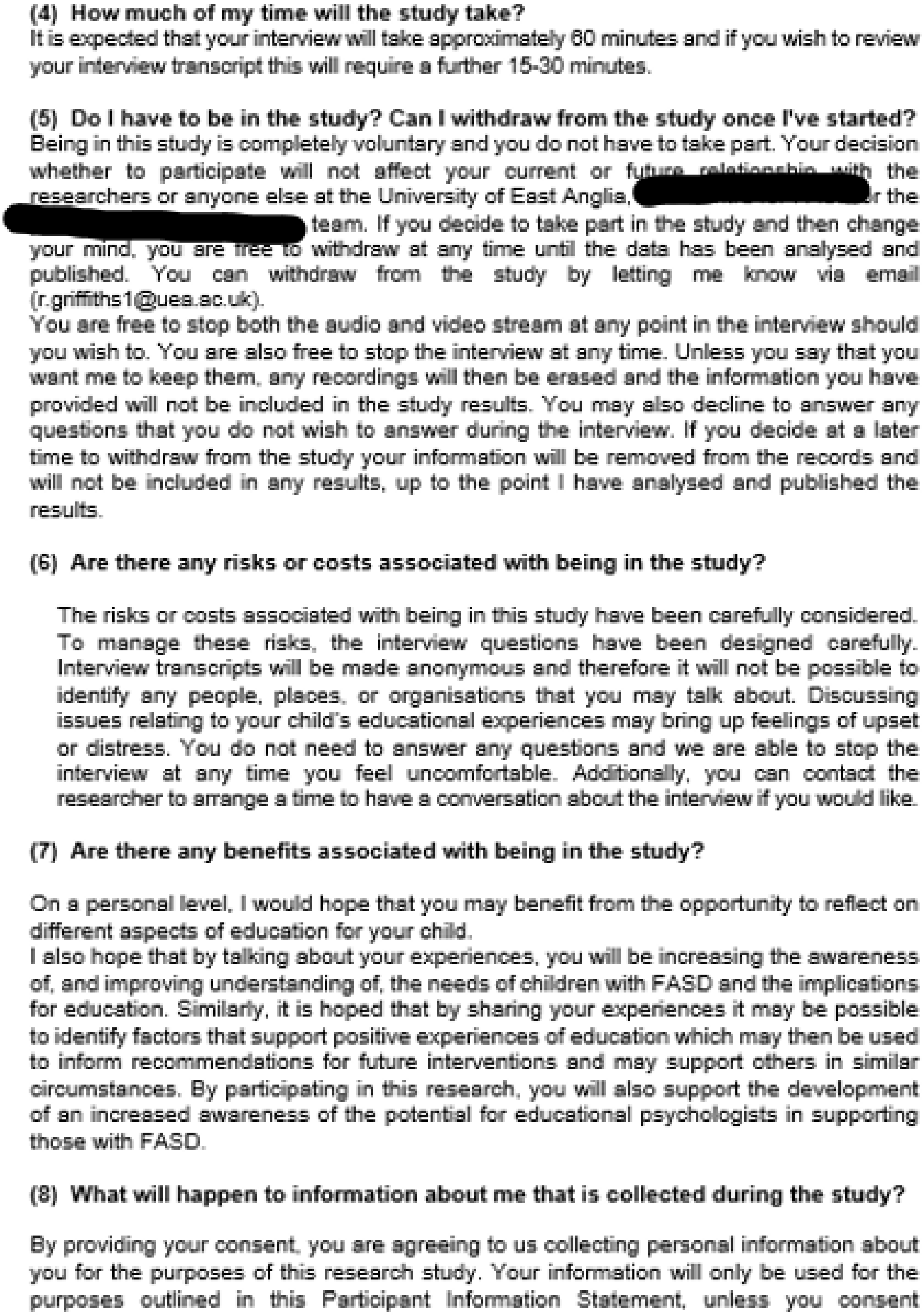
- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.
- ✓ You have received a copy of this Participant Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researcher: Rebecca Griffiths, Trainee Educational Psychologist, University of East Anglia under supervision of Dr Elspeth Davison, Educational Psychologist and Tutor on the Doctorate in Educational Psychology (EdPsyD), School of Education and Lifelong Learning, University of East Anglia.

(3) What will the study involve for me?

You will be invited to participate in an individual interview with the researcher (Rebecca) at a convenient date and time for you between March and July 2021. The interview will be conducted online via Microsoft Teams and the interview will be both video and audio recorded. You will be asked questions about your child's developmental history and story so far. Questions will also require you to think about both retrospective and current experiences of education for your child. You will also be asked about whether your child has been involved with an Educational Psychologist before and if so, in what capacity. You will be able to review the transcript of your interviews, if you wish to ensure they are an accurate reflection of the discussion.



(4) How much of my time will the study take?

It is expected that your interview will take approximately 60 minutes and if you wish to review your interview transcript this will require a further 15-30 minutes.

(5) Do I have to be in the study? Can I withdraw from the study once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or fu[redacted]h the researchers or anyone else at the University of East Anglia, [redacted]r the [redacted] team. If you decide to take part in the study and then change your mind, you are free to withdraw at any time until the data has been analysed and published. You can withdraw from the study by letting me know via email (r.griffiths1@uea.ac.uk).

You are free to stop both the audio and video stream at any point in the interview should you wish to. You are also free to stop the interview at any time. Unless you say that you want me to keep them, any recordings will then be erased and the information you have provided will not be included in the study results. You may also decline to answer any questions that you do not wish to answer during the interview. If you decide at a later time to withdraw from the study your information will be removed from the records and will not be included in any results, up to the point I have analysed and published the results.

(6) Are there any risks or costs associated with being in the study?

The risks or costs associated with being in this study have been carefully considered. To manage these risks, the interview questions have been designed carefully. Interview transcripts will be made anonymous and therefore it will not be possible to identify any people, places, or organisations that you may talk about. Discussing issues relating to your child's educational experiences may bring up feelings of upset or distress. You do not need to answer any questions and we are able to stop the interview at any time you feel uncomfortable. Additionally, you can contact the researcher to arrange a time to have a conversation about the interview if you would like.

(7) Are there any benefits associated with being in the study?

On a personal level, I would hope that you may benefit from the opportunity to reflect on different aspects of education for your child.

I also hope that by talking about your experiences, you will be increasing the awareness of, and improving understanding of, the needs of children with FASD and the implications for education. Similarly, it is hoped that by sharing your experiences it may be possible to identify factors that support positive experiences of education which may then be used to inform recommendations for future interventions and may support others in similar circumstances. By participating in this research, you will also support the development of an increased awareness of the potential for educational psychologists in supporting those with FASD.

(8) What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent

otherwise. Data management will follow the 2018 General Data Protection Regulation Act and the University of East Anglia Research Data Management Policy (2019).
Your information will be stored securely, and your identity/information will be kept strictly confidential, except as required by law. Audio and video recordings will be used for analysis purposes only. These recordings will be used to make interview transcripts. At this point, the contents of your interview will be anonymised. Only myself (Rebecca) and my research supervisor (Dr Elspeth Davison) will have access to this data. Electronic data (consent forms, video and audio recordings and transcripts) will be stored on a secure, encrypted memory stick with industry standard methods and protected by passwords.

The data and findings will be used for my doctoral level thesis. However, the thesis may be published as a journal article and/or used as part of conference presentations in the future. A one-page summary of the study findings will also be made available to The Centre for FASD and the Educational Psychology Service. You will not be identified in these publications if you decide to participate in this study. In this instance, data will be stored for a period of 10 years and then destroyed.

(9) What if I would like further information about the study?
When you have read this information, I (Rebecca) will be available to discuss it with you further and answer any questions you may have. You can contact me on r.griffiths1@uea.ac.uk.

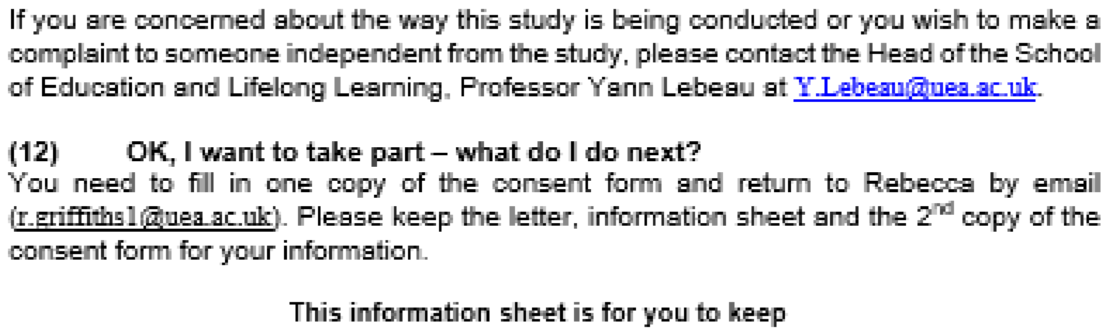
(10) Will I be told the results of the study?
You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by ticking the relevant box on the consent form. This feedback will be in the form of a one-page summary. You will receive this feedback at the end of the study, after July 2022.

(11) What if I have a complaint or any concerns about the study?
The ethical aspects of this study have been approved under the regulations of the University of East Anglia's School of Education and Lifelong Learning Research Ethics Committee.
If there is a problem, please let me know. You can contact me via the University at the following address:

Rebecca Griffiths
School of Education and Lifelong Learning
University of East Anglia
NORWICH NR4 7TJ
r.griffiths1@uea.ac.uk

If you would like to speak to someone else, you can contact my supervisor:

Dr Elspeth Davison
School of Education and Lifelong Learning
University of East Anglia
NORWICH NR4 7TJ
elspeth.davison@uea.ac.uk



If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the Head of the School of Education and Lifelong Learning, Professor Yann Lebeau at Y.Lebeau@uea.ac.uk.

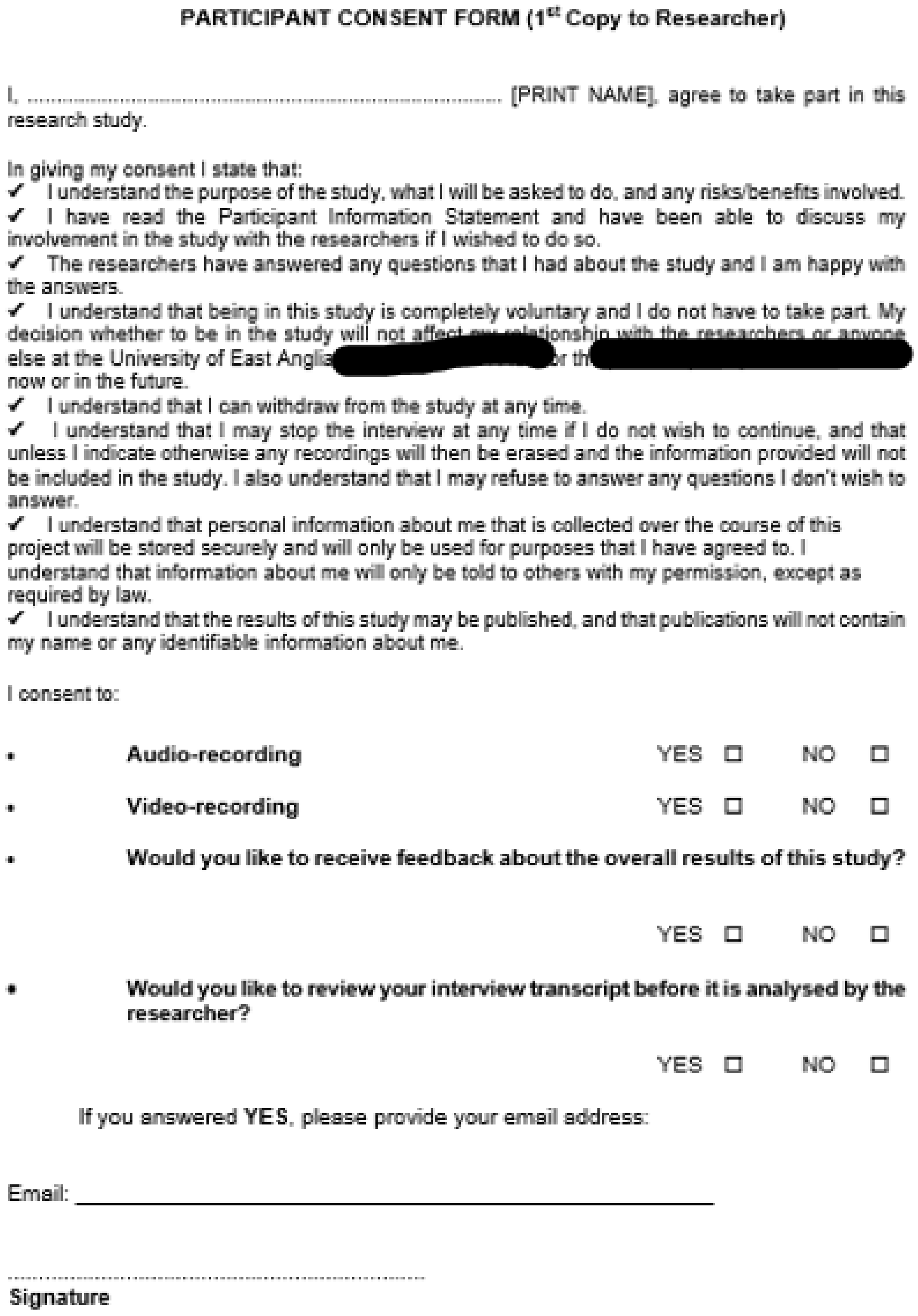
(12) OK, I want to take part – what do I do next?

You need to fill in one copy of the consent form and return to Rebecca by email (r.griffiths1@uea.ac.uk). Please keep the letter, information sheet and the 2nd copy of the consent form for your information.

This information sheet is for you to keep

Appendix D

Participant Consent Form



PARTICIPANT CONSENT FORM (1st Copy to Researcher)

I, ... [PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

✓ I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.

✓ I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.

✓ The researchers have answered any questions that I had about the study and I am happy with the answers.

✓ I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia [redacted] r th [redacted] now or in the future.

✓ I understand that I can withdraw from the study at any time.

✓ I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.

✓ I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

✓ I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

I consent to:

- **Audio-recording** YES ☐ NO ☐
- **Video-recording** YES ☐ NO ☐
- **Would you like to receive feedback about the overall results of this study?**

  YES ☐ NO ☐
- **Would you like to review your interview transcript before it is analysed by the researcher?**

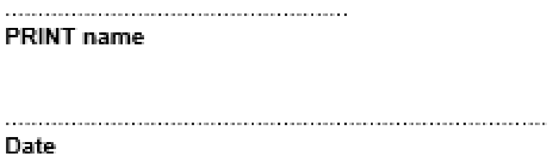
  YES ☐ NO ☐

If you answered **YES**, please provide your email address:

Email: ____

....

Signature



....

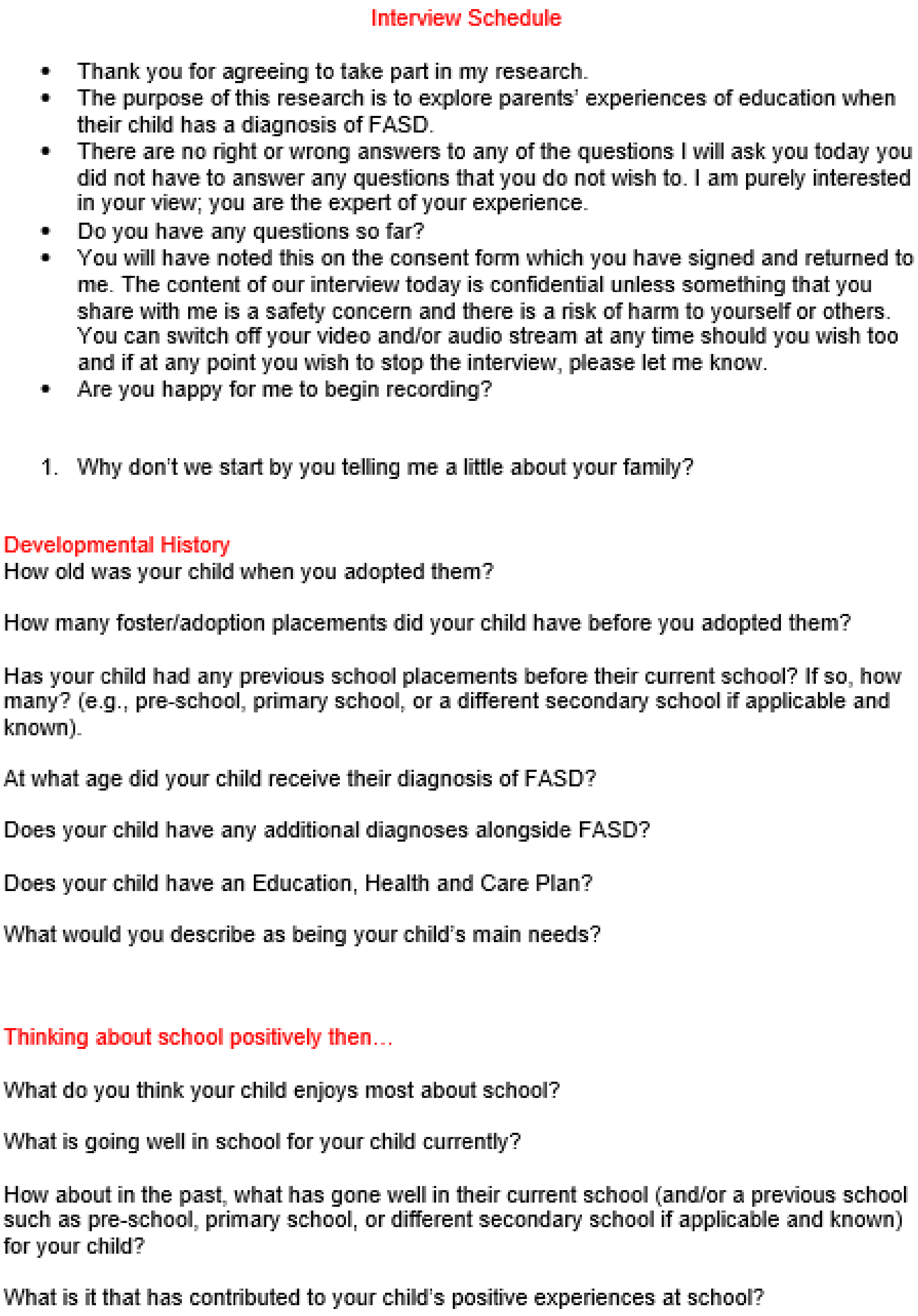
PRINT name

....

Date

Appendix E

Interview Schedule



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?

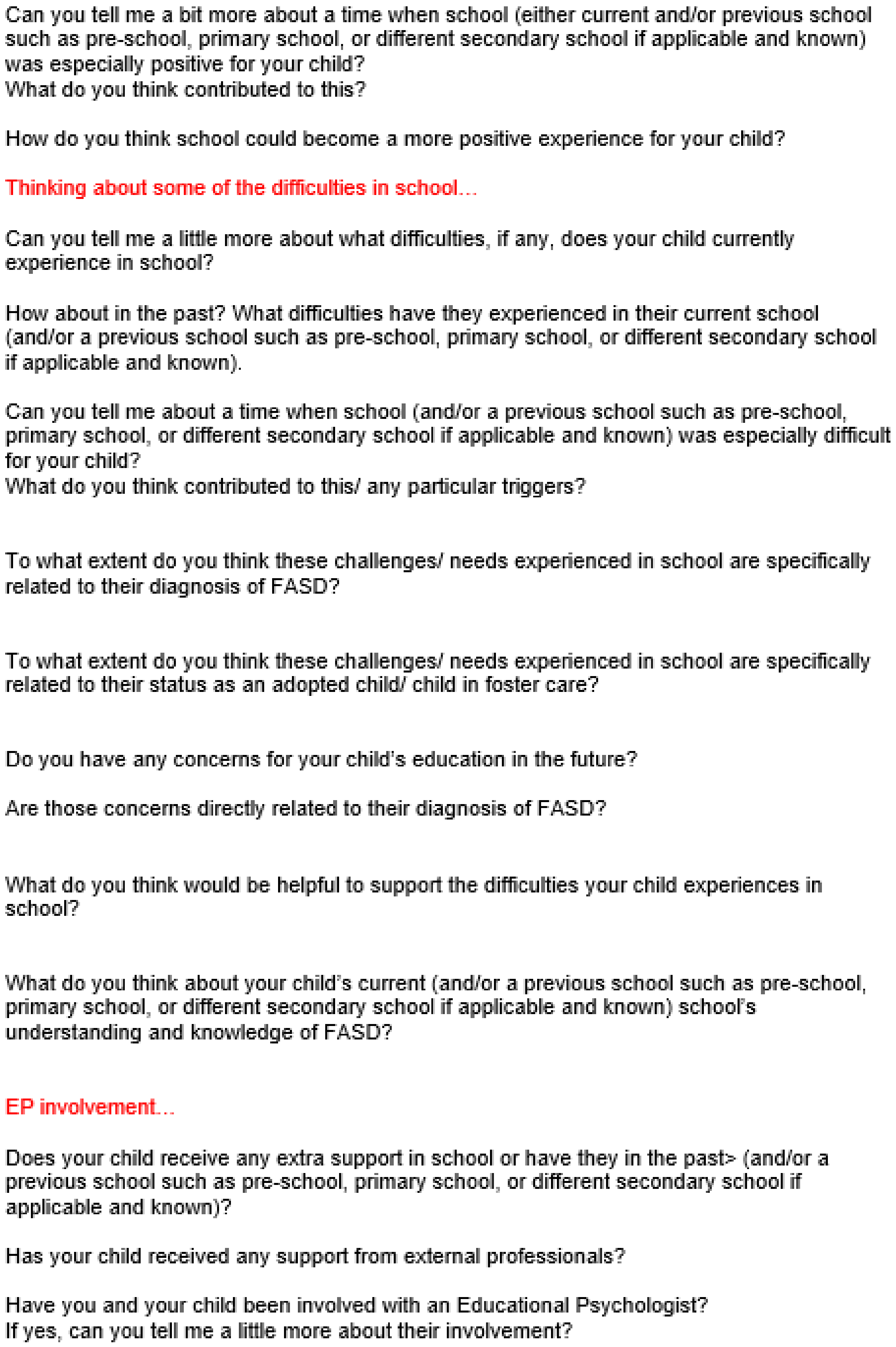
Thinking about school positively then…

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?

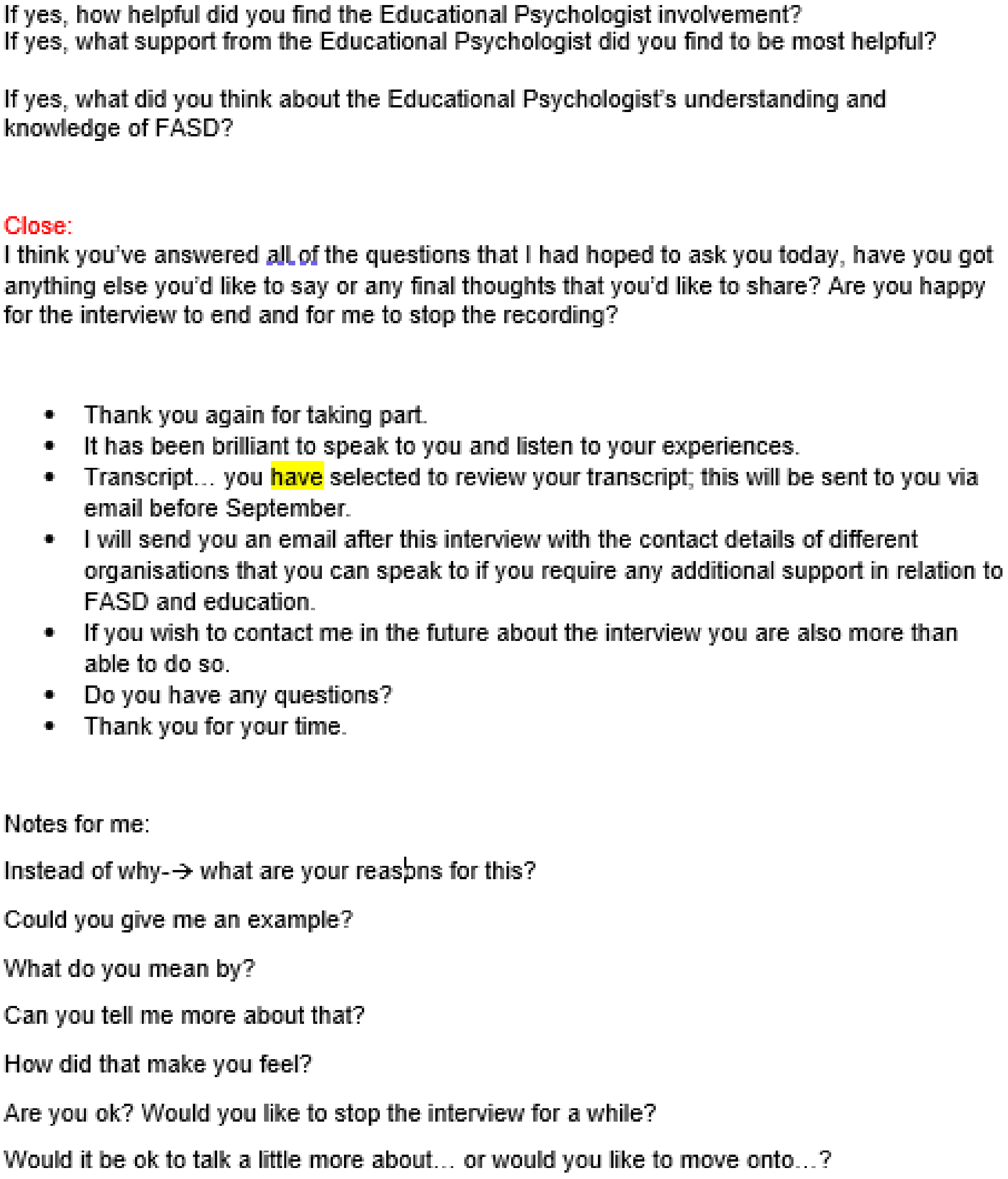
What do you think about your child's current (and/or a previous school such as pre-school, primary school, or different secondary school if applicable and known) school's understanding and knowledge of FASD?

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.

Notes for me:

Instead of why-→ what are your reasons for this?

Could you give me an example?

What do you mean by?

Can you tell me more about that?

How did that make you feel?

Are you ok? Would you like to stop the interview for a while?

Would it be ok to talk a little more about… or would you like to move onto…?

Appendix F

Sample of Transcripts

Key:

Interviewer= I

Participant= P

27.7.21 Interview

I: So, if you could just start them by telling me a little bit about your family.

P: OK so my husband and I, we adopted X age 15 months, he was 15 months old via '---' Council. He's now 16, today funnily enough. Very weird. And then four years later, we adopted Y, who was eleven months old. They're not birth related at all, but she was also a '—' child. Yeah, and so Y is now 12. So that's the four of us. Is that enough detail?

I: Yeah, yeah. So, can I just ask then is it X or Y who has a diagnosis of FASD?

P: X.

I: X, OK, so obviously it's really important to hear about your family in general, but for the rest of the interview, I'm going to talk more about X then if that's OK.

P: Yeah.

I: OK, perfect so you said you adopted him at 15 months and he's obviously now 16. Which yeah, time flies, doesn't it? Before you adopted him at 15 months, how many, sort of, foster placements did he have or adoption placements prior to that?

P: So, he was in, when he was born, he was in hospital for two weeks because he swallowed some meconium, and so he needed to be resuscitated and so they were a little bit concerned about him for the first couple of weeks and then he went straight into the foster placement where he stayed until we met him. It was one placement, but it was a very busy house with a, uh, a sibling group of very traumatized children and lots of foster family, extended family in and out, quite a bit.

I: OK, so for quite a busy foster placement by the sounds of it, OK.

P: Yeah.

I: Just in terms of school then, actually I'll come back to that one, what age did X receive his diagnosis of FASD?

P: About 14, 15, within the last couple of years, I think it was 2018, so 13.

I: Ok, so a few years then, OK brilliant, and does he have any additional diagnosis alongside FASD?

P: Well, for many years, I mean our problem started when he was about four, so he was, sort of, thought to have developmental trauma and attachment disorder for all of those years that we had so many problems really.

I: OK, so is that something that is still kind of a concern? Or do you think now the diagnosis of FASD sort of covered that?

P: Yeah, I think that very much fits the bill with him. It is very much a, you know, pretty much a fit. Obviously, I think with his background it's hard to know, which is which, because you know we would, you know, I think his attachment is quite poor to us, but I don't know how much of that is the foetal alcohol 'cause relationships are hard aren't they?

Interviewer= I

Participant= P

8.6.21 Interview

I: Could we just start by you telling me a little bit about your family?

P: Yeah certainly, so I live with my husband, we've been married for too long… 26 years, we adopted X who has foetal alcohol spectrum disorder when he was 13 months old, umm, and then we went onto adopt a second child, Y, who now has a diagnosis of ASD and she was 11 months old. Y is now 12 and X is now 17.

I: Ok, brilliant, so you adopted two children and one of them has a diagnosis of FASD so for the purpose of today if we could focus on X, if that would be ok?

P: Ok.

I: You've sort of already answered how old he was when you adopted him so prior to adopting him at 13 months did he have any other placements? Foster or adoption placements?

P: Yeah, so he was with umm, he went into emergency foster care from birth, then I think he went into a mother and baby unit for a couple of weeks but that didn't work out and then he went to stay with his second adoptive placement and that's where we collected him from.

I: Ok, so was that an adoption placement or a foster placement that one where you…

P: Yeah foster

I: No that's just helpful to know. Ok brilliant, and that was at the age of 13 months, so just over a year old?

P: Yep

I: And at what age did he receive his diagnosis of FASD?

P: So, he was in Year 6, so he would've been about 10.

I: Yeah, ok so he's had it for about 7 years then?

P: Yeah.

I: Ok, and does he have any additional diagnoses alongside FASD?

P: No.

I: No? Ok so his profile fits within that diagnosis.

P: *nods*

I: Does X have an education health care plan? Or has he had one?

P: He did have an EHCP but that has now been closed, so his EHCP, he didn't actually get it until he was in year 11. We asked the school many times for an EHCP and they said he wouldn't qualify because he wasn't bad enough so my husband actually applied for an EHCP independently, umm, which we then managed to get for him in year 11, just before he left school, but obviously we wanted it for when he went to college, umm, he went to college with his EHCP, but then he was offered an apprenticeship, and you'll love this, his college said they wouldn't be able to meet his needs according to the EHCP so unless we stopped the EHCP he wouldn't be able to do his apprenticeship so that's why we closed it.

Participant laughs

I: *interviewer smiles* Ok, it sounds like we have a lot to discuss then, a lot of unpicking. So, one of my questions was going to be around where he is now, so am I right in thinking that he is doing his apprenticeship?

P: He's now currently doing his apprenticeship and doing very well.

I: Oh brilliant, and what is he doing his apprenticeship in?

P: Personal trainer

I: Oh fantastic...

P: We ought to just put in there that if we had waited, because of Coronavirus, we have to put Coronavirus in the mix here as well, his apprenticeship had been delayed, delayed, delayed and we were given the option that we could go through several months of getting the EHCP re-written, bearing in mind the massive backlog of re-writes and all the other stuff that was going on because of COVID, so we could either have waited and got his EHCP re-written and then the new college would've considered whether or not he could've got on or we could've just gone the quicker route and say look we'll just close the EHCP. We chose the quicker option.

I: Ok, so in terms of what he wanted to do for the future, was his first-choice college or did he want to go onto the apprenticeship?

P: He wanted to go onto the apprenticeship. He was studying sport at '---' in '—' and doing brilliantly actually, umm, but again, something else that you might find of interest, X was put on a level 3 course and accepted onto a level 3 course because all of his grades were estimated, then they caught sight of his EHCP and said he couldn't do the level 3 and they put him down to the level 2 which meant he had to do an additional year. He was doing brilliantly on his course, absolutely fantastic, he was top of his class and helping to teach the other students, so he was clearly capable probably of doing the level 3 but then he got offered this apprenticeship, so it was just, it was an opportunity that just appeared, so he went for that.

I: Ok, so if we can unpick college a little bit first before we sort of go back and think about education more broadly, so in terms of college, am I right in thinking there was one college that he went to then?

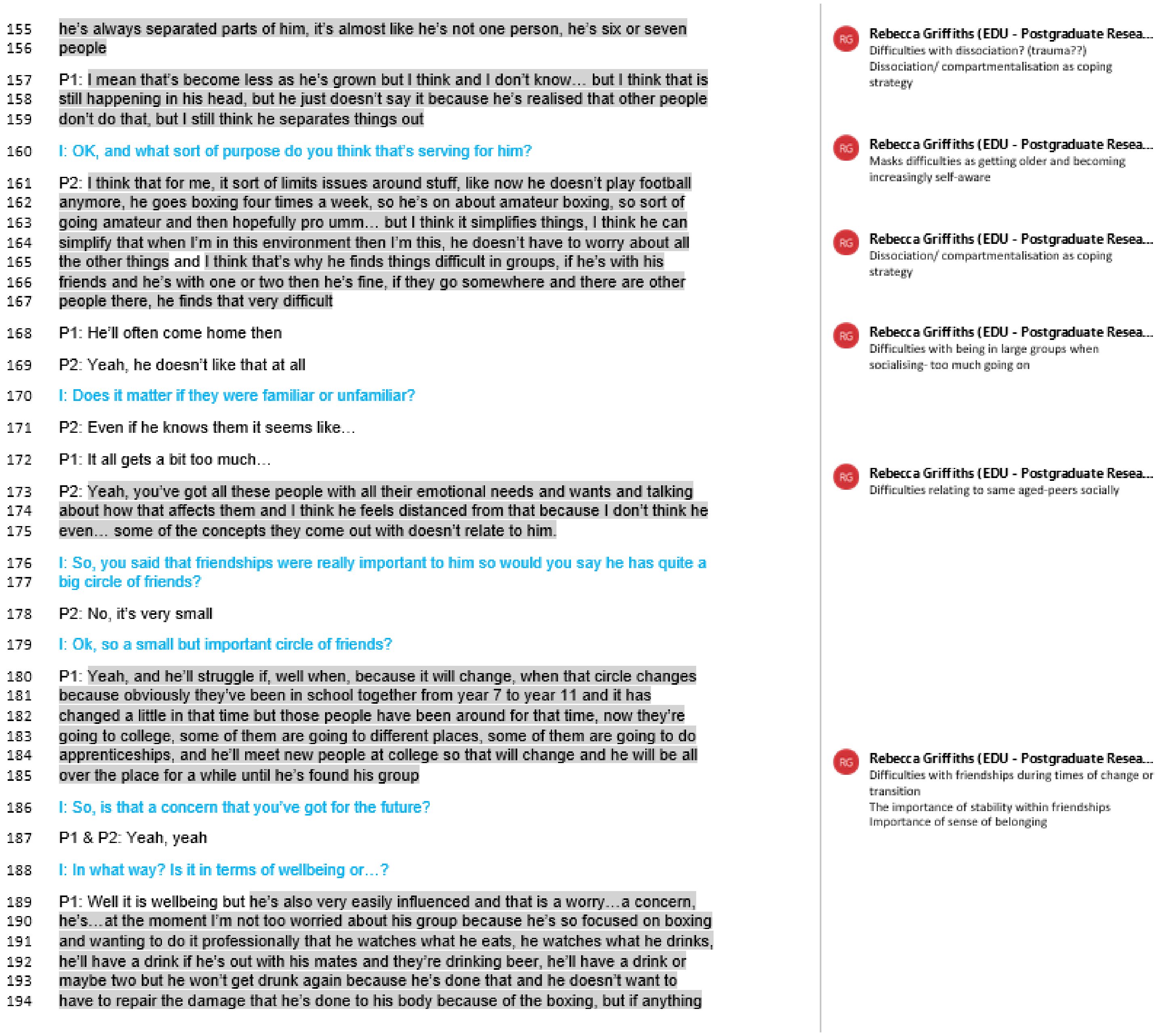
P: *participant nods*, he went to one and now he's at a different one doing his apprenticeship.

I: Ok fantastic, so if we look at the one that he is at, at the moment then, you said he's doing brilliantly, so what is working well for him at the moment?

P: So, where he is at the moment, umm, he doesn't actually go into college, all his learning is done either online or his tutor comes to the gym to do coursework with him there. That suits X, it's a really good way of learning, X finds the classroom environment tricky, because he finds it difficult to sit still, he finds it difficult to process loads of information, umm, so this way of learning suits him much better.

Appendix G

Sample of Data Familiarisation Notes



he's always separated parts of him, it's almost like he's not one person, he's six or seven people

P1: I mean that's become less as he's grown but I think and I don't know… but I think that is still happening in his head, but he just doesn't say it because he's realised that other people don't do that, but I still think he separates things out

I: OK, and what sort of purpose do you think that's serving for him?

P2: I think that for me, it sort of limits issues around stuff, like now he doesn't play football anymore, he goes boxing four times a week, so he's on about amateur boxing, so sort of going amateur and then hopefully pro umm… but I think it simplifies things, I think he can simplify that when I'm in this environment then I'm this, he doesn't have to worry about all the other things and I think that's why he finds things difficult in groups, if he's with his friends and he's with one or two then he's fine, if they go somewhere and there are other people there, he finds that very difficult

P1: He'll often come home then

P2: Yeah, he doesn't like that at all

I: Does it matter if they were familiar or unfamiliar?

P2: Even if he knows them it seems like…

P1: It all gets a bit too much…

P2: Yeah, you've got all these people with all their emotional needs and wants and talking about how that affects them and I think he feels distanced from that because I don't think he even… some of the concepts they come out with doesn't relate to him.

I: So, you said that friendships were really important to him so would you say he has quite a big circle of friends?

P2: No, it's very small

I: Ok, so a small but important circle of friends?

P1: Yeah, and he'll struggle if, well when, because it will change, when that circle changes because obviously they've been in school together from year 7 to year 11 and it has changed a little in that time but those people have been around for that time, now they're going to college, some of them are going to different places, some of them are going to do apprenticeships, and he'll meet new people at college so that will change and he will be all over the place for a while until he's found his group

I: So, is that a concern that you've got for the future?

P1 & P2: Yeah, yeah

I: In what way? Is it in terms of wellbeing or…?

P1: Well it is wellbeing but he's also very easily influenced and that is a worry…a concern, he's…at the moment I'm not too worried about his group because he's so focused on boxing and wanting to do it professionally that he watches what he eats, he watches what he drinks, he'll have a drink if he's out with his mates and they're drinking beer, he'll have a drink or maybe two but he won't get drunk again because he's done that and he doesn't want to have to repair the damage that he's done to his body because of the boxing, but if anything

RG **Rebecca Griffiths (EDU - Postgraduate Resea...**
Difficulties with dissociation? (trauma??)
Dissociation/ compartmentalisation as coping strategy

RG **Rebecca Griffiths (EDU - Postgraduate Resea...**
Masks difficulties as getting older and becoming increasingly self-aware

RG **Rebecca Griffiths (EDU - Postgraduate Resea...**
Dissociation/ compartmentalisation as coping strategy

RG **Rebecca Griffiths (EDU - Postgraduate Resea...**
Difficulties with being in large groups when socialising- too much going on

RG **Rebecca Griffiths (EDU - Postgraduate Resea...**
Difficulties relating to same aged-peers socially

RG **Rebecca Griffiths (EDU - Postgraduate Resea...**
Difficulties with friendships during times of change or transition
The importance of stability within friendships
Importance of sense of belonging

happens to boxing so that's not there to anchor him, until he's found another anchor, he'll be drifting and that'll be a concern…major concern

I: Ok, so it sounds as though having that motivator is a big driver for him and that affects everything around his life?

P1: yeah

I: Ok, so if we think then, still focusing on things that are going really well so you've talked about this past year being quite difficult, if we think about secondary school more generally, what's gone well in secondary school for him?

P1: *sighs*, umm, I don't…. it's very very very difficult to say because he, he's struggled every time someone has changed so if a tutor has changed…he's found that very difficult, I think this is going to sound like we're repeating ourselves but I think the most stable has been the PE because he's been in the same group from when they first put them in groups and the teachers have all…there's a group of teachers and they've all remained the same so I think that's been pretty stable for him…some of the other subjects he's hated and then he's got a good teacher who's got him and understood him and then he's been fine, and then he'll go through another year and the same subject and he'll be oh the teacher hates me, I can't do that

P2: I think probably over the last year or so he's definitely got a huge complex that basically, a lot of the time his opinion is that a lot of the teachers hate me, and I think he genuinely believes that most of the time, so when you're saying what went positive this year, I would probably say very little in real terms simply because I don't think he relates to it… *inaudible*

I: Sorry you're cutting out again, sorry!

P2: If like, for example, if teachers, as they do, say you look like you're not paying very much attention, do you not want to be doing this? he will just say no, he won't even think about consequences, he will just say no, so he ends up spending, or he has ended up spending, the last year or so, two years maybe, a lot of time in isolation and some of it will be because of that, and some of it will be because if he's finding something difficult…I think an easy cop out is well if I don't really understand it and I'm going to look stupid well what I'll do is I'll act like a bit of an idiot and then they'll send me out anyway because I'm bored of this anyway, I don't understand this and they're not explaining it and I don't think… his way of communicating can be quite confrontational…

P1: The logic is really odd as well because he'll get into trouble…the way they worked the discipline at his school was that if he'd done something wrong or forgotten to do homework or it hadn't been handed in, then he would get a 15 minute detention at lunchtime so he should go along to that, but if he'd handed in his homework, because he'd forgotten but then he'd handed it in, then in his mind he didn't need to do the detention because he'd handed it in now so he'd done it, but in the teacher's mind he hadn't done it on time so he needed to do the detention, so he didn't go and then it got doubled so it was half an hour, X is still not going to the detention because he's done the work so they double it again so it gets to an hour, but when it's at half an hour it's in the lunchbreak so he's got half an hour detention and he's got to get his lunch…working out which to do and when to go and all of that sort of thing, well he can't, so he'd rather it be an hour because then he doesn't have to worry about getting lunch because he'll go to detention and he won't have lunch, then if he doesn't go to the hour then they put him in isolation for the day and then he can go and get lunch when he wants with everyone else, so his logic dictates that he doesn't do stuff that they expect, and you can talk to them endlessly about him not understanding the concept and they don't

Rebecca Griffiths (EDU - Postgraduate Resea…
Concerns for the future- vulnerable to being influenced
Extra-curricular interests support to act as a focus

Rebecca Griffiths (EDU - Postgraduate Resea…
Negative school experience:
Secondary school- change of teachers each year

Rebecca Griffiths (EDU - Postgraduate Resea…
Positive school experience:
Stability of teachers- PE

Rebecca Griffiths (EDU - Postgraduate Resea…
Significance of teacher-student relationship on engagement
Importance of feeling understood by teachers

Rebecca Griffiths (EDU - Postgraduate Resea…
YP's perceptions of teachers' opinion/ narrative of them as being negative

Secondary school overwhelmingly negative

Rebecca Griffiths (EDU - Postgraduate Resea…
Literal thinking/ verbalisations result in consequences

Isolation/ use of universal behaviour policies

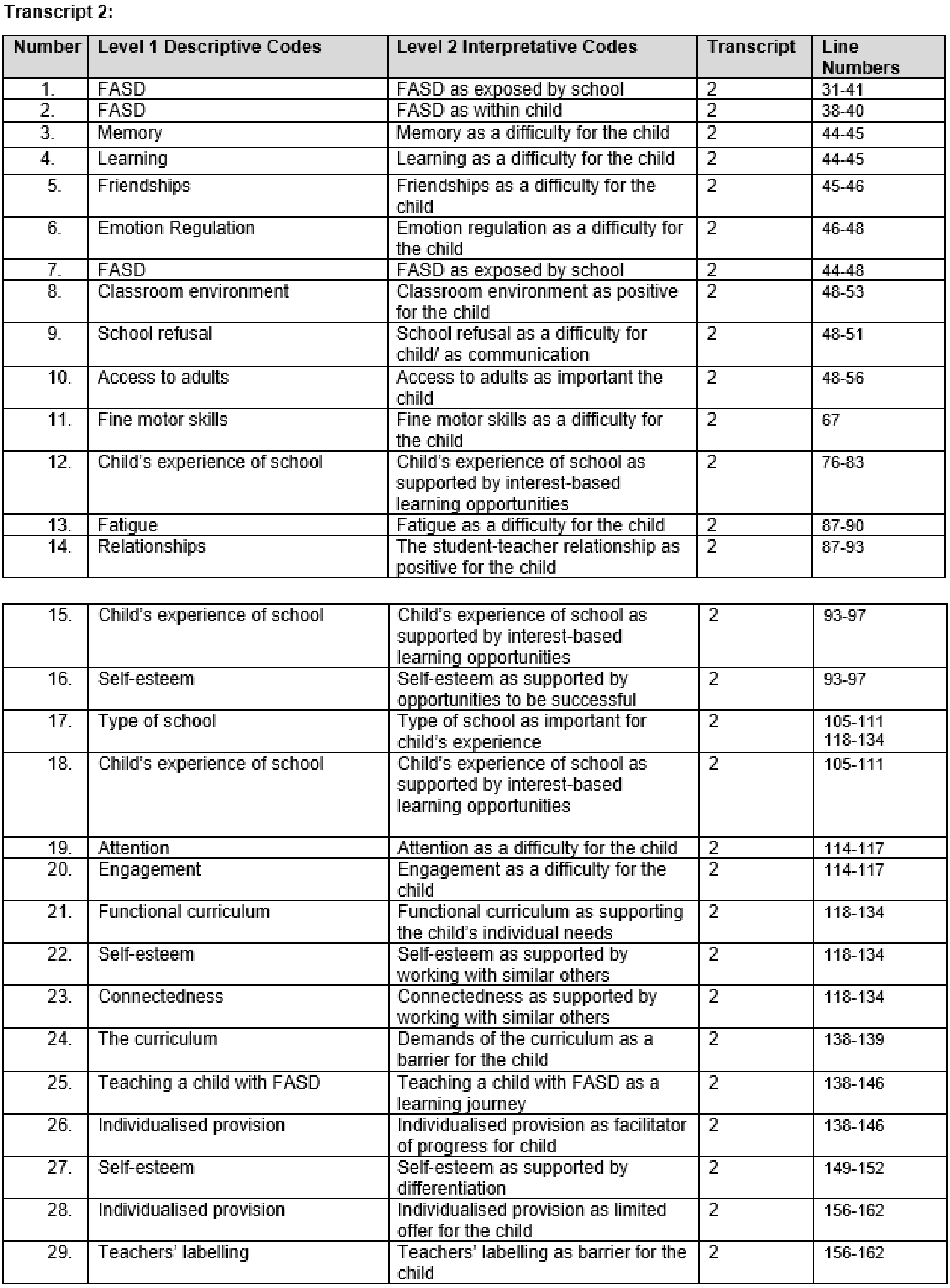
Avoidance of shame or looking different
Behaviour as avoidance of things that are difficult
Behaviour as communication

Rebecca Griffiths (EDU - Postgraduate Resea…
Use of universal behaviour policies do not work
Lack of understanding of child's needs/ thinking- difference between can't and won't
Pupil seeking greater time in isolation as easier to manage
Difficulties understanding the consequences of behaviour

	Familiarisation notes	Transcript
1	Belief that keeping child in one school is lucky	9
2	Difficulties getting EHCP	9
3	Difficulties getting EHCP	9
4	Differences in understanding of need across home and school as a barrier to getting EHCP	9
5	Profile/ presentation of FASD effects the likelihood of obtaining an EHCP- no behavioural problems means it's less likely	9
6	Differences in understanding of need across home and school as a barrier to getting EHCP	9
7	Difficulties with emotional regulation at home	9
8	Continuing to pursue EHCP to support post-16	9
9	Parents need to fight	9
10	Masking/ holding difficulties together in school environment	9
11	Implications of difficulties at school displayed at home	9
12	Complexity of background	9
13	Seeking extracurricular activities outside of school to support need	9
14	Lower-average academic performance	9
15	Differences in presentation across home and school	9
16	Difficulties with life skills: - Money management	9
17	Difficulties with social skills	9
18	Difficulties with fine motor skills	9
19	Difficulties with cognition and learning: Short term memory	9
20	Difficulties with visual-spatial processing	9
21	Difficulties with visual-spatial processing	9
22	Requires verbal support to alleviate difficulties with visual-spatial processing	9
23	Enjoys PE in school	9
24	Enjoys seeing friends	9
25	Impact of lockdown: boundaries between school and home and the need to complete school work at home (rigid thinking around the environment)	9
26	Rigid thinking	9
27	Difficulties with dissociation? (trauma??)	9
28	Dissociation/ compartmentalisation as coping strategy	9
29	Masks difficulties as getting older and becoming increasingly self-aware	9
30	Dissociation/ compartmentalisation as coping strategy	9
31	Difficulties with being in large groups when socialising- too much going on	9
32	Difficulties relating to same aged peers socially	9
33	Difficulties with friendships during times of change or transition	9
34	The importance of stability within friendships	9
35	Importance of sense of belonging	9
36	Concerns for the future- vulnerable to being influenced	9
37	Extra-curricular interests support to act as a focus	9
38	Negative school experience: - Secondary school- change of teachers each year	9
39	Positive school experience: - Stability of teachers- PE	9
40	Significance of teacher-student relationship on engagement	9
41	Importance of feeling understood by teachers	9
42	YP's perceptions of teachers' opinion/ narrative of them as being negative	9
43	Secondary school overwhelmingly negative	9
44	Literal thinking/ verbalisations result in consequences	9
45	Isolation/ use of universal behaviour policies	9
46	Avoidance of shame or looking different	9
47	Behaviour as avoidance of things that are difficult	9
48	Behaviour as communication	9
49	Use of universal behaviour policies do not work	9
50	Lack of understanding of child's needs/ thinking- difference between can't and won't	9
51	Pupil seeking greater time in isolation as easier to manage	9
52	Difficulties understanding the consequences of behaviour	9
53	Positive school experience: Teachers listen to parents	9
54	Maturing has supported social skills with teachers	9
55	Difficulties understanding the pragmatics of socialisation- ie literal thinking	9
56	Parents need to educate the educators	9
57	Negative school experience: - Punished for school's lack of understanding of need - Difficulties with communication between pupil and teacher - Breakdown in communication between pupil and teacher resulted in breakdown in relationship	9

Appendix H

Sample of Coding Process



Transcript 2:

Number	Level 1 Descriptive Codes	Level 2 Interpretative Codes	Transcript	Line Numbers
1.	FASD	FASD as exposed by school	2	31-41
2.	FASD	FASD as within child	2	38-40
3.	Memory	Memory as a difficulty for the child	2	44-45
4.	Learning	Learning as a difficulty for the child	2	44-45
5.	Friendships	Friendships as a difficulty for the child	2	45-46
6.	Emotion Regulation	Emotion regulation as a difficulty for the child	2	46-48
7.	FASD	FASD as exposed by school	2	44-48
8.	Classroom environment	Classroom environment as positive for the child	2	48-53
9.	School refusal	School refusal as a difficulty for child/ as communication	2	48-51
10.	Access to adults	Access to adults as important the child	2	48-56
11.	Fine motor skills	Fine motor skills as a difficulty for the child	2	67
12.	Child's experience of school	Child's experience of school as supported by interest-based learning opportunities	2	76-83
13.	Fatigue	Fatigue as a difficulty for the child	2	87-90
14.	Relationships	The student-teacher relationship as positive for the child	2	87-93
15.	Child's experience of school	Child's experience of school as supported by interest-based learning opportunities	2	93-97
16.	Self-esteem	Self-esteem as supported by opportunities to be successful	2	93-97
17.	Type of school	Type of school as important for child's experience	2	105-111 118-134
18.	Child's experience of school	Child's experience of school as supported by interest-based learning opportunities	2	105-111
19.	Attention	Attention as a difficulty for the child	2	114-117
20.	Engagement	Engagement as a difficulty for the child	2	114-117
21.	Functional curriculum	Functional curriculum as supporting the child's individual needs	2	118-134
22.	Self-esteem	Self-esteem as supported by working with similar others	2	118-134
23.	Connectedness	Connectedness as supported by working with similar others	2	118-134
24.	The curriculum	Demands of the curriculum as a barrier for the child	2	138-139
25.	Teaching a child with FASD	Teaching a child with FASD as a learning journey	2	138-146
26.	Individualised provision	Individualised provision as facilitator of progress for child	2	138-146
27.	Self-esteem	Self-esteem as supported by differentiation	2	149-152
28.	Individualised provision	Individualised provision as limited offer for the child	2	156-162
29.	Teachers' labelling	Teachers' labelling as barrier for the child	2	156-162

Appendix I

Sample of Codes and Related Extracts

EHCP as difficult to obtain	7 8 9	We asked the school many times for an EHCP and they said he wouldn't qualify because he wasn't bad enough so my husband actually applied for an EHCP independently, umm, which we then managed to get for him in year 11 32-36 school were reluctant to do an EHCP at this time. I had to really push for that, in fact I did that all myself. 135-136 The EHCP was turned down initially, so I did get on my high horse about that, and threatened tribunals and we did get it overturned quite quickly because at the time she was out of school, she wasn't even in school and when it got finalised umm or even when they were doing it they said she's making broadly average progress and I said well how do you work that out, she hasn't been to school for ten months, she hasn't seen a teacher. So yeah, that was turned around but 204-210 it's something we've tried to get but we haven't succeeded 57 I think it's basically because he functions at a level at which school thinks that's not an issue…in their opinion 62-63 Yeah, I mean when we first looked at it…he was at primary school and because he doesn't have, or didn't have, any behavioural problems at school, they were looking at his education purely and he was attending school and his levels were adequate so they wouldn't look at any additional help because he didn't need it, he was struggling at home with his emotional regulation, as he's got older he's been more able to deal with that but we're hoping that when he goes to college…we've forwarded loads and loads of stuff to college, that we'll be able to get some sort of EHCP sorted for him then to help with post-16, you know when he leaves college to get some sort of additional help and support then 65-72 I really don't know what school could've done, other than maybe earlier at primary school, when we first enquired about it, put in place an EHCP 319-320

Classroom environment as important for child's experience of school	1 2 3 6 7 9	I: Is there, can you think of times, I know you've talked about nursery and primary school being quite positive, are there particular moments where you think, oh, that was a really brilliant year, or month, or time, or? P: Only really his time in Thrive really, that, I mean… I: What did that look like? Can you just tell me a little bit more about that then? P: So, it, so it was, I mean I, it's a small classroom with children who identified with sort of emotional and learning issues or difficulties. It's got a high ratio of teachers who've been, who've done the course, the Thrive course, I don't really know much about it. I: They become a Thrive practitioner, I think. P: Yeah yeah, it's all around, sort of, self-esteem, building and, sort of, responding differently to yeah. So, I think when X was in mainstream classes, I think the teachers really struggled, and he really struggled so he was put into the Thrive 374-385 the school he's at now has got quite small classes but he was at a different school previously which, umm, he had total school refusal. He wouldn't go, he'd run out of the playground and that was much bigger classes. So, it worked that he worked well in smaller classes 48-51 I moved him from there to his new school now. It only has, sort of, 118 children in the whole school. From reception up to year six, so there's only sort of 15 to 18 in a class and he has thrived and he has improved and he's doing great. He's doing much better, you know. 174-177 yeah, there were smaller classes where she got more attention so there was more opportunity to build on her interests rather than somebody else's. 100-101 they had the THRIVE programme and she attended that but then she'd go in the THRIVE room but she wouldn't come out. She wanted to be in there because it was nice and quiet and there were lots of sensory things to do and you know she felt comfortable in there, she didn't want to be back in the classroom with all the other children. 177-181

Appendix J

Final Codes

Early life experiences as complex

Diagnosis as difficult to obtain

Education professionals’ knowledge of FASD as supportive for child

Education professionals’ assumptions as barrier for child

Other professionals’ role as providing intervention

Other professionals’ role as supporting understanding in school

EP involvement as validating for parents

Learning as a difficulty for child

The student-SENCO relationship as important for child

Emotional literacy as a difficulty for child

Emotional regulation as a difficulty for child

Demands of the curriculum as an increasing difficulty for child

Education professionals’ labelling as difficult for child’s view of self

Education professionals’ knowledge of FASD as barrier for child

Parents’ role as educators of the educators

Memory as a difficulty for child

Parents’ role as advocating for increased knowledge of FASD amongst education professionals

Parents’ role as advocating for additional support in school

EHCP as difficult to obtain

Parents’ role as advocating for accountability

Parent-SENCO relationships as positive for the parents’ experience

Education professionals’ knowledge of student as supportive for child

Communication and interaction as a difficulty for the child

Parents’ role as their child’s external brain

Executive functioning as a difficulty for the child

Shame as a trigger for the child

Parent-teacher relationships as positive for parents

Parenting a child with FASD as a learning journey

Masking as a difficulty for child

Early intervention as supportive for child

The student-key adult relationship as supportive for child

Classroom environment as important for child’s experience of school

Access to adults as important for child

Isolation environment as meeting the needs of the child

COVID-19 School Closures as facilitating a positive learning experience for child

Adolescence as exasperator of difficulties in school for child

Non-relational approach by EPs as barrier for child’s engagement

Relational approach by EPs as facilitating positive involvement with child

EP role as powerful expert in school

EP role as a powerful expert who didn’t work with parents

EPs’ knowledge of FASD as future consideration

Relational approach by EPs as future consideration

EPs’ listening to parents as future consideration

EPs’ supporting understanding/knowledge of FASD in schools as future consideration (educating the educators)

Education professionals’ perceptions and attributions of behaviour as inaccurate

FASD as exposed by school

FASD as within child

Friendships as a difficulty for the child

School refusal as communication

Fine motor skills as a difficulty for the child

Child’s experience of school as supported by interest-based learning opportunities

Fatigue as a difficulty for the child

The student-teacher relationship as important for the child

Self-esteem as supported by opportunities to be successful

Type of educating setting as important for child’s experience

Attention as a difficulty for the child

Engagement as a difficulty for the child

Functional curriculum as supporting the child’s experience of school

Self-esteem as supported by working with similar others

Connectedness as supported by working with similar others

Teaching a child with FASD as a learning journey

Powerlessness as a difficulty for parents

Education professionals’ receptiveness as a barrier to implementation of individualised provision

Parents not being heard in school as a frustration

Behaviour as communication

Behaviour management as successful for child when adopting a nurturing approach

COVID-19 School Closures as difficult for the child

Individualised provision (how and where) as supportive for the child’s experience of school

COVID-19 School Closures as difficult for parents

Parents being heard in school as future consideration (equity of power)

Parents’ role as requiring specialist knowledge

Parenting a child with FASD as having no clear support pathways

Home-school communication as a difficulty for parents

Selecting an education setting as a parental responsibility

Home-school collaboration as facilitating positive outcomes for child

Home-school collaboration as empowering parents

Home-school collaboration as facilitating an equitable learning journey

Parents supporting educators as a role upheld voluntarily

Diagnosis as helpful

Diagnosis as helpful in supporting understanding of need

Diagnosis as falling short

Parents' role as seeking solutions outside of school

Extra-curricular activities (interest based) as supportive for child

Connectedness as supported by psychoeducation amongst peers

Type of education setting as providing different experiences of learning

Learning format (how) as important for child

Education professionals’ knowledge of FASD as future consideration

Social interactions as a difficulty for the child

Behaviour management as unhelpful when adopting a universally punitive approach

School practice/ behaviour management as non-inclusive

Education professional as external brain

Vulnerability within peer relationships as a difficulty for child

Education professionals’ knowledge of FASD as limited

Education professionals’ knowledge of adoption as limited

FASD as primary need

EP involvement as time sensitive

EP involvement as a helpful gatekeeper

Self-esteem as a difficulty for the child

Anxiety as a difficulty for the child

EPs’ knowledge of FASD as limited

Bullying as a difficulty for the child

Parenting a child with FASD as blame laden

Teachers’ receptiveness as supportive for child

Sensory sensitivities as a difficulty for the child

FASD as multifaceted

Masking as barrier to recognition of needs

FASD as evolving with age

Physical safety as a concern in school

Engagement as facilitated by interest-based learning opportunities

Child’s experience of school as negative

COVID-19 School Closures as barrier to home-school communication

Home-school communication as supportive

SENCO role as powerless

EP involvement as difficult to access

Parents’ role as experts of their child

Misidentification as a risk

Impact of adoption as compounding needs and difficulties for child

Hyperactivity as a difficulty for the child

School environment (where) as important for child

School environment as difficult for child

Local authority as powerful decision makers for parents to advocate against

Teachers’ previous experience as positive for child

Relational approach (how) as important for child’s experience

Teachers’ pedagogical approach (how) as important

Parents supporting educators as an assumed role

Parents’ role as empathisers of educators

Life skills as a difficulty for the child

Connectedness as a difficulty for child

EP involvement as supportive for education professionals’ understanding of child’s needs (educating the educators)

EP involvement as helpful in recommending strategies for education professionals (educating the educators)

EP involvement as falling short

EP involvement as unsupportive of implementation

Accountability in school as a concern for parents (trust)

EHCP as unhelpful

EP role in supporting schools with implementation as future consideration (educating the educators)

Attachment as a difficulty for the child

FASD as a spikey profile

Information sharing as a difficulty for parents (inaccurate, absent)

School responsibility as shifted onto parents

CYP with FASD as not fitting neatly into education settings (type of school)

Parents as powerless decision makers

Parents’ experience of the school system as unsupportive

Hierarchy of the school system as a barrier to individualised provision

Processing as a difficulty for the child

Connectedness as reduced by indiscretion (feeling different)

Working memory as a difficulty for child

Strategies (how) to educate CYP with FASD as future consideration (educating the educators)

Progress as supported by interest-based learning

SENCO role within the school system as information distributor

Peer relationships as important for child’s experience of school

Behaviour management as successful when individualised

Behaviour management as time sensitive

Individualised provision (how and where) as facilitating positive outcomes

Education professionals’ knowledge of SEND as future consideration

Education professionals’ knowledge of adoption as future consideration

Environment (where) to educate CYP with FASD as future consideration

Education professionals’ universal expectations as difficult for child

EPs’ role supporting interactions between the family and school system as future consideration

EPs’ role working with the family system as a future consideration

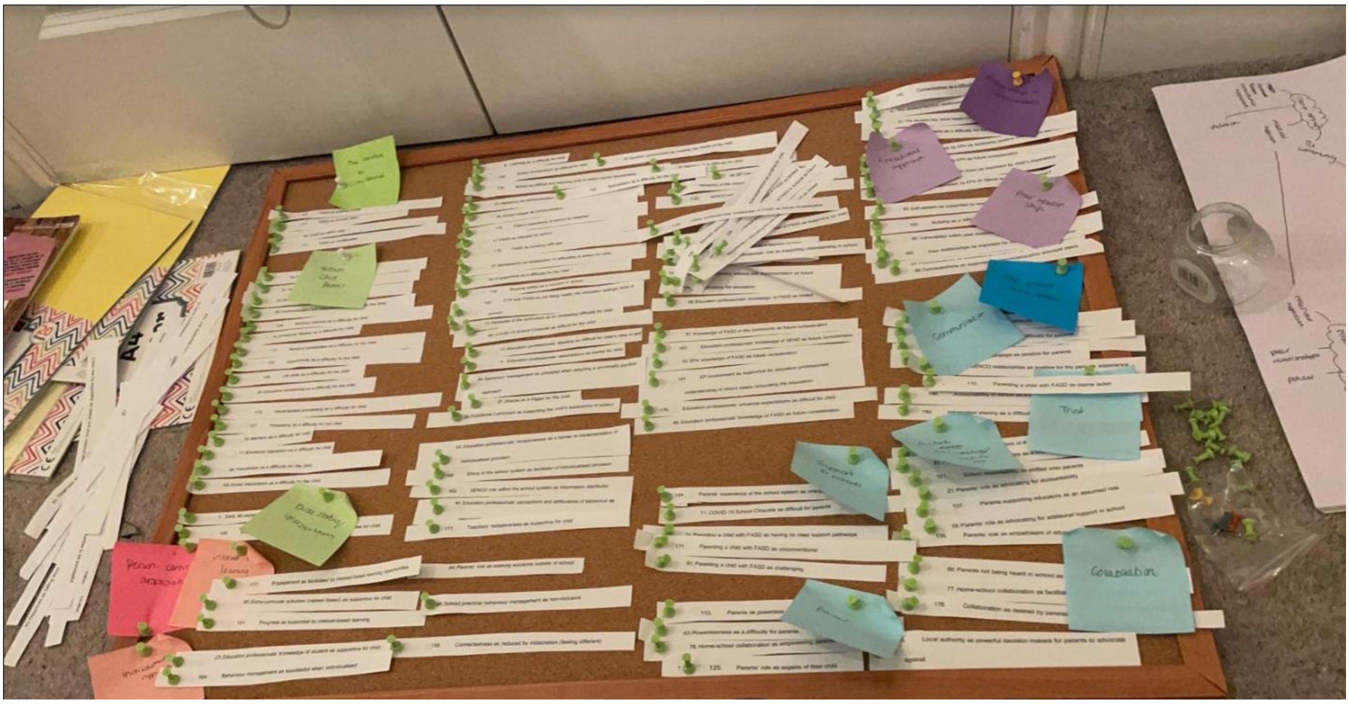
Visual-spatial processing as a difficulty for child

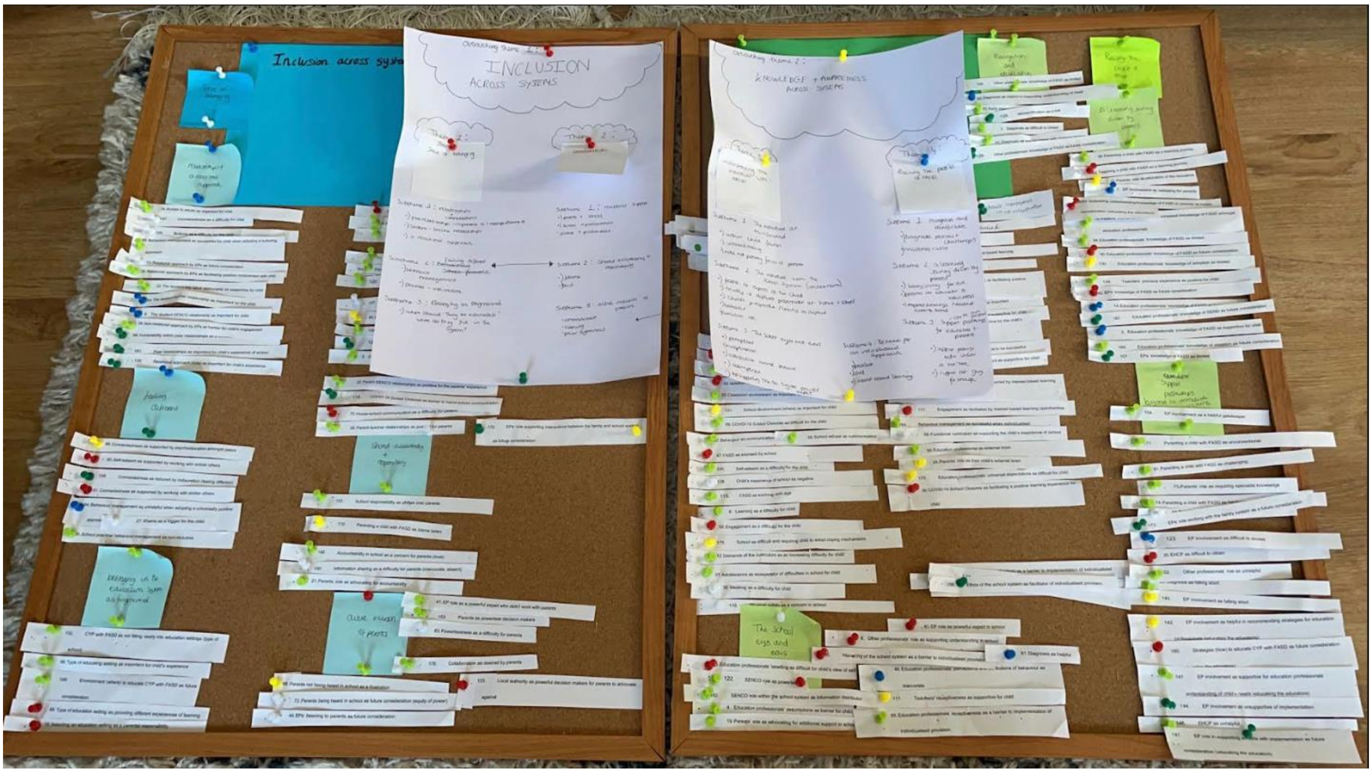
School as difficult and requiring child to adopt coping mechanisms

Collaboration as desired by parents

Appendix K

Developing Themes

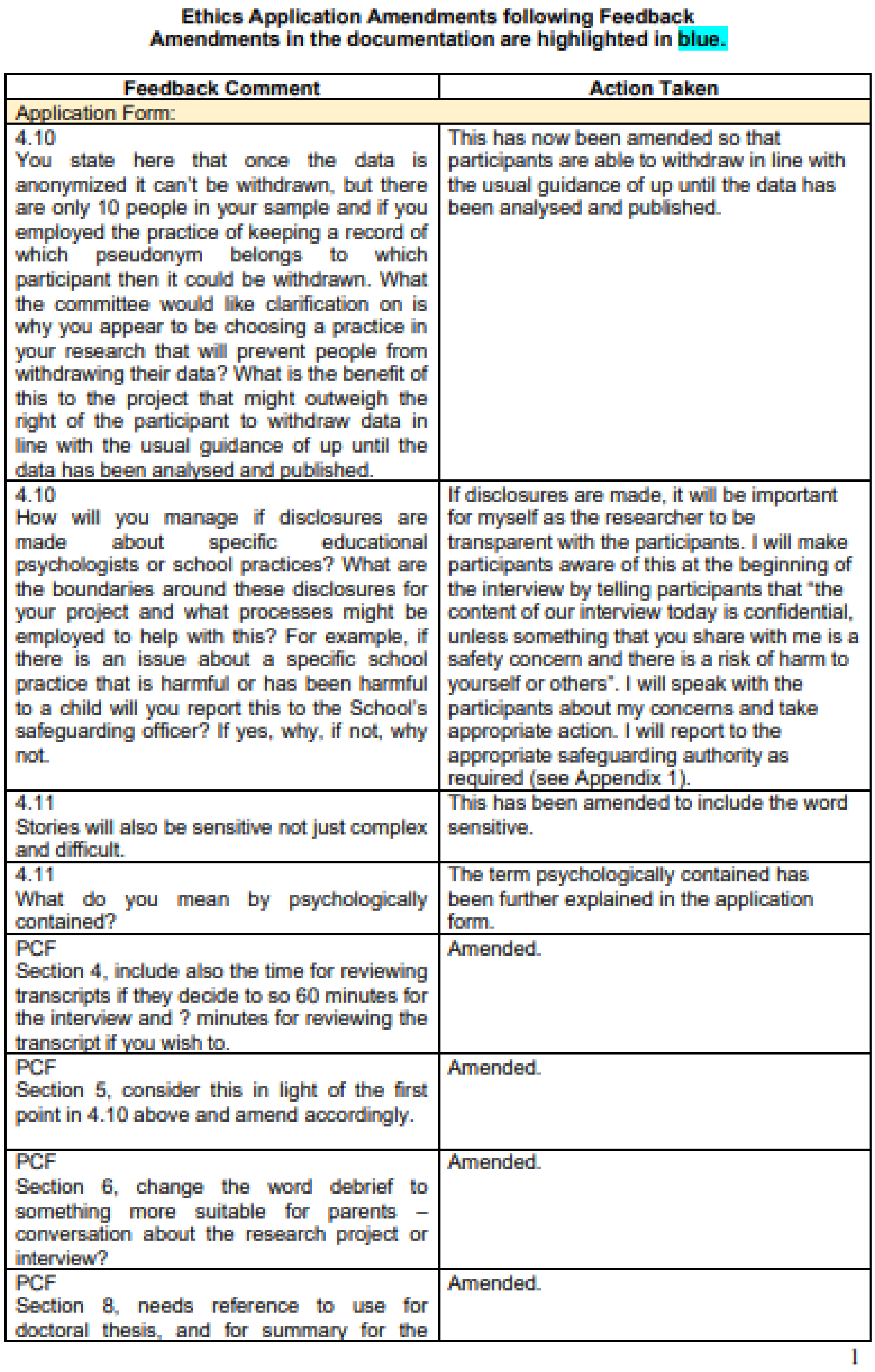




Theme 1: Understanding the individual with FASD in School	**Theme 2:** Sense of Belonging	**Theme 3:** Collaboration and Communication	**Theme 4:** Knowledge and awareness of FASD
Subtheme 1: The Individual as Multifaceted 174, 139, 130, 129, 101,1, 159, 57, 112, 93, 157, 106, 149, 113, 148, 8	**Subtheme 1:** Relationships and Acceptance 34, 140, 109, 32, 54, 9, 98, 163, 86, 96	**Subtheme 1:** Reciprocity 77, 71, 154, 120, 137, 80, 138, 22, 119, 75, 28, 172, 77, 78, 79	**Subtheme 1:** Educating the Educators 62, 141, 142, 144, 147, 160, 13, 122, 162, 4, 40, 6, 81, 46, 111, 65, 105, 82, 31, 128, 15, 108, 42, 45, 14, 7, 3, 99, 90, 100, 134, 167, 168
Subtheme 2: Behaviour as communication 114, 67, 50, 47, 105, 118, 115, 175, 30, 53, 12	**Subtheme 2**: Feeling Safer within a Relational Approach 68, 32, 135, 43, 39, 38	**Subtheme 2:** Shared Accountability and Responsibility 151, 110, 145, 150, 21	**Subtheme 2:** Parents as Knowledgeable disseminators 29, 15, 18, 90, 100, 107, 73, 82, 74
Subtheme 3: An Individualised Approach 165, 124, 103, 161, 89, 166, 136, 85, 70, 55, 23, 52, 117, 164, 59, 25, 170, 36, 94	**Subtheme 3:** Feeling Different and Experiencing Shame 60, 158, 61, 94, 27, 95	**Subtheme 3:** Active Inclusion of Parents 41, 153, 63, 176, 66, 72, 44, 133	**Subtheme 3:** Accessing Systemic Support 104, 20, 146, 74, 123, 83, 143, 19
	Subtheme 4: Fragmented belonging within the education system 152, 56, 169, 88, 76, 60, 173, 105, 132, 35, 33, 131, 69, 58, 37, 116		

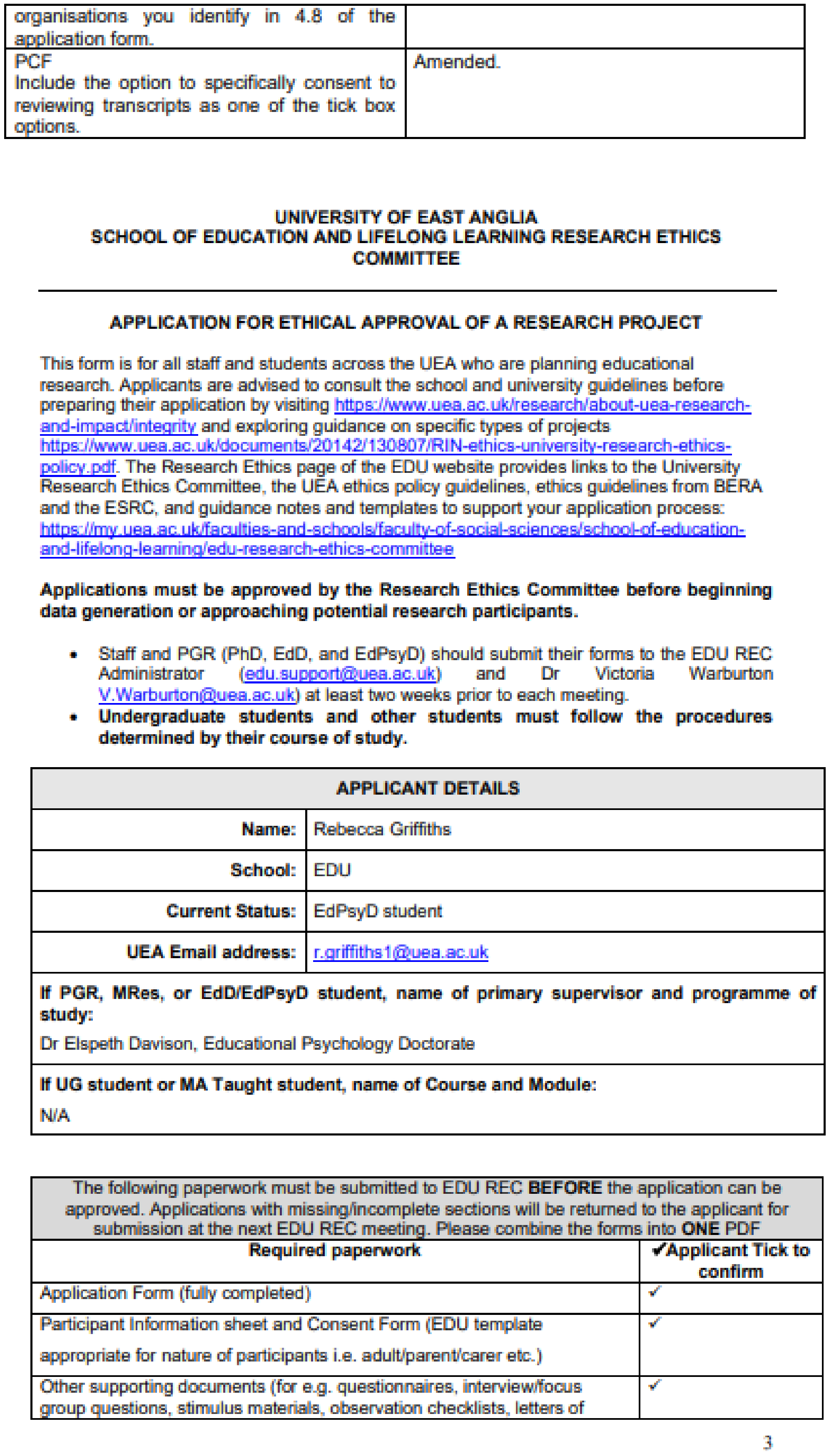
Appendix L

Ethics Application and Approval



Ethics Application Amendments following Feedback
Amendments in the documentation are highlighted in blue.

Feedback Comment	Action Taken
Application Form:	
4.10 You state here that once the data is anonymized it can't be withdrawn, but there are only 10 people in your sample and if you employed the practice of keeping a record of which pseudonym belongs to which participant then it could be withdrawn. What the committee would like clarification on is why you appear to be choosing a practice in your research that will prevent people from withdrawing their data? What is the benefit of this to the project that might outweigh the right of the participant to withdraw data in line with the usual guidance of up until the data has been analysed and published.	This has now been amended so that participants are able to withdraw in line with the usual guidance of up until the data has been analysed and published.
4.10 How will you manage if disclosures are made about specific educational psychologists or school practices? What are the boundaries around these disclosures for your project and what processes might be employed to help with this? For example, if there is an issue about a specific school practice that is harmful or has been harmful to a child will you report this to the School's safeguarding officer? If yes, why, if not, why not.	If disclosures are made, it will be important for myself as the researcher to be transparent with the participants. I will make participants aware of this at the beginning of the interview by telling participants that "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". I will speak with the participants about my concerns and take appropriate action. I will report to the appropriate safeguarding authority as required (see Appendix 1).
4.11 Stories will also be sensitive not just complex and difficult.	This has been amended to include the word sensitive.
4.11 What do you mean by psychologically contained?	The term psychologically contained has been further explained in the application form.
PCF Section 4, include also the time for reviewing transcripts if they decide to so 60 minutes for the interview and ? minutes for reviewing the transcript if you wish to.	Amended.
PCF Section 5, consider this in light of the first point in 4.10 above and amend accordingly.	Amended.
PCF Section 6, change the word debrief to something more suitable for parents – conversation about the research project or interview?	Amended.
PCF Section 8, needs reference to use for doctoral thesis, and for summary for the	Amended.



organisations you identify in 4.8 of the application form.	
PCF Include the option to specifically consent to reviewing transcripts as one of the tick box options.	Amended.

UNIVERSITY OF EAST ANGLIA
SCHOOL OF EDUCATION AND LIFELONG LEARNING RESEARCH ETHICS COMMITTEE

APPLICATION FOR ETHICAL APPROVAL OF A RESEARCH PROJECT

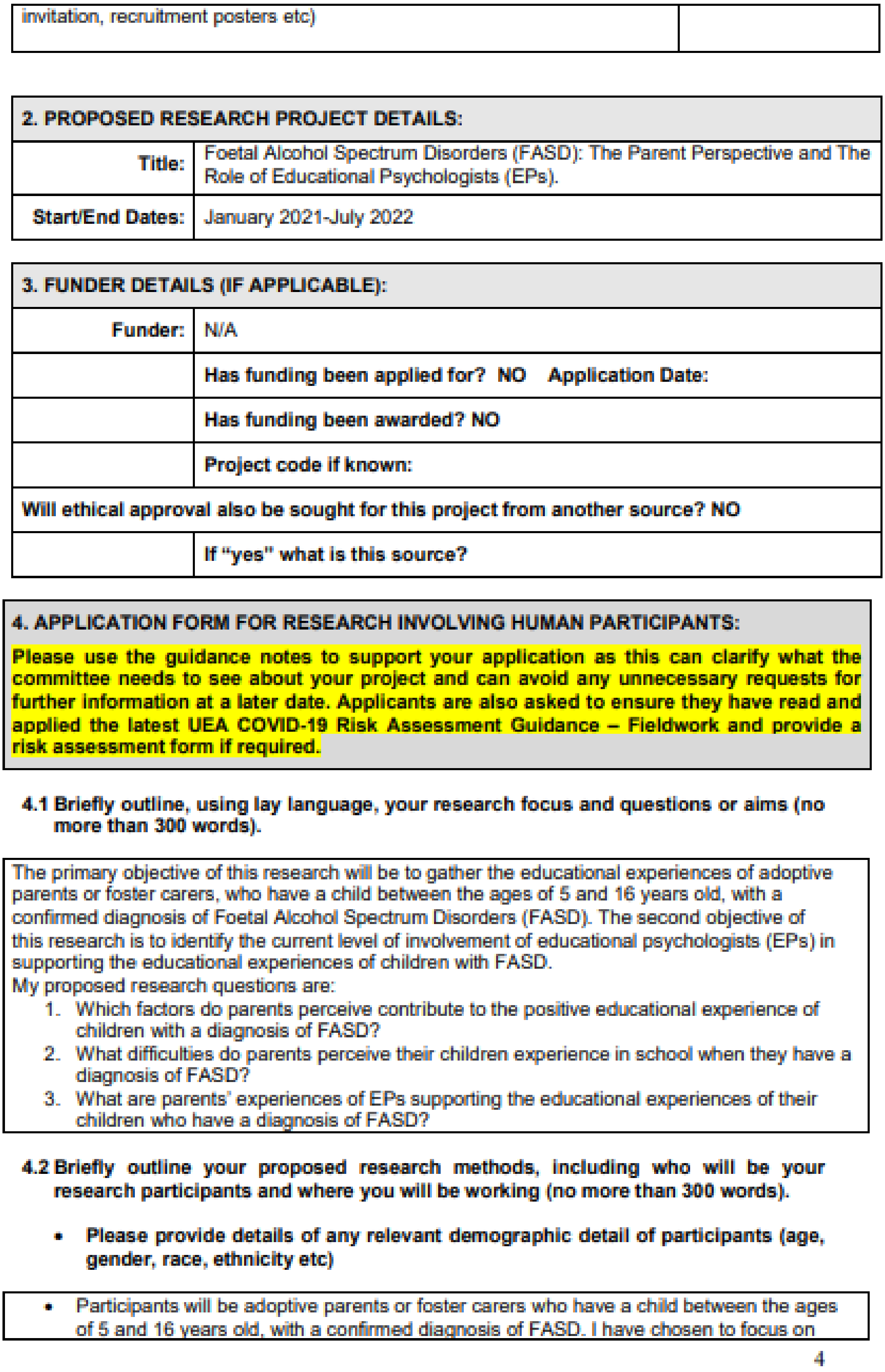
This form is for all staff and students across the UEA who are planning educational research. Applicants are advised to consult the school and university guidelines before preparing their application by visiting https://www.uea.ac.uk/research/about-uea-research-and-impact/integrity and exploring guidance on specific types of projects https://www.uea.ac.uk/documents/20142/130807/RIN-ethics-university-research-ethics-policy.pdf. The Research Ethics page of the EDU website provides links to the University Research Ethics Committee, the UEA ethics policy guidelines, ethics guidelines from BERA and the ESRC, and guidance notes and templates to support your application process: https://my.uea.ac.uk/faculties-and-schools/faculty-of-social-sciences/school-of-education-and-lifelong-learning/edu-research-ethics-committee

Applications must be approved by the Research Ethics Committee before beginning data generation or approaching potential research participants.

- Staff and PGR (PhD, EdD, and EdPsyD) should submit their forms to the EDU REC Administrator (edu.support@uea.ac.uk) and Dr Victoria Warburton V.Warburton@uea.ac.uk) at least two weeks prior to each meeting.
- **Undergraduate students and other students must follow the procedures determined by their course of study.**

APPLICANT DETAILS	
Name:	Rebecca Griffiths
School:	EDU
Current Status:	EdPsyD student
UEA Email address:	r.griffiths1@uea.ac.uk
If PGR, MRes, or EdD/EdPsyD student, name of primary supervisor and programme of study: Dr Elspeth Davison, Educational Psychology Doctorate	
If UG student or MA Taught student, name of Course and Module: N/A	

The following paperwork must be submitted to EDU REC **BEFORE** the application can be approved. Applications with missing/incomplete sections will be returned to the applicant for submission at the next EDU REC meeting. Please combine the forms into **ONE** PDF	
Required paperwork	**✓Applicant Tick to confirm**
Application Form (fully completed)	✓
Participant Information sheet and Consent Form (EDU template appropriate for nature of participants i.e. adult/parent/carer etc.)	✓
Other supporting documents (for e.g. questionnaires, interview/focus group questions, stimulus materials, observation checklists, letters of	✓



invitation, recruitment posters etc)	

2. PROPOSED RESEARCH PROJECT DETAILS:	
Title:	Foetal Alcohol Spectrum Disorders (FASD): The Parent Perspective and The Role of Educational Psychologists (EPs).
Start/End Dates:	January 2021-July 2022

3. FUNDER DETAILS (IF APPLICABLE):	
Funder:	N/A
	Has funding been applied for? NO Application Date:
	Has funding been awarded? NO
	Project code if known:
Will ethical approval also be sought for this project from another source? NO	
	If "yes" what is this source?

4. APPLICATION FORM FOR RESEARCH INVOLVING HUMAN PARTICIPANTS:

Please use the guidance notes to support your application as this can clarify what the committee needs to see about your project and can avoid any unnecessary requests for further information at a later date. Applicants are also asked to ensure they have read and applied the latest UEA COVID-19 Risk Assessment Guidance – Fieldwork and provide a risk assessment form if required.

4.1 Briefly outline, using lay language, your research focus and questions or aims (no more than 300 words).

The primary objective of this research will be to gather the educational experiences of adoptive parents or foster carers, who have a child between the ages of 5 and 16 years old, with a confirmed diagnosis of Foetal Alcohol Spectrum Disorders (FASD). The second objective of this research is to identify the current level of involvement of educational psychologists (EPs) in supporting the educational experiences of children with FASD.

My proposed research questions are:

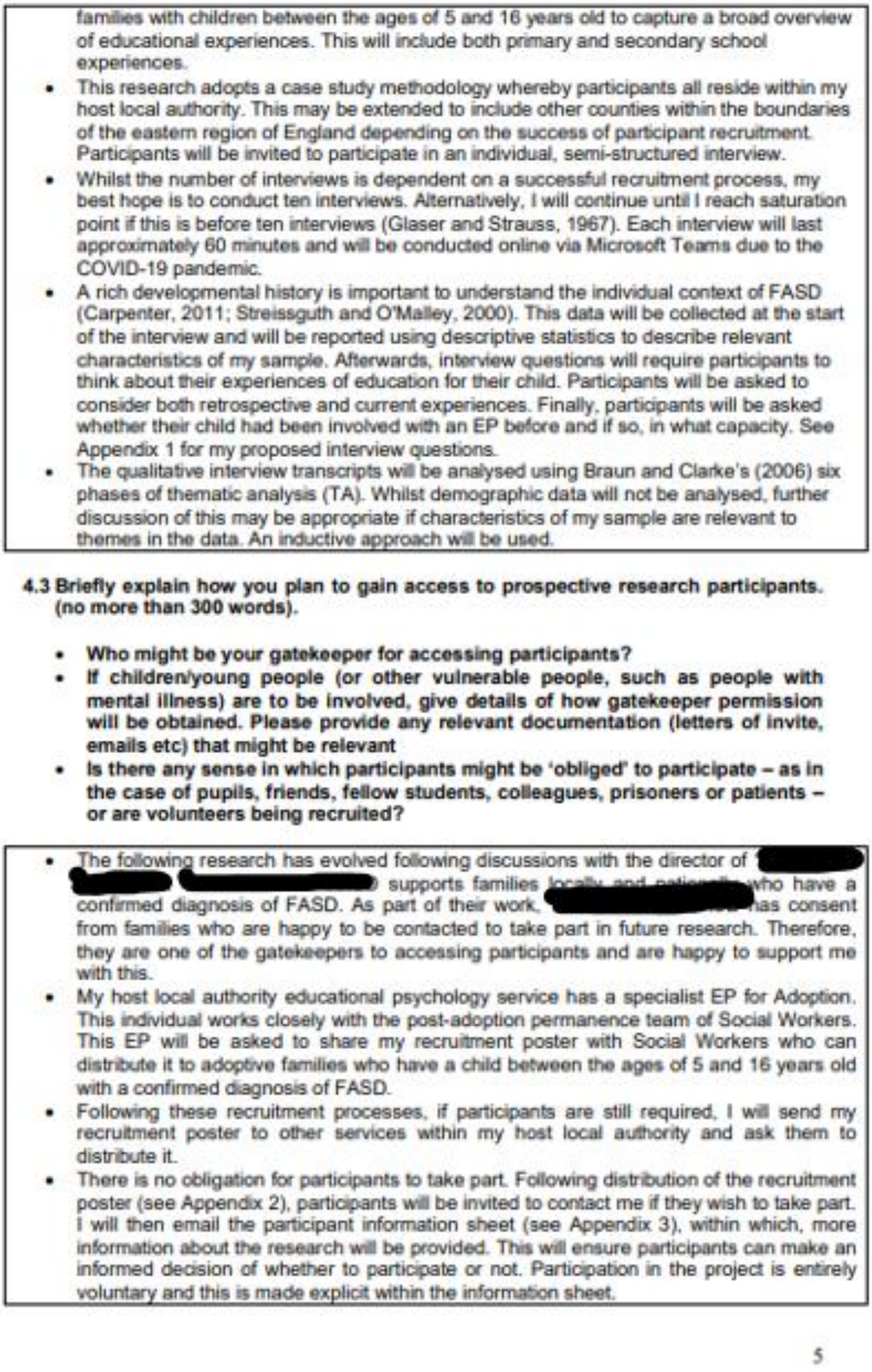
1. Which factors do parents perceive contribute to the positive educational experience of children with a diagnosis of FASD?
2. What difficulties do parents perceive their children experience in school when they have a diagnosis of FASD?
3. What are parents' experiences of EPs supporting the educational experiences of their children who have a diagnosis of FASD?

4.2 Briefly outline your proposed research methods, including who will be your research participants and where you will be working (no more than 300 words).

- **Please provide details of any relevant demographic detail of participants (age, gender, race, ethnicity etc)**

- Participants will be adoptive parents or foster carers who have a child between the ages of 5 and 16 years old, with a confirmed diagnosis of FASD. I have chosen to focus on

4



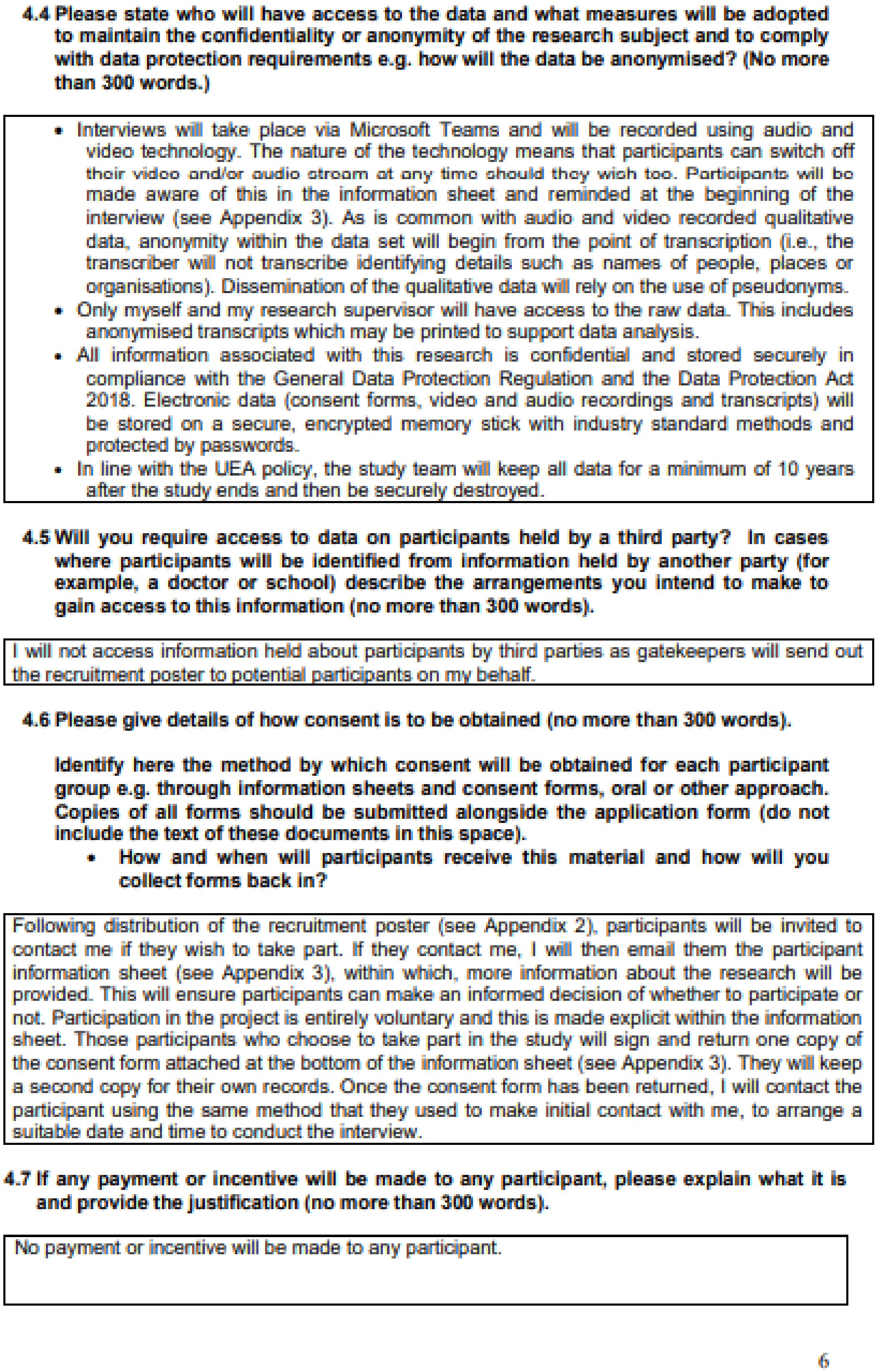
families with children between the ages of 5 and 16 years old to capture a broad overview of educational experiences. This will include both primary and secondary school experiences.

- This research adopts a case study methodology whereby participants all reside within my host local authority. This may be extended to include other counties within the boundaries of the eastern region of England depending on the success of participant recruitment. Participants will be invited to participate in an individual, semi-structured interview.
- Whilst the number of interviews is dependent on a successful recruitment process, my best hope is to conduct ten interviews. Alternatively, I will continue until I reach saturation point if this is before ten interviews (Glaser and Strauss, 1967). Each interview will last approximately 60 minutes and will be conducted online via Microsoft Teams due to the COVID-19 pandemic.
- A rich developmental history is important to understand the individual context of FASD (Carpenter, 2011; Streissguth and O'Malley, 2000). This data will be collected at the start of the interview and will be reported using descriptive statistics to describe relevant characteristics of my sample. Afterwards, interview questions will require participants to think about their experiences of education for their child. Participants will be asked to consider both retrospective and current experiences. Finally, participants will be asked whether their child had been involved with an EP before and if so, in what capacity. See Appendix 1 for my proposed interview questions.
- The qualitative interview transcripts will be analysed using Braun and Clarke's (2006) six phases of thematic analysis (TA). Whilst demographic data will not be analysed, further discussion of this may be appropriate if characteristics of my sample are relevant to themes in the data. An inductive approach will be used.

4.3 Briefly explain how you plan to gain access to prospective research participants. (no more than 300 words).

- **Who might be your gatekeeper for accessing participants?**
- **If children/young people (or other vulnerable people, such as people with mental illness) are to be involved, give details of how gatekeeper permission will be obtained. Please provide any relevant documentation (letters of invite, emails etc) that might be relevant**
- **Is there any sense in which participants might be 'obliged' to participate – as in the case of pupils, friends, fellow students, colleagues, prisoners or patients – or are volunteers being recruited?**

- The following research has evolved following discussions with the director of [redacted] supports families [redacted] who have a confirmed diagnosis of FASD. As part of their work, [redacted] has consent from families who are happy to be contacted to take part in future research. Therefore, they are one of the gatekeepers to accessing participants and are happy to support me with this.
- My host local authority educational psychology service has a specialist EP for Adoption. This individual works closely with the post-adoption permanence team of Social Workers. This EP will be asked to share my recruitment poster with Social Workers who can distribute it to adoptive families who have a child between the ages of 5 and 16 years old with a confirmed diagnosis of FASD.
- Following these recruitment processes, if participants are still required, I will send my recruitment poster to other services within my host local authority and ask them to distribute it.
- There is no obligation for participants to take part. Following distribution of the recruitment poster (see Appendix 2), participants will be invited to contact me if they wish to take part. I will then email the participant information sheet (see Appendix 3), within which, more information about the research will be provided. This will ensure participants can make an informed decision of whether to participate or not. Participation in the project is entirely voluntary and this is made explicit within the information sheet.



4.4 Please state who will have access to the data and what measures will be adopted to maintain the confidentiality or anonymity of the research subject and to comply with data protection requirements e.g. how will the data be anonymised? (No more than 300 words.)

- Interviews will take place via Microsoft Teams and will be recorded using audio and video technology. The nature of the technology means that participants can switch off their video and/or audio stream at any time should they wish too. Participants will be made aware of this in the information sheet and reminded at the beginning of the interview (see Appendix 3). As is common with audio and video recorded qualitative data, anonymity within the data set will begin from the point of transcription (i.e., the transcriber will not transcribe identifying details such as names of people, places or organisations). Dissemination of the qualitative data will rely on the use of pseudonyms.
- Only myself and my research supervisor will have access to the raw data. This includes anonymised transcripts which may be printed to support data analysis.
- All information associated with this research is confidential and stored securely in compliance with the General Data Protection Regulation and the Data Protection Act 2018. Electronic data (consent forms, video and audio recordings and transcripts) will be stored on a secure, encrypted memory stick with industry standard methods and protected by passwords.
- In line with the UEA policy, the study team will keep all data for a minimum of 10 years after the study ends and then be securely destroyed.

4.5 Will you require access to data on participants held by a third party? In cases where participants will be identified from information held by another party (for example, a doctor or school) describe the arrangements you intend to make to gain access to this information (no more than 300 words).

I will not access information held about participants by third parties as gatekeepers will send out the recruitment poster to potential participants on my behalf.

4.6 Please give details of how consent is to be obtained (no more than 300 words).

Identify here the method by which consent will be obtained for each participant group e.g. through information sheets and consent forms, oral or other approach. Copies of all forms should be submitted alongside the application form (do not include the text of these documents in this space).

- **How and when will participants receive this material and how will you collect forms back in?**

Following distribution of the recruitment poster (see Appendix 2), participants will be invited to contact me if they wish to take part. If they contact me, I will then email them the participant information sheet (see Appendix 3), within which, more information about the research will be provided. This will ensure participants can make an informed decision of whether to participate or not. Participation in the project is entirely voluntary and this is made explicit within the information sheet. Those participants who choose to take part in the study will sign and return one copy of the consent form attached at the bottom of the information sheet (see Appendix 3). They will keep a second copy for their own records. Once the consent form has been returned, I will contact the participant using the same method that they used to make initial contact with me, to arrange a suitable date and time to conduct the interview.

4.7 If any payment or incentive will be made to any participant, please explain what it is and provide the justification (no more than 300 words).

No payment or incentive will be made to any participant.

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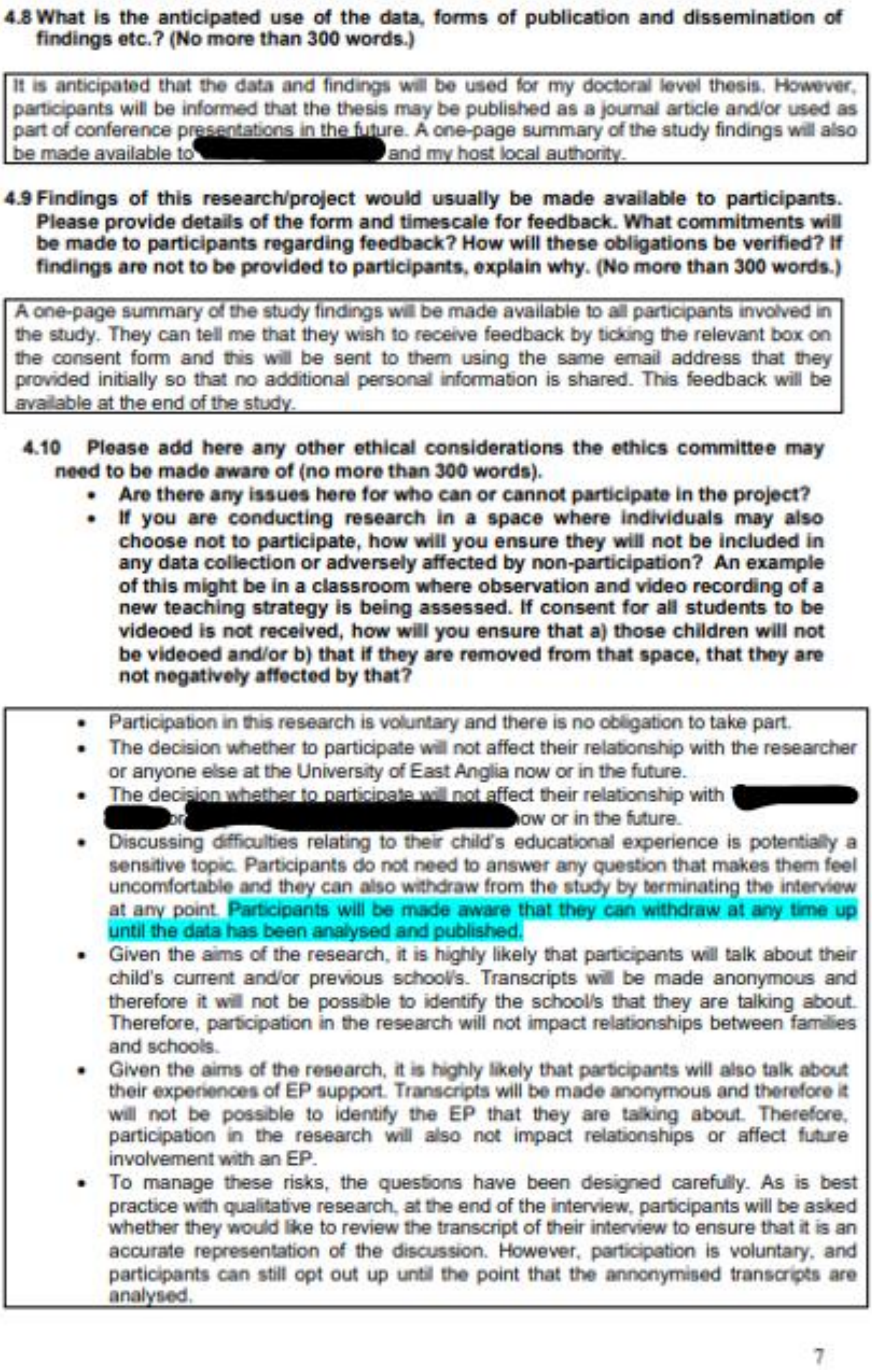


4.8 What is the anticipated use of the data, forms of publication and dissemination of findings etc.? (No more than 300 words.)

It is anticipated that the data and findings will be used for my doctoral level thesis. However, participants will be informed that the thesis may be published as a journal article and/or used as part of conference presentations in the future. A one-page summary of the study findings will also be made available to [redacted] and my host local authority.

4.9 Findings of this research/project would usually be made available to participants. Please provide details of the form and timescale for feedback. What commitments will be made to participants regarding feedback? How will these obligations be verified? If findings are not to be provided to participants, explain why. (No more than 300 words.)

A one-page summary of the study findings will be made available to all participants involved in the study. They can tell me that they wish to receive feedback by ticking the relevant box on the consent form and this will be sent to them using the same email address that they provided initially so that no additional personal information is shared. This feedback will be available at the end of the study.

4.10 Please add here any other ethical considerations the ethics committee may need to be made aware of (no more than 300 words).

- **Are there any issues here for who can or cannot participate in the project?**
- **If you are conducting research in a space where individuals may also choose not to participate, how will you ensure they will not be included in any data collection or adversely affected by non-participation? An example of this might be in a classroom where observation and video recording of a new teaching strategy is being assessed. If consent for all students to be videoed is not received, how will you ensure that a) those children will not be videoed and/or b) that if they are removed from that space, that they are not negatively affected by that?**

- Participation in this research is voluntary and there is no obligation to take part.
- The decision whether to participate will not affect their relationship with the researcher or anyone else at the University of East Anglia now or in the future.
- The decision whether to participate will not affect their relationship with [redacted] or [redacted] now or in the future.
- Discussing difficulties relating to their child's educational experience is potentially a sensitive topic. Participants do not need to answer any question that makes them feel uncomfortable and they can also withdraw from the study by terminating the interview at any point. Participants will be made aware that they can withdraw at any time up until the data has been analysed and published.
- Given the aims of the research, it is highly likely that participants will talk about their child's current and/or previous school/s. Transcripts will be made anonymous and therefore it will not be possible to identify the school/s that they are talking about. Therefore, participation in the research will not impact relationships between families and schools.
- Given the aims of the research, it is highly likely that participants will also talk about their experiences of EP support. Transcripts will be made anonymous and therefore it will not be possible to identify the EP that they are talking about. Therefore, participation in the research will also not impact relationships or affect future involvement with an EP.
- To manage these risks, the questions have been designed carefully. As is best practice with qualitative research, at the end of the interview, participants will be asked whether they would like to review the transcript of their interview to ensure that it is an accurate representation of the discussion. However, participation is voluntary, and participants can still opt out up until the point that the annonymised transcripts are analysed.

4.11 What risks or costs to the participants are entailed in involvement in the research/project and how will you manage that risk?

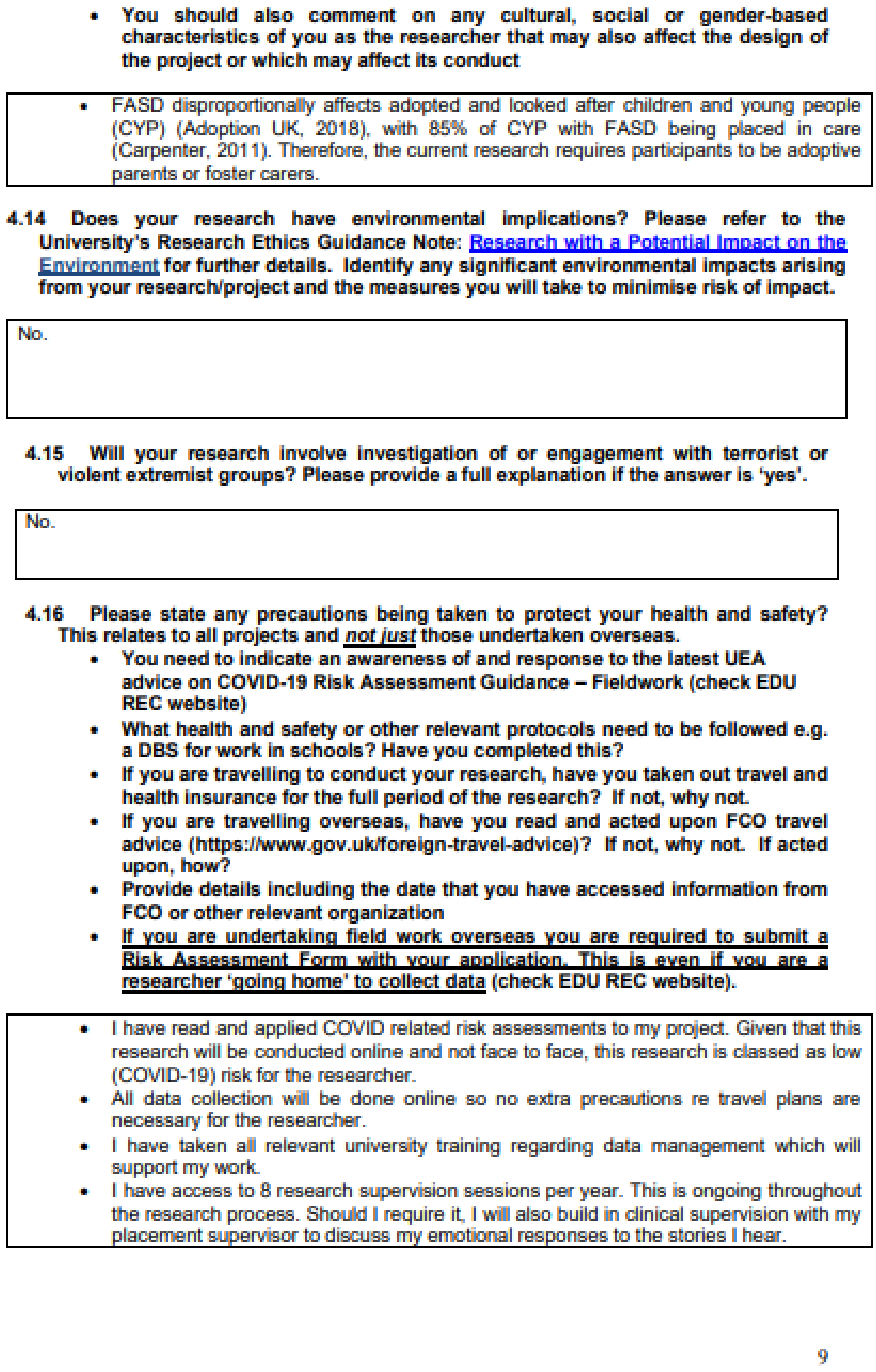
- **Are there any potential physical, psychological or disclosure dangers that can be anticipated? What is the possible harm to the participant or society from their participation or from the project as a whole?**
- **What procedures have been established for the care and protection of participants (e.g. insurance, medical cover, counselling or other support) and the control of any information gained from them or about them?**

- The risks or costs associated with being in this study have been carefully considered. This includes considering psychological harms (ie feelings of distress, anxiety or upset), social harms (ie damage to relationships) and inconvenience (ie giving up time). Some of the stories shared during the interviews may be sensitive, very complex and difficult. Therefore, thought has been given to ensure that participants are psychologically contained before leaving the research interview. Before ending the interview, it is important to ensure that participants are feeling safe, happy, and not distressed. Contact details of both the researcher and research supervisor are provided should participants feel they need to arrange a debrief time to talk about the interview. Furthermore, participants will be provided with contact details of organisations that are available for additional support.
  This includes:
  https://nationalfasd.org.uk/helpline-contact/
  https://www.adoptionuk.org/
  Participants residing within my host local authority will be provided with contact details for the post adoption permanence team helpline which is run by qualified social workers. This is a service within my host local authority only. If participants are recruited from the wider eastern region, I will make sure I explore the social services support available in their local authority and signpost to this.
- Please see 4.10 for additional ethical considerations and how these have been addressed.

4.12 What is the possible benefit to the participant or society from their participation or from the project as a whole?

- The purpose of this research is to increase awareness of, and improve understanding of, the needs of children with FASD and the implications for education. This will likely be a benefit to both the participant and society.
- Research questions aim to identify factors that support positive experiences of education which can then be used to inform recommendations for possible future interventions. This will likely be a benefit to both the participant and society.
- By discussing a range of educational experiences, participants may benefit from the opportunity to reflect and review more difficult times.
- By discussing positive educational experiences, participants may benefit from the opportunity to reflect and remind themselves of positive times which may support participant wellbeing.
- By taking part, participants are contributing to a limited UK research base about FASD.
- The current research answers Westrup's (2013) call to identify whether EPs are working with these families and if so, how? Consequently, by participating in this research, participants are supporting the development of an increased awareness of the potential for the EP role in supporting this group and add to a limited literature base within the field. This will likely be a benefit to both the participant and society.

4.13 Comment on any cultural, social or gender-based characteristics of the participants which have affected the design of the project or which may affect its conduct. This may be particularly relevant if conducting research overseas or with a particular cultural group



- **You should also comment on any cultural, social or gender-based characteristics of you as the researcher that may also affect the design of the project or which may affect its conduct**

• FASD disproportionally affects adopted and looked after children and young people (CYP) (Adoption UK, 2018), with 85% of CYP with FASD being placed in care (Carpenter, 2011). Therefore, the current research requires participants to be adoptive parents or foster carers.

4.14 Does your research have environmental implications? Please refer to the University's Research Ethics Guidance Note: Research with a Potential Impact on the Environment for further details. Identify any significant environmental impacts arising from your research/project and the measures you will take to minimise risk of impact.

No.

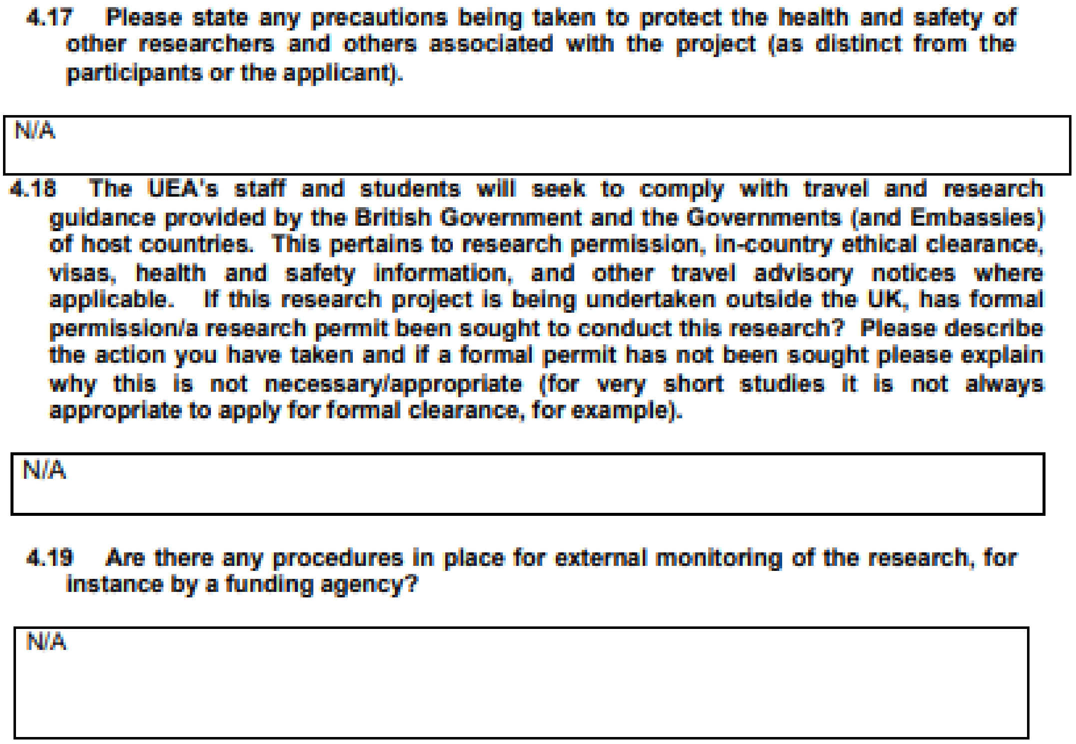
4.15 Will your research involve investigation of or engagement with terrorist or violent extremist groups? Please provide a full explanation if the answer is 'yes'.

No.

4.16 Please state any precautions being taken to protect your health and safety? This relates to all projects and *not just* those undertaken overseas.

- **You need to indicate an awareness of and response to the latest UEA advice on COVID-19 Risk Assessment Guidance – Fieldwork (check EDU REC website)**
- **What health and safety or other relevant protocols need to be followed e.g. a DBS for work in schools? Have you completed this?**
- **If you are travelling to conduct your research, have you taken out travel and health insurance for the full period of the research? If not, why not.**
- **If you are travelling overseas, have you read and acted upon FCO travel advice (https://www.gov.uk/foreign-travel-advice)? If not, why not. If acted upon, how?**
- **Provide details including the date that you have accessed information from FCO or other relevant organization**
- **If you are undertaking field work overseas you are required to submit a Risk Assessment Form with your application. This is even if you are a researcher 'going home' to collect data (check EDU REC website).**

• I have read and applied COVID related risk assessments to my project. Given that this research will be conducted online and not face to face, this research is classed as low (COVID-19) risk for the researcher. • All data collection will be done online so no extra precautions re travel plans are necessary for the researcher. • I have taken all relevant university training regarding data management which will support my work. • I have access to 8 research supervision sessions per year. This is ongoing throughout the research process. Should I require it, I will also build in clinical supervision with my placement supervisor to discuss my emotional responses to the stories I hear.



4.17 Please state any precautions being taken to protect the health and safety of other researchers and others associated with the project (as distinct from the participants or the applicant).

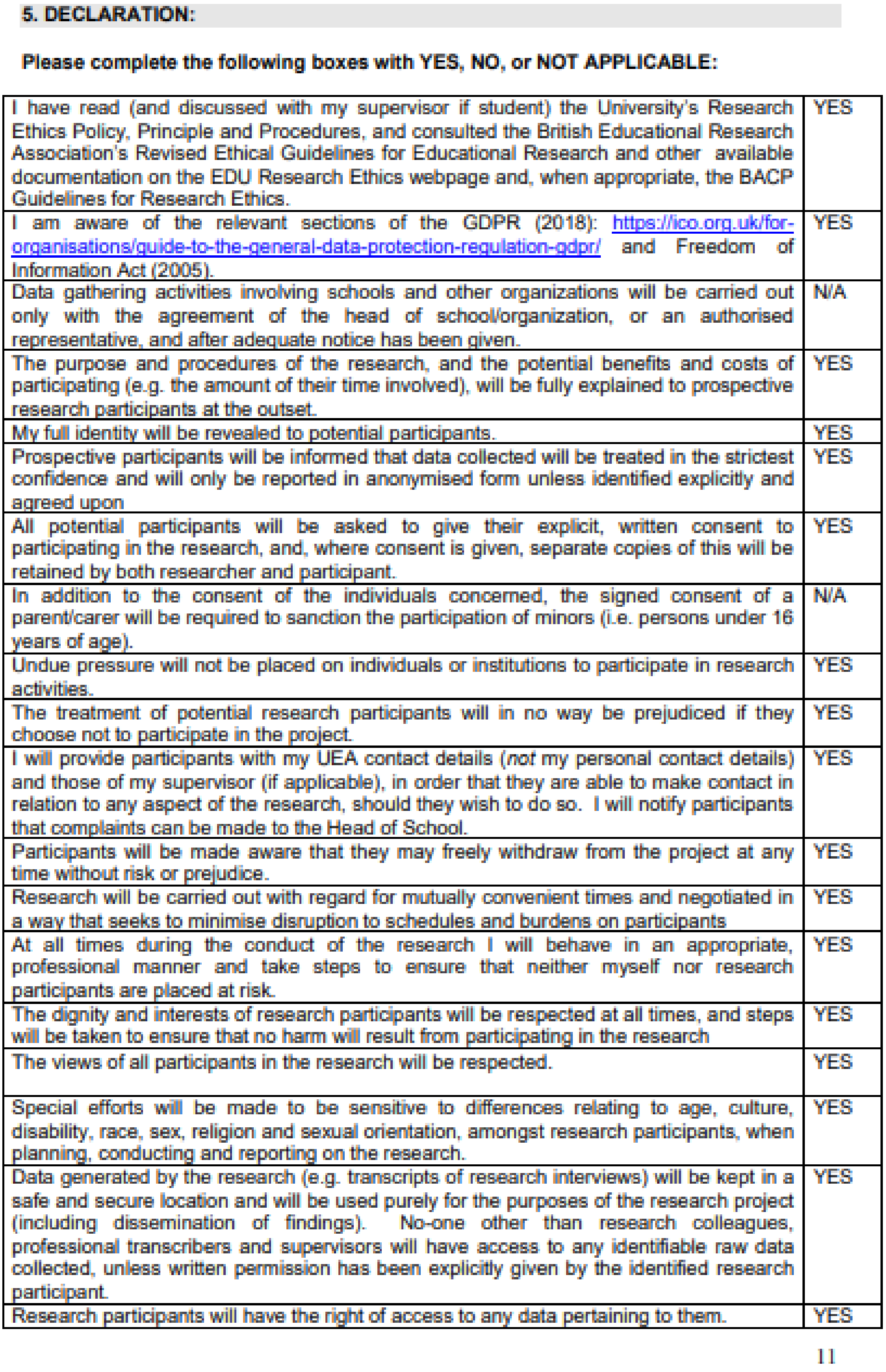
N/A

4.18 The UEA's staff and students will seek to comply with travel and research guidance provided by the British Government and the Governments (and Embassies) of host countries. This pertains to research permission, in-country ethical clearance, visas, health and safety information, and other travel advisory notices where applicable. If this research project is being undertaken outside the UK, has formal permission/a research permit been sought to conduct this research? Please describe the action you have taken and if a formal permit has not been sought please explain why this is not necessary/appropriate (for very short studies it is not always appropriate to apply for formal clearance, for example).

N/A

4.19 Are there any procedures in place for external monitoring of the research, for instance by a funding agency?

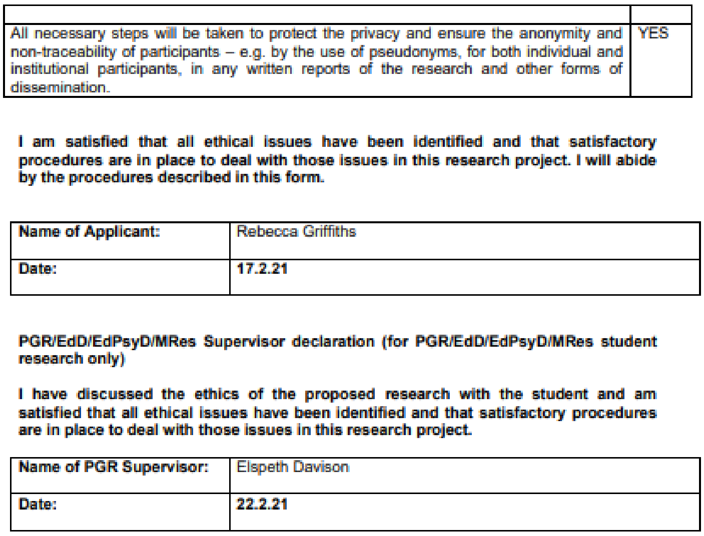
N/A



5. DECLARATION:

Please complete the following boxes with YES, NO, or NOT APPLICABLE:

I have read (and discussed with my supervisor if student) the University's Research Ethics Policy, Principle and Procedures, and consulted the British Educational Research Association's Revised Ethical Guidelines for Educational Research and other available documentation on the EDU Research Ethics webpage and, when appropriate, the BACP Guidelines for Research Ethics.	YES
I am aware of the relevant sections of the GDPR (2018): https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/ and Freedom of Information Act (2005).	YES
Data gathering activities involving schools and other organizations will be carried out only with the agreement of the head of school/organization, or an authorised representative, and after adequate notice has been given.	N/A
The purpose and procedures of the research, and the potential benefits and costs of participating (e.g. the amount of their time involved), will be fully explained to prospective research participants at the outset.	YES
My full identity will be revealed to potential participants.	YES
Prospective participants will be informed that data collected will be treated in the strictest confidence and will only be reported in anonymised form unless identified explicitly and agreed upon	YES
All potential participants will be asked to give their explicit, written consent to participating in the research, and, where consent is given, separate copies of this will be retained by both researcher and participant.	YES
In addition to the consent of the individuals concerned, the signed consent of a parent/carer will be required to sanction the participation of minors (i.e. persons under 16 years of age).	N/A
Undue pressure will not be placed on individuals or institutions to participate in research activities.	YES
The treatment of potential research participants will in no way be prejudiced if they choose not to participate in the project.	YES
I will provide participants with my UEA contact details (*not* my personal contact details) and those of my supervisor (if applicable), in order that they are able to make contact in relation to any aspect of the research, should they wish to do so. I will notify participants that complaints can be made to the Head of School.	YES
Participants will be made aware that they may freely withdraw from the project at any time without risk or prejudice.	YES
Research will be carried out with regard for mutually convenient times and negotiated in a way that seeks to minimise disruption to schedules and burdens on participants	YES
At all times during the conduct of the research I will behave in an appropriate, professional manner and take steps to ensure that neither myself nor research participants are placed at risk.	YES
The dignity and interests of research participants will be respected at all times, and steps will be taken to ensure that no harm will result from participating in the research	YES
The views of all participants in the research will be respected.	YES
Special efforts will be made to be sensitive to differences relating to age, culture, disability, race, sex, religion and sexual orientation, amongst research participants, when planning, conducting and reporting on the research.	YES
Data generated by the research (e.g. transcripts of research interviews) will be kept in a safe and secure location and will be used purely for the purposes of the research project (including dissemination of findings). No-one other than research colleagues, professional transcribers and supervisors will have access to any identifiable raw data collected, unless written permission has been explicitly given by the identified research participant.	YES
Research participants will have the right of access to any data pertaining to them.	YES



All necessary steps will be taken to protect the privacy and ensure the anonymity and non-traceability of participants – e.g. by the use of pseudonyms, for both individual and institutional participants, in any written reports of the research and other forms of dissemination.	YES

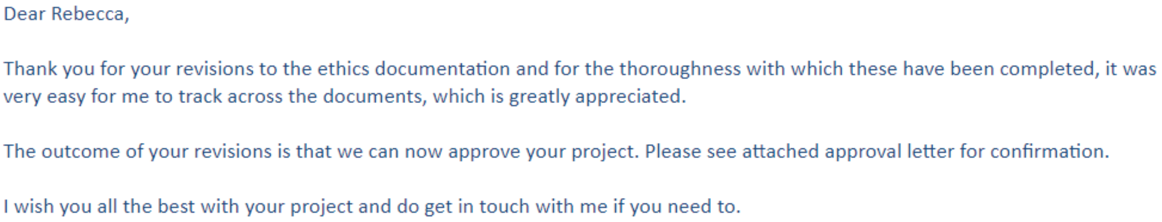
I am satisfied that all ethical issues have been identified and that satisfactory procedures are in place to deal with those issues in this research project. I will abide by the procedures described in this form.

Name of Applicant:	Rebecca Griffiths
Date:	**17.2.21**

PGR/EdD/EdPsyD/MRes Supervisor declaration (for PGR/EdD/EdPsyD/MRes student research only)

I have discussed the ethics of the proposed research with the student and am satisfied that all ethical issues have been identified and that satisfactory procedures are in place to deal with those issues in this research project.

Name of PGR Supervisor:	Elspeth Davison
Date:	**22.2.21**

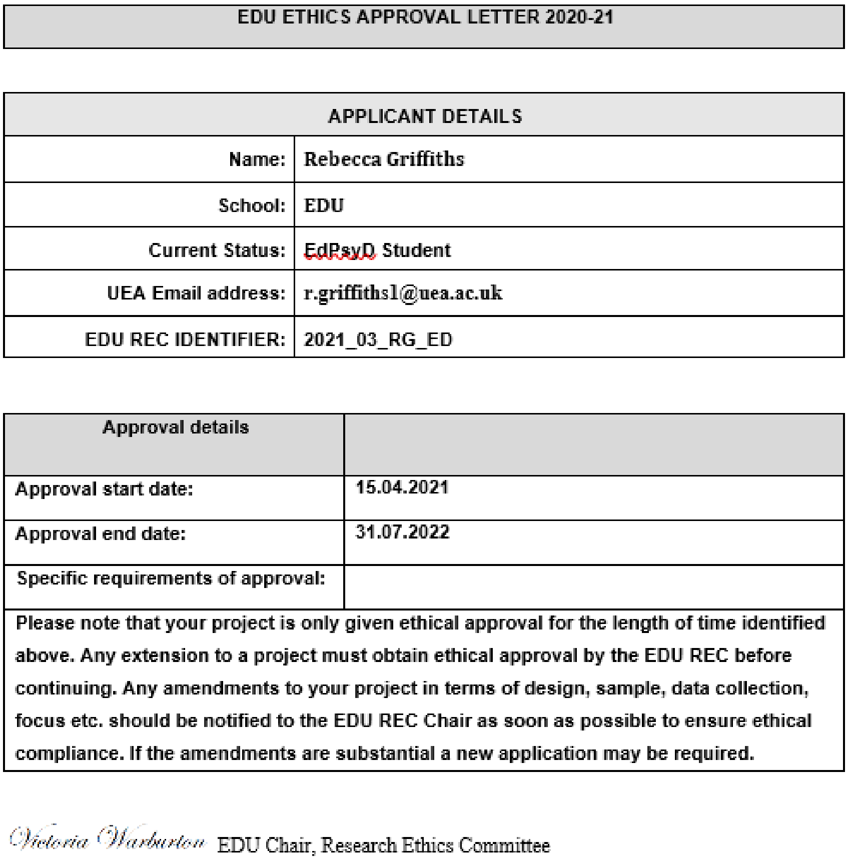


Dear Rebecca,

Thank you for your revisions to the ethics documentation and for the thoroughness with which these have been completed, it was very easy for me to track across the documents, which is greatly appreciated.

The outcome of your revisions is that we can now approve your project. Please see attached approval letter for confirmation.

I wish you all the best with your project and do get in touch with me if you need to.



EDU ETHICS APPROVAL LETTER 2020-21

APPLICANT DETAILS	
Name:	Rebecca Griffiths
School:	EDU
Current Status:	EdPsyD Student
UEA Email address:	r.griffiths1@uea.ac.uk
EDU REC IDENTIFIER:	2021_03_RG_ED

Approval details	
Approval start date:	**15.04.2021**
Approval end date:	**31.07.2022**
Specific requirements of approval:	
Please note that your project is only given ethical approval for the length of time identified above. Any extension to a project must obtain ethical approval by the EDU REC before continuing. Any amendments to your project in terms of design, sample, data collection, focus etc. should be notified to the EDU REC Chair as soon as possible to ensure ethical compliance. If the amendments are substantial a new application may be required.	

Victoria Warburton EDU Chair, Research Ethics Committee

Appendix M

Handout of Recommendations and Implications for Stakeholders

Implications for Schools

All Education Settings, including Primary:

- Improved knowledge of FASD and how it affects the individual that they are supporting specifically. This should include understanding that ‘behaviour is communication’ and is not a choice, what the individual’s strengths, interests, likes and dislikes are, how best to communicate with them, how best to engage them and how to maximise their opportunities to be successful. Training should also address common misconceptions such as all those with FASD sharing the same challenges and require the same support, as well as the idea that the individual’s presentation is related in some way to ‘parenting’. This information sharing should extend beyond the SENCO and include all school staff, not only those who have regular direct contact with the individual. This will ensure all interactions are recognised as an intervention.
- School staff should work to develop close and collaborative working relationships with parents and families of those affected by FASD. This includes clear, transparent, respectful, and open communication pathways. It is important that schools are available to support parents, listen authentically to them, and are willing to learn from them and their experiences. Work closely in the form of regular review meetings to collaborate upon necessary adaptations or provision that the pupil requires.
- All school staff should seek to adopt a relational approach when working

with individuals with FASD. This includes nurture rather than punishment and developing consistent, strong, and reliable relationships between students with FASD and adults in school.

- School staff should review their behaviour policies to ensure there is flexibility to address behavioural concerns through nurture and accounting for the needs of the individual. For example, the use of punishment and reward is highly unlikely to be successful for all and may trigger further difficulties with shame and self-esteem which this study has found to be pertinent amongst this population.
- School staff should be aware of the possible relationship between shame, school non-attendance and FASD as identified by this study. It is important that schools are aware that those with FASD may be at increased risk of school non-attendance and take appropriate action to minimise this risk and intervene swiftly.
- Individuals with FASD will require careful and considered transitions between year groups and when working with new members of staff. Thought should be given to how schools can develop multiple relationships to mitigate potential difficulties at times of staff sickness for example. Similarly, this applies to peer relationships which are fundamental to the wellbeing of pupils with FASD. Where possible friendship groups should be maintained through transitions.
- Use of simplified and clear language is important when communicating with those with FASD. Avoid use of abstract concepts or complex language which may have multiple or an unclear meaning/relevance. Ensure time is

given to ascertain the level of understanding the pupil has before assuming they have understood an instruction or task.

- Pupils with FASD should be encouraged to explore new subjects to uncover new interests or hidden strengths which can be celebrated to support self-esteem.
- Extensive efforts should be made to ensure that pupils are not made to feel different and adaptations to learning are made discretely, thus maintaining the individual's right to dignity.
- In consultation with the pupil with FASD and their family, discussion should be had around what is shared with members of the school community, who it is shared with, when it is shared, and how this is done. For instance, psychoeducation approaches may work for some but not others and school staff should be mindful that not all those with FASD may be aware of their diagnosis. Similarly, they may not know they are adopted or fostered if this is the case or have knowledge of their earlier life experiences.

Secondary Only:

- Recognition should be given to the fact that the developmental profile of those with FASD is 'spikey' and whilst they may excel in one area, there may be extreme difficulties in other areas. It is important that differences between their chronological age and developmental age in different areas of functioning are understood and supported, regardless of the age of the peer group who they are being educated alongside. For example, adaptations that may 'typically' be found in primary school should continue or be further adapted to support discretion if desired by the pupil with FASD and their family.

- Consideration should be given to the increased number of teachers that pupils will have contact compared to their primary school experience. Transition will need to be considered for each year group and where possible continuation of teachers will be beneficial to ensure ongoing student-teacher relationships and home-school collaboration.
- Behaviour policies which involve public approaches such as ‘isolation’ should be revised considering the findings of this study and the impact upon the emotional wellbeing of those with FASD.
- Additional support is important in relation to the susceptibility that those with FASD face with regards to peer pressure. Explicit teaching and guidance is necessary around PSHE that is typically taught in secondary schools (e.g., drug taking, alcohol consumption, criminal activities, sexualised behaviours, consent etc). It is important that adaptations are made to ensure the content of this learning is fully understood and is developmentally appropriate/accessible for the individual with FASD.
- Consideration should be given to how pupils with FASD can be most successful in years with public assessments if this is an area of difficulty. For example, adaptations such as completing less exams, taking coursework-based subjects, practice-based learning, having a scribe/reader, and exploration of the appropriate ‘level’ of examination for each individual is important for their future years.

Further Education Only:

- Consideration should be given to how pupils with FASD can be most successful, without placing a glass ceiling on opportunities. This should include exploration of alternatives to college where this is not appropriate or desired. This might involve remote/online working, placement-based apprenticeships, practical learning and interest-based learning for example. Likewise, where college is chosen, adaptations made earlier in their education settings (primary, secondary etc) should be ongoing.

- It is important that during these years, life skills including independence and preparation for adulthood is prioritised and necessary adaptations to this teaching are made to enable those with FASD to be successful, reach their potential, and remain safe.

Implications for EPs

Individual Level

- Improved knowledge of FASD. Weighting needs to be given to increasing EPs' recognition of their own biases and assumptions, including the influence these have upon their practice. Emphasis should be given to viewing the individual with FASD as exactly that, an individual.
- Adoption of a relational approach with CYP and families who are affected by FASD. This includes establishing rapport, allowing sufficient time to build trust, and consideration should be given to how relationships may be best developed over multiple visits.
- EPs should recognise their duty to listen and respect parents' views according to the SEND CoP (DfE, 2015). This study highlights the importance of EPs of empowering parents by accounting for power differentials/imbalances and hierarchy.

- EPs should include questions relating to maternal alcohol consumption/ experiences during pregnancy routinely as part of gathering developmental histories in consultation. This should especially happen where other conditions such as ADHD, AD or ASD are suspected. This is important for information gathering which can in turn support accurate early identification and ensures exploration of all alternative hypotheses when developing formulations.

Organisational/ System Level

- EPs should support schools to fulfil their duty in accordance with the SEND CoP (DfE, 2015) by seeking and valuing parental contributions, and the expertise they bring. This includes upskilling educational professionals around how to receive their input favourably. EPs can support communication between the family and school systems as a bridge between the two.
- EPs should advocate for and encourage organisational change which enables a narrative shift around behaviour and inclusivity for those with FASD. This could include reviewing behaviour policies to account for the unique needs of each individual pupil.
- EPs should advocate for the SENCO to be a member of school leadership to enable their voice and the best interests of those with FASD to be represented amongst key stakeholders.
- Provide school staff and the SENCO with training and supervision to help get all members of education staff ‘on board’ and implement necessary adaptations for those with FASD in the classroom. Use of tools such as

functional behavioural analysis (FBA) and video enhanced reflective practice (VERP) may be particularly helpful where EPs and/or SENCOs are met with resistance from school staff. Upskilling staff in use of tools such as One Page Profiles (OPP) will support understanding of the individual with FASD.

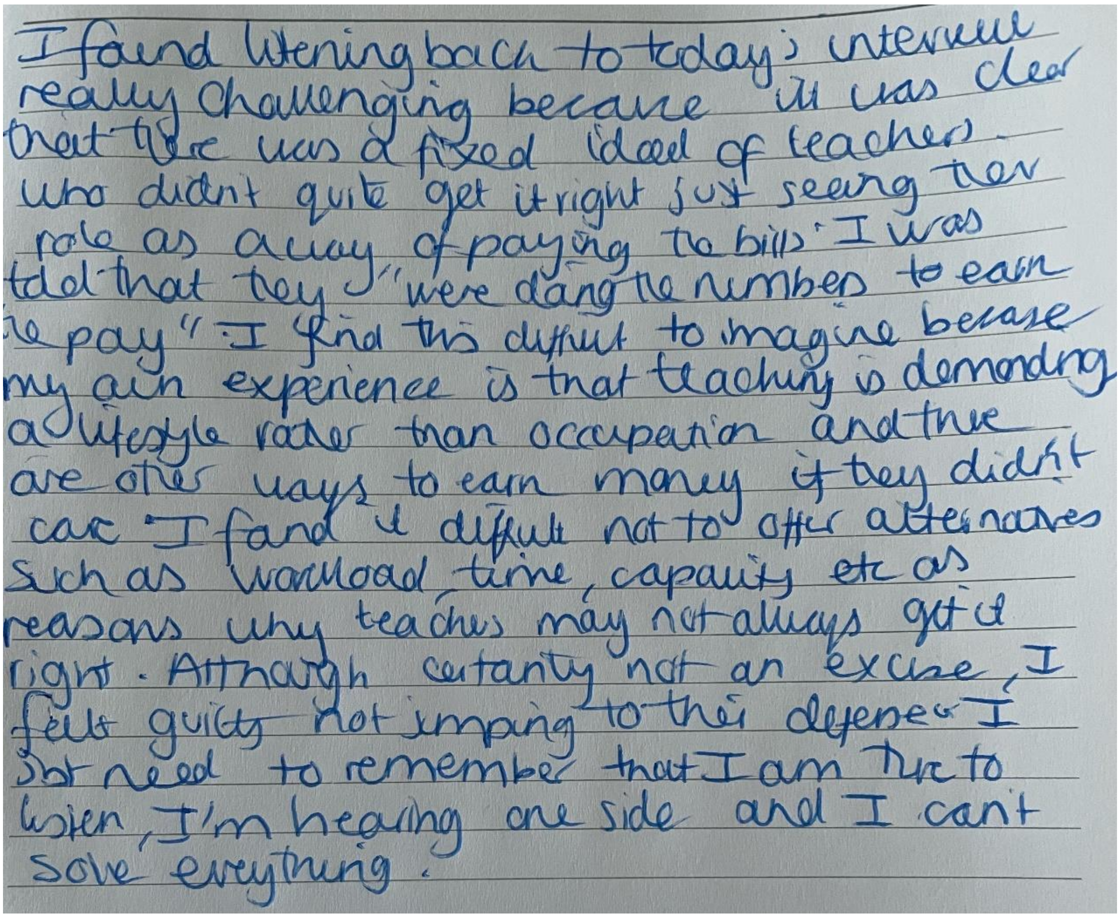
- EPs should be a voice in wider systems (i.e. local authorities) to advocate for the availability of additional provision and educate those involved in the allocation of placements about FASD.
- EPs should explore the scope for them to taker a greater role in working within the family system, by providing support to parents. This could include parental support groups, forums or signposting to relevant information which is specific to the locality in which parents reside. Similarly, EP services should reflect upon how accessible and ‘user-friendly’ their offer is to families.

Implications for Parents

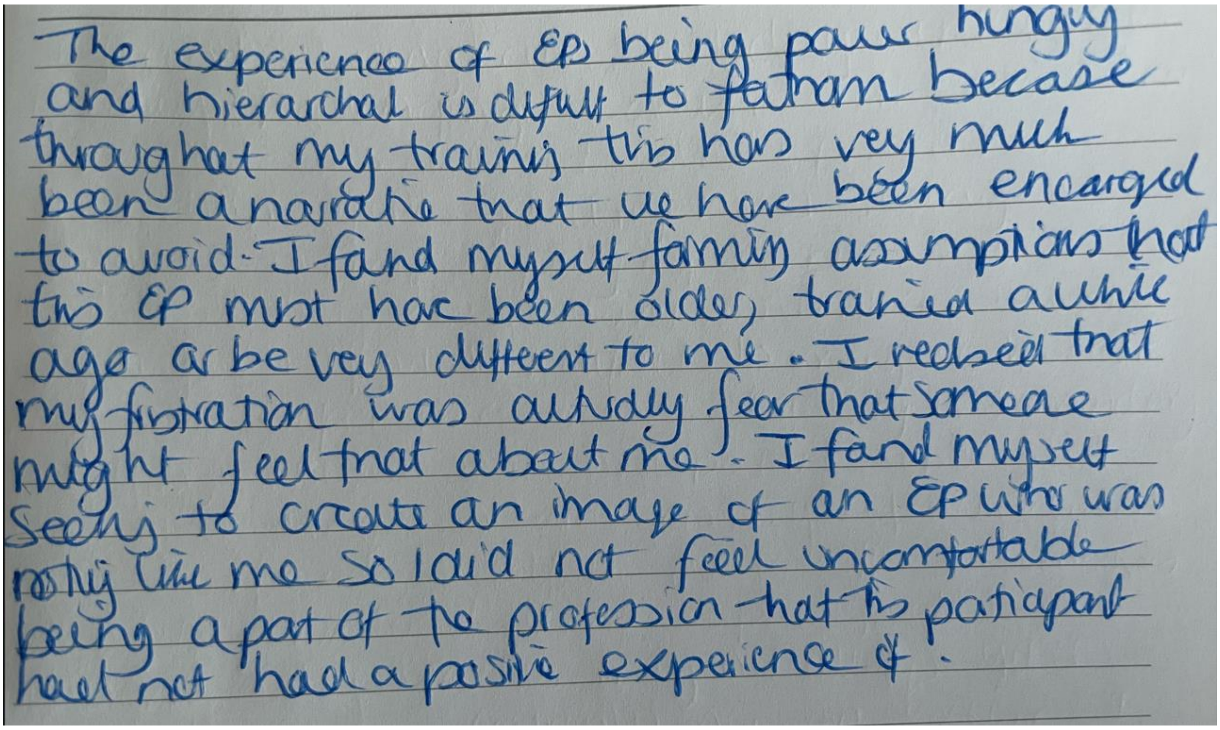
- With support, parents should continue to develop the confidence to recognise and value their expertise both about FASD and their child specifically.
- Findings from this study suggest that the parental approach towards schools impacts upon school receptiveness. Perhaps there is room for parents to consider how best to address concerns they may have.

Appendix N

Sample of Reflective Diary



I found listening back to today's interview really challenging because it was clear that there was a fixed idea of teachers who didn't quite get it right just seeing their role as a way of paying the bills. I was told that they "were doing the numbers to earn the pay". I find this difficult to imagine because my own experience is that teaching is demanding a lifestyle rather than occupation and there are other ways to earn money if they didn't care. I found it difficult not to offer alternatives such as workload, time, capacity etc as reasons why teachers may not always get it right. Although certainly not an excuse, I felt guilty not jumping to their defence. I just need to remember that I am there to listen, I'm hearing one side and I can't solve everything.



The experience of EPs being power hungry and hierarchal is difficult to fathom because throughout my training this has very much been a narrative that we have been encouraged to avoid. I found myself forming assumptions that this EP must have been older, trained a while ago or be very different to me. I realised that my frustration was actually fear that someone might feel that about me. I found myself seeking to create an image of an EP who was nothing like me so I did not feel uncomfortable being a part of the profession that this participant had not had a positive experience of.