

The Educational Experiences of Young People with a Diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in UK Secondary Schools: An Interpretative Phenomenological Analysis.

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Summary

The current study aims to contribute to a limited body of research focusing on education and Fetal Alcohol Spectrum Disorder (FASD), particularly that which elicits the voice of children and young people (CYP). The research aims to raise awareness of FASD both within education and more broadly, guiding professionals, inclusive of Educational Psychologists (EPs), in supporting CYP with FASD.

This thesis has been written and organised into four chapters, an introduction and overview, a literature review, an empirical chapter and a reflective account of the research process. The first chapter introduces the research topic and gives a summary of the researcher's positionality.

Chapter two gives a broad overview of literature exploring the educational experiences of CYP with FASD. Framing this through the lens of Bronfenbrenner's (Bronfenbrenner & Morris, 2006) Bioecological Model of Human Development, the researcher considers how CYP's interactions within broader contexts can shape development and educational experiences. Literature is cross-examined and critiqued to provide an overarching understanding of current research, to inform further research.

Chapter three details an Interpretative Phenomenological Analysis study, using semi-structured interviews with four adolescents with FASD, to explore their educational experiences in secondary schools. Through seeking to understand the meaning given to such experiences, data analysis identified five group experiential themes and seventeen subthemes. Implications for EPs and professionals more broadly are considered, alongside limitations and directions for future research.

Chapter four provides the researcher's critical reflections on the research journey, exploring how reflexivity was embedded throughout the research, the researcher's positionality, decisions made and challenges encountered. The researcher's personal development is also discussed, alongside plans for dissemination.

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Contents

List of Tables	10
List of Figures	11
Glossary of Terms.....	12
Chapter One: Introduction and Overview	13
1.1 Thesis Structure	13
1.2 Researcher Background and Developing Positionality.....	13
1.3 Gaps in Literature and Aims of Current Research.....	15
Chapter Two: Literature Review	16
2.1 Introduction.....	16
2.1.1 History of FASD.....	16
2.1.2 Understanding FASD.....	17
2.1.3 Diagnostic Challenges and Support	18
2.1.4 Prevalence.....	20
2.1.7 Comorbidity	22
2.1.5 Legislative Context.....	22
2.1.6 Developmental Implications	22
2.2 Literature Review Aims and Terminology	23
2.2.1 The Developing Person: Individual Characteristics, Meaning-Making and Educational Experience.	27
2.2.2 Microsystem	31

2.2.3 <i>Mesosystem</i>	40
2.2.4 <i>Exosystem</i>	42
2.2.5 <i>Macrosystem</i>	44
2.3 Conclusions and Research Aims.....	45
Chapter Three: Empirical Paper.....	47
3.1 Abstract.....	47
3.2 Introduction and Legislative Context.....	48
3.3 Current Research.....	49
3.4 Educational Psychology	50
3.5 Research Aims and Rationale	51
3.6 Research Question	51
3.7 Methodology	52
3.7.1 <i>Ontology and Epistemology</i>	52
3.7.2 <i>Qualitative Methodology</i>	53
3.7.3 <i>Interpretative Phenomenological Analysis (IPA)</i>	53
3.7.4 <i>Participants</i>	57
3.7.5 <i>Data Collection</i>	62
3.7.6 <i>Data Analysis</i>	63
3.8 <i>Ethical Considerations</i>	65
3.9 Findings.....	68
3.9.1 <i>Participant Profiles</i>	68

3.9.2 Cross-Case Analysis: Group Experiential Themes (GETs).....	81
3.9.2.1 GET 1: Adults as Shaping Safety, Trust and Access to Learning	84
3.9.2.2 GET 2: Reliance on Trusted Peers to Navigate Learning and Social Interactions	89
3.9.2.3 GET 3: School Ethos Shaping Experiences of Inclusive Practice	94
3.9.2.4 GET 4: Making Sense of Academic Challenges	99
3.9.2.5 GET 5: Sensory Support as Fundamental to Educational Experiences	106
3.9.3 Summary of Findings.....	109
3.10 Discussion	111
3.10.1 RQ1: What are the educational experiences of young people with a diagnosis of FASD in UK secondary education settings?	111
3.10.2 Implications for Practice and Future Research.....	121
3.10.3 Limitations	127
3.10.4 Conclusion	129
Chapter Four: Reflective Account	132
4.1.1 Positionality	132
4.2 Reflections on my Research Journey	133
4.2.1 Identifying a Research Topic	133
4.2.2 Reviewing Literature.....	134
4.2.3 Theoretical Framework	135
4.3 Research Design	136
4.3.2 Participants.....	138

4.3.3 <i>Methodology and Design Decisions</i>	140
4.4 Research Contributions and Implications	146
4.4.1 <i>Personal Development</i>	146
4.4.2 <i>Dissemination and Implications</i>	147
4.5 Conclusion	150
References	152
Appendices.....	188
Appendix A Diagnostic Algorithm for FASD Produced by SIGN (2019).....	188
Appendix B Flow Diagram of the Eligible and Final Sample for the Primary FASD Prevalence Estimates by Missing Data Strategy (McQuire et al., 2019).....	189
Appendix C Initial Search Terms Applied in Scoping Literature Review Searches, Before Extending Outside of the UK due to the Scarcity of Research	190
Appendix D Recruitment Poster	192
Appendix E Semi-Structured Interview Schedule	193
Appendix F Scaling Activity	195
Appendix G Blob Classroom Resource	196
Appendix H Card Sorting Activity (blank).....	197
Appendix I Drawing Sheet.....	198
Appendix J Sample of Transcript	199
Appendix K Step Two and Three of IPA, Exploratory Noting and Constructing Experiential Statements	201

Appendix L Step Four of IPA, Searching for Connections Across Experiential Statements	203
Appendix M Step Four of IPA, Naming Personal Experiential Themes (PETs), Consolidating and Organising into a Table	206
Appendix N Step Seven of IPA, Working with PETS to develop Group Experiential Themes (GETs) Across Cases	208
Appendix O Table of Group Experiential Themes GETs (sample).....	210
Appendix P Ethical Approval from UEA Ethics Committee (following amendments to extend to specialist settings and units).....	215
Appendix Q Information Sheet and Consent Form	225
Appendix R Adapted Child Friendly Information Sheet and Consent Forms	228
Appendix S Debrief Forms	231
Appendix T Thematic Map for Personal Experiential Statement for Each Participant	232
Appendix U Example Research Diary Entries During Recruitment	239

List of Tables

Table 1 Literature Review Search Terms.....	24
Table 2 Inclusion/Exclusion Criteria of Literature Search.....	25
Table 3 Addressing the Four Principles in Yardley’s (2017) Framework for Validity and Quality.....	56
Table 4 Overview of GETs and Subthemes	83
Table 5 Prevalence of Sub-themes Related to ‘Adults as Shaping Safety, Trust and Access to Learning’	84
Table 6 Prevalence of Sub-themes Related to ‘Reliance on Trusted Peers to Navigate Learning and Social Interactions’	89
Table 7 Prevalence of Sub-themes Related to ‘School Ethos Shaping Experiences of Inclusive Practice’	94
Table 8 Prevalence of Sub-themes Related to ‘Making Sense of Academic Challenges’	99
Table 9 Prevalence of Sub-themes Related to ‘Sensory Support as Fundamental to Educational Experiences’	106

List of Figures

Figure 1 Palpebral Fissure Length	19
Figure 2 Lip-Philtrum Guide, 5-Point Pictorial Scale	19
Figure 3 A Visualisation of Bronfenbrenner and Morris' (2006), Bioecological Model of Development, Created by the Researcher	26
Figure 4 Blob Chosen by Lily to Represent her Experiences in a Lesson she Dislikes	76
Figure 5 Blob Chosen by Lily to Represent her Experiences in a Lesson she Enjoys	77
Figure 6 Blob Chosen by Thomas to Represent his Experiences in a Lesson he Enjoys	78
Figure 7 Blob Chosen by Thomas to Represent his Experiences Asking for Help	79
Figure 8 Blob Chosen by Thomas to Represent his Experiences of Confusion in Lessons ..	80
Figure 9 Blob Chosen by Thomas to Represent his Experiences Seeking Regulatory Support	80

Glossary of Terms

ACE	Adverse Childhood Experiences
ADHD	Attention Deficit Hyperactivity Disorder
ARBD	Alcohol Related Birth Defect
ARND	Alcohol Related Neurodevelopmental Disorder
ASD	Autism Spectrum Disorder
BMA	British Medical Association
CNS	Central Nervous System
CYP	Children and Young People
DfE	Department for Education
DoH	Department of Health
EHCP	Education, Health, and Care Plan
EHCNA	Education, Health, and Care Needs Assessment
EP	Educational Psychologist
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorder
GDPR	General Data Protection Regulation
HCPC	Health and Care Professionals Council
LAC	Looked After Child
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
PAE	Prenatal Alcohol Exposure
pFAS	Partial Fetal Alcohol Syndrome
RQ	Research Question
SDT	Self-Determination Theory
SEMH	Social, Emotional and Mental Health
SENCo	Special Educational Needs Co-ordinator
SEND	Special Educational Needs and Disabilities
SEND CoP	Special Educational Needs and Disabilities Code of Practice
SIGN	Scottish Intercollegiate Guidelines Network
SIM	Student Integration Model
TEP	Trainee Educational Psychologist
UEA	University of East Anglia
USA	United States of America

Chapter One: Introduction and Overview

1.1 Thesis Structure

The thesis comprises four chapters. Chapter one is an introduction to the research topic and overview of the researcher's positionality. Chapter two is a narrative literature review focusing on research exploring the educational experiences of children and young people (CYP) with FASD, structured through the lens of Bronfenbrenner's Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006). Chapter three, the empirical chapter, reflects four interviews with young people with Fetal Alcohol Spectrum Disorder (FASD), exploring their educational experiences in UK secondary schools. Data was analysed using Interpretative Phenomenological Analysis (IPA), giving value to individual accounts alongside identifying group experiential themes. Yardley's (2017) principles were used to evaluate the validity of this qualitative research. Chapter three also considers how the findings contribute to our understanding of FASD and scarcity of literature, alongside practical implications, inclusive of the implications for educational psychologists (EPs). Chapter four is a reflexive account of the research journey, considering challenges, decisions, personal development, and dissemination.

1.2 Researcher Background and Developing Positionality

This subsection uses first-person to describe the researcher's background, positionality and provide context for the current research. Throughout the research, it was essential to consider how my values, positionality and experiences may impact my approach to the literature review and interpretation of participants' experiences (Braun & Clark, 2013). The importance of reflexivity is particularly key in IPA research due to the double hermeneutic, whereby the researcher makes sense of participants making sense of their experiences, to ensure rigour and trustworthiness (Smith & Osborn, 2015; Teh & Lek, 2018).

I began working in education in 2021 as a Teaching Assistant, progressing to a dual role as Assistant SENCo. I worked closely with CYP with special educational needs and disabilities (SEND). While I was unaware of FASD, I witnessed the importance of tailored support, relationships and listening to CYP to effectively support them. I consider these experiences poignant in establishing my values of inclusion and equity.

FASD was brought to my attention during my role as Assistant Psychologist, when a colleague presented her thesis on parental perspectives of FASD in education and implications for EPs. This highlighted the detrimental impacts of prenatal alcohol exposure (PAE) on the developing fetus, with educational and lifelong implications, alongside gaps in

understanding. This sparked my interest in FASD and prompted reflection within practice, considering how PAE is often overlooked as a potential contributing factor. I critically considered why limited understanding and awareness existed, particularly among EPs who have extensive knowledge of child development.

I assumed my limited understanding reflected inexperience and would be addressed during the doctorate through lectures and placement. While PAE arose in some cases, I noticed knowledge was often situated with families, rather than schools. Discussions with colleagues further highlighted gaps in EP training and limited evidence-based guidance. As a result, EPs often rely on more familiar frameworks, like trauma, which can overlook the neurological basis (e.g., brain damage in utero) of these CYP's needs. These experiences demonstrated a need for greater understanding of these CYP's experiences to inform practice.

No lectures focused specifically on FASD, though a session exploring prematurity and birth trauma highlighted some emotive and alarming statistics that PAE can have more significant short and long-term effects on a developing fetus (e.g., growth, behaviour, cognition) than nicotine, marijuana, opiates and cocaine (Behnke & Smith, 2013). However, I considered this to contrast societal narratives that often position drugs as more harmful, likely reflecting differences in legalities and public messages. While alcohol is known to be harmful, it remains legal in the UK and guidance promoting abstinence during pregnancy has only emerged more recently. Using Bronfenbrenner's framework, this prompted curiosity and reflection on how wider systemic factors, like policy, societal attitudes and public health guidance can shape perceptions of PAE and FASD, thus impacting CYP's experiences.

This curiosity shaped my research lens, approach to the topic, and engagement with literature. My practice aligns with the social model of disability, emphasising how societal contexts shape how disabilities are experienced (Oliver, 2013). While it cannot be disputed that FASD has a medical basis of brain damage resulting from PAE, interpretation of 'difficulty' is influenced by context and individuals' interactions with their environment, aligning with the social model. Although much research adopts a medical model and focuses on deficits, my critique of literature and approach is grounded in the social model, considering how unique experiences shape the meanings CYP with FASD give to their educational experiences.

I recognise my experiences and background differ from the CYP I have engaged with through my career and within this research. Arguably, I have been afforded privileges in society, which mean I can never truly understand their challenges, strengths and experiences. However, I aim to develop understanding through listening to CYP's experiences, using my

positionality to amplify their voices. Moreover, my outsider status and differing experiences supported a reflective stance, allowing me to remain attentive to participants' experiences and minimising influence of my assumptions and experiences.

1.3 Gaps in Literature and Aims of Current Research

The educational experiences of CYP with FASD are significantly under-researched, particularly in the UK. While some recent research includes the perspectives of adolescents with FASD across home, school and community, and primary-aged students' experiences of school belonging, most research focuses on caregivers' views. Subsequently, the current research seeks to explore the experiences of young people with FASD in UK secondary education settings, amplifying their voices to understand how they interpret their experiences. The findings hope to inform practice in educational contexts, alongside increasing understanding, thereby raising the profile of FASD.

Chapter Two: Literature Review

2.1 Introduction

This chapter critically reviews literature exploring the educational experiences of children and young people (CYP) with Fetal Alcohol Spectrum Disorder (FASD), or those who have experienced prenatal alcohol exposure (PAE). While terminology varies between Fetal and Foetal, Fetal is the spelling used within UK diagnostic guidelines and is therefore used throughout this research, alongside fetus instead of foetus (National Institute for Health and Care Excellence (NICE), 2022; Scottish Intercollegiate Guidelines Network (SIGN), 2019). The chapter outlines FASD terminology, prevalence, and the diagnostic context. The researcher then reviews and critiques research, through the lens of Bronfenbrenner's (Bronfenbrenner & Morris, 2006) Bioecological Model of Human Development, supporting the researcher to take a systemic lens and a framework which has been identified as relevant to FASD (Flannigan et al., 2021). Gaps in literature are highlighted, informing the rationale for the study.

2.1.1 History of FASD

The effects of maternal alcohol consumption during pregnancy have been suspected for centuries (Sanders., 2009; Warren & Foundin., 2001). Fetal Alcohol Syndrome (FAS) was first recognised by Jones and Smith (1973), highlighting a pattern of developmental differences in children exposed to significant alcohol in utero. They were the first to provide a comprehensive description of the features associated with FASD (growth deficiency, physical abnormalities, central nervous system effects and confirmed PAE), laying the diagnostic foundations of FAS (Calhoun & Warren, 2007; Room, 2005). Over time, the term Fetal Alcohol Effects (FAE) was introduced to capture individuals affected by PAE who demonstrated behavioural and cognitive deficiencies, though who did not present with growth deficiencies and sentinel facial features (Benz et al., 2009; Clarren & Smith, 1978).

In 1996, The United States Institute of Medicine (IOM) identified five categories of prenatal alcohol effects; FAS with and without confirmed alcohol exposure, partial FAS (pFAS), Alcohol-Related Birth Defects (ARBD) and Alcohol-Related Neurodevelopmental Disorder (ARND) (Battaglia et al., 1996). However, these guidelines were criticised for vague categories, which resulted in inconsistencies (Manning & Hoyme, 2007). Consequently, the 4-digit diagnostic code was developed in America (Astley, 2004), providing standardised scales across four diagnostic features (growth deficiency, facial

phenotype, brain damage and PAE) (Astley & Clarren, 2000). While these guidelines reduced ambiguity, professionals had difficulty reaching diagnostic agreement (Hoyme et al., 2005).

In 2005, the Canadian Diagnostic Guidelines integrated the 4-digit code and IOM guidelines, introducing Fetal Alcohol Spectrum Disorder (FASD), encapsulating the wide range of PAE implications. These guidelines emphasised multidisciplinary assessment and FASD as a diagnosis of exclusion, exploring all other possible causes (e.g., genetics) (Chudley et al., 2005). These guidelines were reviewed in 2015 (Brown et al., 2019), and laid the foundations for current UK guidelines, discussed later.

2.1.2 Understanding FASD

FASD, is a complex and multifaceted neurodevelopmental condition caused by PAE (Riley et al., 2011; SIGN, 2019), which reflects the range of developmental differences which can result from PAE, like craniofacial maldevelopment and neurodevelopmental abnormalities (Chudley et al., 2005; Ryan & Ferguson, 2006a). This umbrella term encompasses sub-terms of FAS, pFAS and ARND, each reflecting clusters of symptoms in the spectrum of FASD characteristics (Chudley et al., 2005; Duquette et al., 2006).

Alcohol is a teratogenic substance, which interferes with development of an embryo or fetus and can cause birth defects or developmental issues related to emotional, physical, behavioural and cognitive development (British Medical Association (BMA), 2016; Mattson et al., 2001). When alcohol is consumed during pregnancy, it can pass directly into the placenta, entering amniotic fluid (BMA, 2016). Without a developed blood filtration system, the fetus removes the toxic substance much slower than the mother, creating a reservoir which is consumed and circulated (Gupta et al., 2016), disrupting cell growth and causing cell death (BMA, 2016; Chung et al., 2021; Cook et al., 2023). The most significant effects are related to neural development, as central nervous system (CNS) cells have a lower toxicity threshold for alcohol and thus, experience more rapid cell death.

Not every woman who consumes alcohol during pregnancy gives birth to a child with FASD (Warren & Foudin, 2001). The extent and severity of the effects of PAE are dependent on several factors like volume, frequency of consumption and pregnancy stage (Mattson et al., 2001), which are difficult to determine due to self-report measures (Brenna et al., 2017). The first and third trimesters are particularly vulnerable periods to the effects of alcohol; the first is critical for brain development, and the third relates to development of the cerebellum, prefrontal cortex and hippocampus (BMA, 2016).

Over the last two decades, understanding of FASD has shifted from moderate alcohol consumption (one-two units) during pregnancy considered safe and reflected in UK guidance, to recognising the damaging effects of PAE (Raymond et al., 2009; McQuire et al., 2019). Research by Nykjaer et al. (2014) who surveyed 1,262 low-risk pregnant women across 2003-2006 exploring alcohol consumption during pregnancy, highlighted alcohol consumption above the then government guidelines (≤ 2 units per week), was highest in the first trimester. Importantly, even ‘low’ consumption aligning with government guidance, was associated with increased risk of adverse birth outcomes (e.g., low birth weight), compared to non-drinking mothers. This growing evidence contributed to updated UK guidance in 2016, advising abstinence from alcohol during pregnancy (DoH, 2016), alongside increased policy attention, funding and development of FASD research and services (Mukherjee, 2022).

2.1.3 Diagnostic Challenges and Support

There are no specific diagnostic tests or biomarkers for FASD. Instead FASD is identified through assessment of all aspects of the clinical inclusion and exclusion criteria, ruling out possibility of other conditions (BMA, 2016). Diagnosis requires a multidisciplinary approach completed by a range of professionals such as clinical psychologists, speech and language therapists, paediatricians, educational psychologists (EPs) and occupational therapists (Cook et al., 2016; NICE, 2022).

In 2015, the All-Party Parliamentary Group (APPG) for FASD was established to raise awareness and influence policy. Despite this, UK support and diagnostic services remain limited and inconsistent (Carrick & Hamilton, 2023), with support largely provided by charities like The National Organisation for FASD (NO-FASD) and FASD Awareness. Currently, the National FASD Clinic in Surrey is the only specialist NHS service, though the centre faces resource constraints, waiting lists and limited capacity (BMA, 2016; NO-FASD, 2022; Westrup, 2013). Consequently, families have to seek private assessment, highlighting ongoing inequalities in accessing services (APPG, 2015). Moreover, caregivers often experience challenges obtaining professional support, limited pre-adoption information and feel blamed for their child’s behaviour due to lack of knowledge and understanding of FASD (Mukherjee et al., 2013)

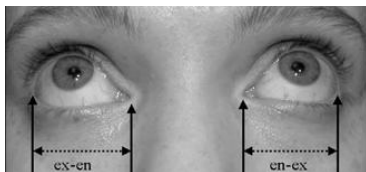
In 2019, the first UK national clinical guidelines for CYP exposed prenatally to alcohol were produced in Scotland (SIGN, 2019). In line with international guidelines, three diagnostic labels were developed: *FASD with sentinel facial features*, *FASD without sentinel facial features* and *at risk for neurodevelopmental disorder and FASD*. These guidelines

outline there must be consideration for and documentation of any growth impairment or growth defects, genetic factors and hereditary, prenatal or postnatal factors which may influence developmental outcomes (SIGN, 2019). To meet criteria for diagnosis of *FASD with sentinel facial features* all of the following must be present (SIGN, 2019):

- Simultaneous presentation of three sentinel facial features (short palpebral fissures- narrow opening between upper and lower eyelids, smooth philtrum, thin upper lip) (Figures 1 and 2).
- PAE confirmed or unknown
- Severe impairment (global score or major subdomain score on a standardised neurodevelopmental measure ≥ 2 SDs below the mean), in three or more identified neurodevelopmental areas (brain structure, motor skills, cognition, language, academic achievement, memory, attention, executive functioning, affect regulation and adaptive behaviour, social skills or social communication) or, in infants presence of microcephaly (head circumference $< 2^{\text{nd}}$ percentile).

Figure 1

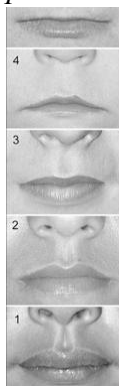
Palpebral Fissure Length



Note. Measured by identifying the inner and outer corner of the eye. Reprinted with permission from Canadian Medical Association Journal (Chudley et al., 2005).

Figure 2

Lip-Philtrum Guide, 5-Point Pictorial Scale



Note. Reprinted with permission from Canadian Medical Association Journal (Chudley et al., 2005).

In the absence of facial features, to meet criteria for *FASD without sentinel facial features*, there must be both:

- Confirmed PAE
- Evidence of severe impairment in three or more identified neurodevelopmental areas (SIGN, 2019).

Given that sentinel facial features are present in less than 10% of cases, FASD has been coined a ‘hidden’ condition, creating diagnostic challenges (Millar et al., 2017). For children who have confirmed PAE and evidence of neurodevelopmental impairment, but do not meet either aforementioned categories, *at risk for neurodevelopmental disorder and FASD* was developed. This label may also be considered for individuals with all three sentinel facial features, but who do not yet have evidence of impairment of at least three neurodevelopmental areas; this label cannot be used when PAE is confirmed as absent. Often, effects of PAE may not be present during early development, thus ‘at risk’ ensures continued access to services. The diagnostic algorithm is detailed in Appendix A.

Although the UK is considered behind in FASD diagnosis and prevention, there have been positive developments in service delivery. Building on SIGN (2019) guidelines, NICE (2022) introduced quality standards for assessment and diagnosis, which applies across England and Wales. NICE outline diagnosis should include review of family, social and medical history, physical examination and assessment should result in Individualised Management Plans.

2.1.4 Prevalence

FASD is considered the most common preventable developmental disability worldwide (Hoyme et al., 2016). While knowledge of the damaging effects of PAE is developing, fetal damage resulting from alcohol continues to occur (SIGN, 2019) and is considered a public health concern (Riley et al., 2011; Scott & Sher, 2023).

Alcohol consumption data during pregnancy is limited, and reliability of self-report measures should be interpreted with caution, as inaccuracies may exist due to fear of judgement and stigmatising beliefs (BMA, 2016; Wilson et al., 2024). While the UK is estimated to have the 4th highest prevalence of prenatal alcohol consumption worldwide (Popova et al., 2017), limited studies have explored the UK FASD prevalence. Consequently, the APPG for FASD and BMA highlighted the need for a UK population-based prevalence study. In response, McQuire et al. (2019) sought to quantify the UK prevalence, to guide policy and service development. They developed a novel FASD screening algorithm,

developed from the Canadian diagnostic guidelines (Chudley et al., 2005), applied to pre-existing data from a population-based birth cohort of pregnant women in Bristol between 1991-1992, ($n=13,495$). Findings indicated a prevalence of 6-17%, ranging depending on the analysis strategy used (e.g., if data was available for all areas of CNS, growth, facial and PAE measures (7.2%), data was assumed to be missing (6%), or statistical estimations were made for missing data (17%) (Appendix B). Children from lower socioeconomic backgrounds, unplanned pregnancies and males were more likely to positively screen. Despite limitations like classifications by screening algorithms not reflecting formal diagnostic processes, the study demonstrated the UK prevalence may be higher than estimations from studies across Europe and the USA, which suggest 1-10% of children in the general population have FASD (Lange et al., 2017; May et al., 2018; Roozen et al., 2016). Moreover, these figures suggest the prevalence of FASD may be higher than the estimated UK prevalence of autism (1.1% in adults, 1–2% in children) (Huang, 2020; NICE, 2025), though in comparison FASD remains misunderstood and under-researched (Westrup, 2013). Despite this, McQuire et al. (2019) drew on data collected in the 1990s, when no formal UK guidelines for alcohol consumption during pregnancy existed, which therefore may not reflect current alcohol exposure aligning with new guidance.

To address this and further explore the UK prevalence, McCarthy et al. (2021) completed a two-phase active case ascertainment across three mainstream primary schools in Manchester, considered the gold standard in prevalence research (Roozen et al., 2016). Using prespecified criteria for elevated FASD risk (small for age, SEND, social, emotional and mental health (SEMH) needs, care experienced), two hundred and three, 8-9-year-olds took part in initial assessments of physical measures. Of the fifty children who screened positive for elevated risk factors, twenty-six subsequently completed a detailed FASD assessment, with the other twenty-four assessments not possible due to consent and contact difficulties. Despite no participants having previously been identified with a developmental diagnosis, twenty participants had a developmental disorder (inclusive of autism, attention deficit hyperactivity disorder (ADHD), developmental language disorder and general learning disability), of which four had FASD and four had possible FASD. Prevalence therefore ranged from 1.8%-3.6% when including possible cases. Of the four cases which met criteria for FASD, 75% had reported significant risk of PAE (4 or more drinks, on 4 or more occasions, or >7 units a week during pregnancy) and 25% had no reported PAE. Despite limits to generalisability outside this community, findings highlight the prevalence of FASD is likely higher than current diagnosis rates, though may not be as high as estimates drawn

from 1990s data (McQuire et al., 2019). This suggests a need for increased recognition and diagnostic capacity for FASD, alongside a larger FASD prevalence study across the UK.

2.1.7 Comorbidity

Research indicates a substantial proportion of CYP with FASD remain undiagnosed or misdiagnosed (Chasnoff et al., 2015; Hoyme et al., 2016), with four hundred and twenty-eight identified co-morbid conditions, underscoring the complexities of diagnosis and support (Popova et al., 2016). Diagnostic challenges are exacerbated by overlapping neurodevelopmental and behavioural profiles with genetic syndromes like Williams Syndrome, Cornelia de Lange Syndrome (BMA, 2016), and neurodivergent conditions like ADHD, autism and reactive attachment disorder (RAD) (Bruer-Thompson, 2016; Kingdon et al., 2015). Although NICE (2022) guidelines outline assessments should consider PAE as a potential cause of neurodiversity, it can be overlooked (SIGN, 2019). Therefore, often CYP are given alternative diagnoses, limiting access to support (APPG, 2015; Popova et al., 2016).

2.1.5 Legislative Context

The SEND Code of Practice (DfE & DoH., 2015) highlights the need for educational professionals to maintain high expectations for CYP with SEND and promote inclusion, with a focus on early identification and response to needs across four key areas. Although CYP with FASD often present with needs across all areas, their needs are frequently overlooked within the classroom (Blackburn, 2017). Therefore, recognition and support often depend on diagnosis, despite persistent challenges accessing diagnostic services (Carrick & Hamilton., 2023; Mukherjee et al., 2013). Moreover, under the Equality Act 2010, educational settings must take steps to support CYP with disabilities, like FASD, promoting inclusion and equal opportunities (Blackburn, 2017). However, limited diagnostic services mean many CYP remain undiagnosed and therefore are not protected under the act, despite often having needs beyond ordinarily available support (Lamb, 2021). Without diagnosis and support, CYP are at greater risk of adverse outcomes in education, employment, substance use, and criminal activity (House of Commons Education Committee, 2010), highlighting a gap between legislation and access to support, with a need to raise understanding of FASD.

2.1.6 Developmental Implications

PAE can result in a range of adverse outcomes which persist across the lifespan such as neurodevelopmental abnormalities, growth deficiencies, cognitive, social, emotional and behavioural challenges (Chudley et al., 2005; Hoyme et al., 2016), alongside later risks of substance misuse, involvement in youth justice, unemployment and social difficulties (Knorr

& McIntyre, 2016; Salmon & Beutow, 2012). While effects are not homogenous, studies highlight commonalities in observed implications on brain development and resulting needs (BMA, 2016; Mattson et al., 2011). One of the most commonly reported implications is cognitive difficulties (Dalen et al., 2009), with particular difficulties with short-term memory, attention and understanding mathematical concepts (Blackburn, 2010a). Moreover, difficulties with executive functioning are considered a hallmark of FASD, with difficulties with self-regulation, planning, flexible thinking and inhibition (Kingdon et al., 2015; Martinez-Cengotitabengoa et al., 2023; Mattson et al., 2011). PAE also likely disrupts development of brain regions involved in language development, resulting in speech and language difficulties (Hendricks et al., 2018; Martinez-Cengotitabengoa et al., 2023). Individuals with FASD can also experience SEMH challenges (Knorr & McIntyre, 2016), social difficulties (Davis et al., 2013; Duquette et al., 2007) and sensory processing needs (Carr et al., 2010; Du Plooy, 2017). Together, these differences can make it challenging to manage daily life (Blackburn, 2010a) and can become more apparent in educational contexts due to the social and academic demands (Price et al., 2017), with school reported as a primary stressor (Millar et al., 2017).

In summary, FASD is a lifelong, brain-based disorder which requires ongoing support across health, education and social care (Chudley et al., 2005; Mukherjee et al., 2012). While the UK has progressed its diagnostic approach since SIGN, (2019) and NICE, (2022) guidelines were introduced, there exists limited understanding, with challenges accessing diagnostic services, support and navigating life with FASD. Given the estimated prevalence of FASD (McCarthy et al., 2021), there is a need to raise awareness, reduce stigma and enhance support.

2.2 Literature Review Aims and Terminology

This literature review provides a critical overview of research exploring the educational experiences of CYP with FASD. A narrative review was adopted, organising literature into themed subheadings to explore how FASD presents across educational contexts, including associated barriers, facilitators, strengths and needs (Collins & Fauser, 2005; Sukhera, 2022). Narrative reviews allow critical analysis of existing literature to provide a comprehensive overview of a topic through identifying themes, offering flexibility and relying on the researcher to select, interpret and synthesise studies into a coherent account, identifying research gaps (Bryne, 2016; Ferrari, 2015; Sukhera, 2022). It is also hoped the review can provide a resource to raise awareness and understanding of FASD. This

approach was appropriate given that narrative reviews can be useful in exploring under-researched topics, like FASD, and aligned with an interpretivist paradigm adopted within this research, recognising reality and knowledge as dynamic and subjective (Sukhera, 2022). A systematic review was not deemed suitable, as its focus on strategically evaluating identified studies to answer a specific question may restrict exploration of lived experiences (Grant & Booth, 2007; Nightingale, 2009). Instead, the review prioritised CYP's perspectives to explore; *What are the educational experiences of CYP with a diagnosis of FASD?* Acknowledging individuals are not independent of their contexts (Orsini, 2012) and there is limited research eliciting CYP's views, broader literature was explored to understand the ecological and systemic impacts of FASD, including perspectives of those supporting CYP across home, school, healthcare and community contexts.

To develop a conceptual understanding of FASD, associated terminology and language to inform the review search terms, the researcher explored sources like Google Scholar, NICE, National FASD, FASD Awareness, SIGN, and government publications. As aforementioned, of note is the variation in fetal and foetal within publications and research, reflected within search terms. The main search was conducted using EBSCO Host, alongside databases like ERIC and Science Direct, and was extended using snowballing techniques exploring relevant cited materials, alongside supplementary Google Scholar searches.

While more typical of systematic literature reviews, Table 1 provides the review search terms to improve transparency and reproducibility (Collins & Fauser, 2005), stating the boundaries of the topic search (Sukhera, 2022). The Boolean operator 'OR' was used to encapsulate the variable terminology associated with FASD. The Boolean operator 'AND' was applied to identify research relating to CYP's perspectives and experiences, alongside a focus on education. Initially the search was limited to UK-based research, however this yielded fourteen articles, two of which met inclusion criteria (Appendix C), reflecting the scarcity of UK-research. Consequently, the search was extended to include relevant international literature from Canada, New Zealand, Australia, and the USA. Much of the existing evidence originates from Canada, likely reflecting earlier diagnostic guidelines (2005), comparative to the UK (2019), alongside support for research (Chudley et al., 2005; NICE, 2022; SIGN, 2019).

Table 1

Literature Review Search Terms

Search Terms

"Foetal alcohol spectrum disorder" OR "fetal alcohol spectrum disorder" OR "foetal alcohol syndrome" OR "fetal alcohol syndrome" OR "partial foetal alcohol syndrome" OR "partial fetal alcohol syndrome" OR "alcohol related neurodevelopmental disorder" OR "alcohol related birth defects" OR "prenatal alcohol" OR "pre-natal alcohol."

AND

"Education" OR "school" OR "teaching" OR "classroom"

AND

"Views" OR "experiences" OR "opinions" OR "perspective" OR "voice"

AND

"Child" OR "children" OR "young people" OR "student" OR "pupil"

The review was initiated in August 2024 with additional searches conducted intermittently until March 2026 to incorporate publications meeting inclusion criteria (Table 2).

Table 2

Inclusion/Exclusion Criteria of Literature Search

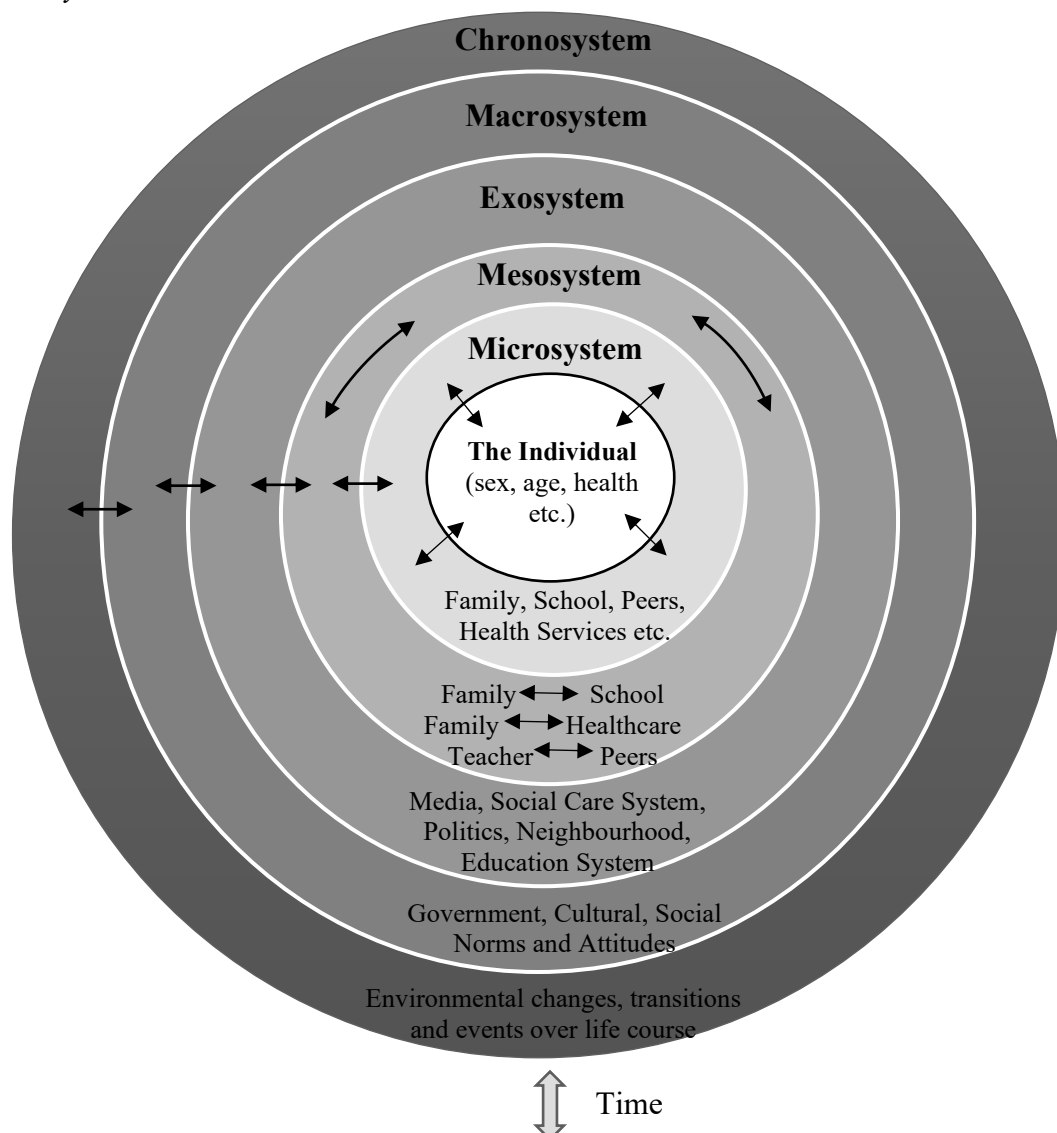
Inclusion/Exclusion Criteria
- Published and peer-reviewed research was preferred. Given the scarcity of research, 'grey' literature which was pertinent and relevant was included (e.g., theses). - Research available in English Language was included, due to not having access to translation services. - Research conducted after 2000 was preferred to ensure the review was current; pertinent studies published prior were included given the limited literature and historical context of FASD. - Primary research exploring other teratogens (e.g., drugs) were not included, as alcohol is the only teratogen included under FASD (SIGN, 2019).

The review considers factors relating to school, home, healthcare, community, society and implications for CYP's experiences. Several studies are pertinent to multiple themes, thus are explained in-depth when introduced and referenced in later subthemes. Recognising development is dynamic and individuals do not develop in isolation (Orsini, 2012), literature was viewed through the lens of Bronfenbrenner's Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006). This framework highlights the multilayered, interconnected systems in which development occurs, which interact reciprocally with each other and the developing individual (Figure 3). This framework supported consideration of

how different contexts and interactions at multiple systems can shape experiences. The model builds on Bronfenbrenner's (1979) Ecological Systems Theory, incorporating the 'bio' aspect to acknowledge the active role of the child and influence of individual characteristics on development (Tudge et al., 2009). This is key in the context of FASD, given its' medical basis and thus, influence of biological factors on experiences and development. Moreover, this model aligns with the interpretivism paradigm adopted in this research, highlighting interpretations of experience are shaped by interactions within societal and cultural contexts (Chowdhury, 2014; Whitley, 1984). The dynamic nature of development was further captured through the Process-Person-Context-Time Model, which emphasises the central role of proximal processes (ongoing interactions between an individual and their environment), in driving development (Tudge et al., 2009). Thus, the later model shifted away from viewing individuals as bystanders of environmental influence, instead recognising how personal characteristics influence development (Bronfenbrenner & Morris, 2006).

Figure 3

A Visualisation of Bronfenbrenner and Morris' (2006), Bioecological Model of Development, Created by the Researcher



Four of five systems of the Bioecological Model were pertinent in this review: microsystem, mesosystem, exosystem and macrosystem. Central to the model is the microsystem, encompassing individuals' immediate environments and direct interactions which most strongly influence daily experiences (e.g., family and school). The mesosystem reflects interconnections between two or more microsystems (e.g. home-school). The exosystem includes indirect influences on the child, but which influence development and experiences, like mass media, education policies and social care systems. The macrosystem captures broader cultural and societal values, ideologies and beliefs like educational values and responsibility of the individual or collective (Bronfenbrenner & Morris, 2006).

The chronosystem was later introduced to reflect the influence of time and historical context on development (Bronfenbrenner, 1986), such as attitudes towards childhood. However, it was not considered relevant to this review due to the individualistic nature of chronosystem factors on development, which are not typically reflected in research exploring multi-sample populations. Nevertheless, it would be valuable to explore the impact of chronosystem-events like the COVID-19 pandemic on educational experiences and the importance of chronosystem influences is reflected on further in chapter three.

While broader systems provide important context, the microsystem was the most prominent within this review related to educational experiences. Viewing literature through this framework (Bronfenbrenner & Morris, 2006) supports understanding of CYP's experiences as multifaceted and shaped by interactions across multiple systems. Their experiences therefore cannot be understood in isolation, but through the influence of multiple interacting factors.

2.2.1 The Developing Person: Individual Characteristics, Meaning-Making and Educational Experience.

As highlighted by Bronfenbrenner and Morris (2006), CYP play an active role in their development. Therefore, this section explores how individual characteristics can shape interactions and the educational experiences of CYP with FASD.

Cognition and Learning. PAE is associated with various cognition and learning needs (Millians, 2015), described as primary effects (Wilson et al., 2024). These can contribute to later secondary effects, impacting educational experiences, employment, mental health and involvement with the justice system (Streissguth et al., 1996; Wilson et al., 2024). Research highlights poorer educational outcomes for CYP with, than without sentinel facial features, performing lower across processing speed, IQ and executive functioning (Martinez-

Cengotitabengoa et al., 2023), highlighting the need for individualised support. Despite recognised challenges, learning needs are frequently overlooked as these CYP often score within the average or borderline range on IQ tests, which provide a partial view of cognitive abilities (Mattson et al., 2001). Such assessments can miss significant impairments frequently observed in individuals with FASD, like memory, attention, executive functioning, language development and visual-spatial abilities (Davis et al., 2011; Kodituwakka 2007; Mattson et al., 2011), which has implications for support provided. Moreover, due to the broad variation in strengths and needs, CYP with FASD often present with ‘spiky’ neurodevelopmental profiles (Blackburn et al., 2012; Henshaw, 2012). Therefore, while cognitive measures can provide understanding, reliance on these assessments can limit more complex understanding of FASD and CYP’s experiences and may adversely shape support.

Cognitive difficulties have clear implications for learning and thus, educational experiences. A consistent finding is CYP with FASD experience difficulties in maths (Howell et al 2006; Knorr & McIntyre, 2016), described as “one of the hallmarks of FAS” (Duquette & Orders, 2013, p.73). These difficulties may be underpinned by atypical development in parietal and frontal brain regions, (Dehaene et al., 2004), and commonly experienced working memory difficulties (Adams & Hitch, 1997; Klein & Bisanz, 2000), which are crucial for mathematical thinking (Rasmussen, 2005). However, research exploring this area (Rasmussen, 2005; Rasmussen & Bisanz, 2011) is limited by only including younger children (aged 4-6) and narrowly focusing on maths performance, limiting understanding of how these difficulties may present across subjects and as education becomes more complex, such as in secondary school.

Although not all children with FASD have SEND, attainment gaps between these CYP and their peers often widens as children progress into secondary school (Roberts, 2015). Despite this, research exploring school experiences remains limited and often focuses on small samples or retrospective accounts. Duquette et al. (2006) used a multiple case study approach to explore the secondary school experiences of eight CYP (aged 15-20), with FASD living in America or Canada, considering why these adolescents persist in school (complete their education). Tinto’s (1975, 1997) Student Integration Model (SIM) was adopted as a theoretical framework, exploring the interplay between background characteristics and attributes which contribute to goal attainment, academic and social integration. Questionnaires and semi-structured interviews were inductively analysed by coding data, organised into categories informed by Tinto’s SIM. All participants experienced academic challenges, particularly in maths and reading, becoming easily frustrated by failure and

challenge. The research's focus on CYP perspectives was unique, as prior research primarily focused on adult's (e.g. teachers or caregiver) perspectives. Moreover, a multiple-case approach allowed the researcher to make comparisons between participants data, and such conclusions are more powerful than single case studies, (Yin, 2003) increasing generalisability (Baxter & Jack, 2008; Vannoni, 2015). Despite this, all participants were adopted so the experiences of CYP who remain with their birth parents or have unstable care placements may differ, particularly in relation to parental advocacy and support, which was identified as a theme in the research.

Knorr and McIntyre (2016) also highlighted academic challenges experienced by CYP with FASD, through retrospective experiences of four adults (aged 19-30) with FASD from Canada. The research hoped to understand participants' experiences and successes, moving away from deficit-orientated research. Semi-structured interviews were qualitatively analysed into three themes: "I don't fit in", negative school experiences leading to anger and frustration toward diagnosis; intergenerational alcoholism, child abuse, and drug addiction; healing the wounds, sources of strength, success, and helping others. All participants highlighted difficulties with academics, particularly maths, with frustrations understanding learning and applying this independently, despite desire to do well. Difficulties understanding resulted in disengagement, inattention and frustration, leading to participants getting into trouble and causing anger towards their diagnosis.

The literature highlights links between the cognitive implications of FASD and difficulties experienced in education, yet there remains limited research exploring these CYP's educational experiences in the UK, particularly that which elicits CYP's voices.

Self-Advocacy and Individual Strengths. Aforementioned Knorr and McIntyre's (2016) research exploring the retrospective experiences of four adults with FASD from Canada, highlighted individual's strengths in overcoming challenges and achieving success. Although participants faced multiple adverse experiences, they demonstrated resilience and perseverance in school and general life. Participants had a resilient attitude towards adversity and their experiences as a result of their diagnosis, expressing their diagnosis did not define them and their capabilities. One participant's resilient attitude helped her overcome an alcohol and drug addiction, manage years of abuse and access her post-secondary programme. Although this study relied on self-reported experiences which may differ from caregivers' accounts, it highlighted the resilience and perseverance of these individuals in navigating life and education with FASD.

Research highlights that for CYP with FASD, accessing the curriculum may rely on self-advocacy. Brenna et al. (2017) highlighted how awareness of strengths and difficulties can support engagement in learning, through an in-depth case study of a young adult with FASD (Nathan) in Canada, using photovoice methodology and semi-structured interviews. Data was deductively analysed identifying four themes; need to balance support with desire for independence, self-awareness of strengths and challenges, attitude and adaptation strategies for navigating life with FASD, identified needs and advice for others. Nathan demonstrated awareness of his learning challenges in reading, maths, writing, memory and attention, though his attention and motivation increased when he had strengths in the topic, suggesting a link between motivation and self-efficacy. Nathan's account demonstrated his ability to seek support, while advocating for independence in areas of strength. However, his experiences suggest accessing learning places overreliance on CYP to understand their needs and advocate for support. This raises concern as although Nathan could advocate, this may not represent experiences of the broader FASD population, particularly when considering the broad spectrum of implications and needs. Therefore, overreliance on self-advocacy to access learning may exacerbate educational difficulties.

Although generalisability to the wider FASD population is limited by the single-case design (Brenna et al., 2017; Priya, 2020), the researchers clearly state their intentions to recruit a limited sample and provide a rich understanding of an individual's experiences to inform possibilities in the wider population (Maxwell, 2021). Moreover, consideration of individual experience is pertinent given the heterogeneity of FASD (Brenna et al., 2017). It is important to highlight Nathan's account was retrospective which may impact accuracy, though triangulation of interviews with Nathan and his parents' somewhat controls for this. Despite limitations, the study provides valuable insights into the educational experiences of an individual with FASD, taking a novel strengths-based and participatory approach using photovoice, shifting away from deficit-orientated literature and meaningfully including this underrepresented population (Fladet & Nes, 2021; Wang & Burris, 1997). Their approach also enabled participant-led identification of pertinent topics, addressing power dynamics in research exploring lived experiences of phenomena that researchers likely do not have direct experience of (Brenna et al., 2017; Sutton-Brown, 2014). While the research highlights the potential role of self-advocacy in accessing learning, it also identifies a gap in understanding how CYP with FASD navigate learning environments, particularly in the UK-context.

2.2.2 *Microsystem*

The educational experiences of CYP with FASD are shaped not only by individual characteristics, but also by interactions in immediate environments, reflecting the microsystem (Blackburn, 2017; Bronfenbrenner & Morris, 2006). The microsystem refers to settings and relationships CYP directly interact with such as parents, siblings, peers and teachers (Bronfenbrenner, 1979). This section explores how these interactions shape these CYP's educational experiences.

2.2.2.1 The School System. School plays a key role in shaping educational experiences through classroom practices, relationships, peer interactions and systemic factors.

Belonging. Despite predominance of international research in this field, Hammond's (2021) doctoral thesis represents the first UK-based study to explore school belonging with CYP with FASD (aged 7-10) in mainstream settings. Using a participatory, mosaic approach, data was collected using semi-structured interviews and analysed using IPA. All participants felt they belonged in their settings, attributed to four themes. 'School Ethos and Sense of Community' was fundamental in fostering a positive sense of belonging, supported by school rules and values, extracurricular activities, responsibility for pets and parental support bridging the gap between home and school. 'Relatedness to Peers' highlighted inclusion in peer groups as instrumental to belonging, reflecting the importance of play and support from friends in school, with one participant naming his peers as more supportive in learning than teachers. Participants reported attributes of staff who helped them feel safe, secure and accepted and CYP benefitted from being held in mind during the COVID-19 pandemic, captured within 'Staff Attributes and Teaching Practices'. When teachers understood participants' needs, they provided more tailored support. 'Myself as a Learner' captured participants' awareness of their strengths, needs and factors which helped them to feel academically integrated such as working hard, praise, agency and autonomy in learning.

The findings highlight the relational and contextual nature of belonging, alongside the role of self-awareness in navigating educational experiences. Hammond's strengths-based, participatory research, framed in 'what works' is a notable contribution to the evidence base which primarily focuses on deficits, demonstrating how a mosaic approach can capture these CYP's voices, which are underrepresented in research. However, the research is not in a peer reviewed journal and generalisability is limited by the small sample, who were primary-aged, mainstream-educated and adopted or fostered. Thus, there is a need to explore the experiences of school belonging for CYP with FASD in secondary settings, where social and

academic contexts are typically more complex, alongside seeking to include CYP across more diverse contexts (e.g. care status and education setting).

Social Integration and Managing Emotions. While some research highlights positive experiences of belonging (Hammond, 2021), wider literature suggests CYP with FASD often experiences social exclusion within school. Despite desires to fit in, academic challenges mean these CYP are often placed in specialist classes, contributing to social isolation and difficulties with peer relationships (Dow, 2020; Wilson et al., 2024). Findings from Knorr and McIntyre (2016) similarly indicate CYP's experiences of limited belonging in educational settings, with CYP's heightened awareness of difference, "I didn't fit in", "loner" and "outcast" (p.60-61), resulting in frustration towards their diagnosis and difficulties managing emotions. Social challenges were reflected in one participant acting out in an attempt to seek any attention, reported as behaviour learnt through the home context to be noticed. All participants reported difficulties making friends, attributed to being "shy" (p.61), peers being "mean" (p.61) and not wanting "to be friends with anyone who was slow" (p.60).

Participants also reported being bullied in school (Knorr & McIntyre, 2016), resulting in reluctance to attend. One participant reported being extremely impressionable, highlighting the vulnerability of these individuals to social exclusion within education and society (Mukherjee et al., 2013; Skorka et al., 2020). The findings highlighted a cycle of limited belonging and social isolation. In attempts to gain acceptance or attention with awareness they did not fit in, CYP adopted maladaptive coping strategies (e.g., acting out), resulting in increased social isolation. Similarly, not fitting in led to bullying, which resulted in further isolation through reluctance attending or engaging in antisocial behaviours, intensifying difficulties navigating school. The findings highlight the social integration difficulties in education for these CYP, shaped by academic challenge, emotional, behavioural and relational factors. However, the findings are drawn from research outside the UK and thus further exploration in UK education contexts is needed to better understand how experiences may differ between contexts.

Establishing and Maintaining Appropriate Friendships. Research highlights these CYP's difficulties establishing and maintaining friendships in school. Duquette et al. (2007) used questionnaires and open-ended interviews with eight CYP with FASD from Canada who were attending high school or had recently graduated, and their parents, to explore secondary school experiences and inhibitory or contributing factors to persistence, informed by Tinto's SIM (1975, 1997). Social integration was one of three overarching themes. Most participants reported having friends and feeling socially comfortable, with connections associated with

peers rather than teacher relationships. Although CYP valued peer relationships, 50% noted difficulties sustaining friendships. Participants' social experiences varied, dependent on situational factors such as peers and the environment of interactions. One participant reported being more comfortable in special classes because of the peers present. Adoptive parents reported that although CYP expressed a sense of belonging, they often chose inappropriate friendships and struggled to distinguish between friends and acquaintances, attributed to developmental immaturity associated with FASD. Worryingly, the two CYP who attended private settings adapted their behaviour to socially survive, viewing peer relationships as vital in navigating school. While conducted outside the UK, these findings highlight the social vulnerability of CYP with FASD in educational contexts.

Similar findings were highlighted in Duquette et al. (2006) prior research exploring persistence in high school. Data collected from questionnaires and semi-structured interviews were inductively analysed and organised into categories. All eight CYP reported having friendships, though four CYP indicated difficulties keeping friendships and three acknowledged they were not accepted by their peers. Peers helped participants socially and academically survive, such as dealing with bullies and supporting with learning. Moreover, parents highlighted CYP considered themselves to be more socially integrated than they were, and those they considered friends were acquaintances, with superficial understanding of friendship. The findings highlight CYPs reliance on peers to navigate school, alongside difficulties establishing and maintaining relationships, reinforcing their social vulnerability.

In contrast, Duquette and Orders (2013) suggest social integration may become less prominent in post-16 education. They explored post-16 experiences of four individuals with FAS or ARND in Canada or the USA, and what helps secondary students persist beyond compulsory school age. Participants were 26-43 years old, thus reported on their retrospective experiences. In-depth interviews with CYP were analysed and grouped into categories, informed by Tinto's SIM (1975, 1997). A key aspect of the SIM is social integration, though only one participant reported being socially integrated in their post-secondary setting. This participant's mother highlighted their vulnerability, as they become friends with people who were negative influences and were easily influenced to participate in activities like drinking, which were linked to him dropping out of education. For the other participants, the researcher highlighted their limited reports of social integration may relate to negative social experiences in primary and secondary settings, which may have resulted in caution of friendships in post-16 settings. Therefore, in contrast to Duquette et al. (2006, 2007) previous research, for these CYP, social integration did not contribute to persistence to complete

college, though this highlights the ongoing experiences of social vulnerability for these CYP, which should be explored further in different contexts. Moreover, due to participants' age, reliability of retrospective accounts should be interpreted with caution, as time between their lived experiences and recall may impact accuracy of accounts.

Although Knorr and McIntyre (2016), Duquette et al. (2006, 2007), and Duquette and Orders (2013) studies were conducted in Canada and may not reflect experiences in UK-contexts, findings provide insights into the social challenges experienced by CYP with FASD within education. Therefore, further UK-based research is needed, particularly exploring how CYP interpret and understand their experiences of social integration, as findings suggest caregivers may be more aware than CYP themselves, of the extent of their social integration difficulties.

Classroom Environment and Individualised Support. Research suggests CYP with FASD benefit from structured, individualised classroom support. Duquette et al. (2007) aforementioned research exploring inhibitory or contributing factors to persistence in secondary school, highlighted successful school experiences were associated with being able to participate academically through passing courses, completing work and obtaining certification. CYP benefited from classroom adaptations, high expectations and challenge, which was particularly reflected in specialist, private schools with smaller classes. Similar findings were highlighted by Duquette et al. (2006) whereby participants who moved to private schools commented on their positive experiences, with one participant highlighting how this improved her confidence and involvement in her setting. Another benefited from teachers' hands-on approach and influence from positive role models, identifying friends as the reason she persisted. However, within Duquette et al. (2007) research, the curriculum and teachers were identified as factors inhibiting school persistence. Some CYP experienced mismatches between their needs and curriculum demands, with work being insufficiently challenging or overly difficult. Parental accounts further highlighted barriers to accessing learning, such as teachers' inflexibility to make adaptations and lack of understanding, attributed to the lack of physical visibility of FASD, resulting in fighting for teachers to implement support.

Together these findings suggest instead of removal of educational challenge, these CYP require adjustments tailored to individual needs, alongside support from attuned adults. The findings also suggest links between adaptations, expectations and smaller class sizes in supporting motivation and positive engagement, though these findings are limited by the focus on experiences in Canada. However, UK-based research (Hammond, 2021) focusing on

primary-aged CYP's experiences of school belonging similarly highlights the importance of an individualised approach and tailored provision. When teachers understood participants' needs, they were perceived as skilled in offering adjustments, and such adaptations contributed to perceptions of school success. Therefore, research conducted in the UK and Canada highlights the importance of individualised support for CYP with FASD, supported by staff understanding CYP's needs and flexibility of adjustments. While this has been explored in UK primary contexts and internationally in secondary contexts, there remains limited understanding of how such support is experienced in UK secondary schools, where increased teachers, transitions between classes and often reduced parental involvement may exacerbate challenges.

Relationships as a Protective Factor. Supportive relationships appear central to positive educational experiences. Skorka et al. (2022) explored the lived experiences of four adolescents (aged 12-18) with FASD in Australia, through semi-structured interviews and photo elicitation analysed using IPA. The findings highlighted the key role of positive relationships with caregivers and friends in supporting participants to navigate their daily lives. The importance of such relationships was also reflected in educational contexts, with greater enjoyment in lessons when teachers took time to form relationships. These findings highlight how relationships can be a protective factor to these CYP's educational and daily experiences, with strengths in adopting a photo elicitation approach, to support inclusion of these CYP.

Similarly, Duquette and Stodel (2005), highlighted the importance of relationships through their pilot study which preceded their later research, exploring the educational experiences of CYP with FASD and factors which make school positive. Within this study, questionnaires were completed by seven adopted CYP who had FASD (aged 9-28) and eleven parents. These participants were invited to take part in semi-structured interviews and four CYP and five parents agreed to take part. Themes were identified through qualitative analysis which highlighted that although experiences of positive teachers varied, a key element which contributed to successful school experiences was caring teachers who were knowledgeable about FASD and made accommodations. CYP found it supportive when teachers helped them achieve their goals, supported their behaviour, used simple language, visuals and slow explanations and a peer buddy system to support understanding. These findings highlight the positive influence accommodating and understanding teachers can have on these CYP's educational experiences. However, there are validity concerns about data collection methods as questionnaires were completed at home, thus it is hard to ensure CYP's

views were not influenced by caregivers. However, triangulating differing viewpoints through questionnaires and semi-structured interviews increases the trustworthiness of accounts. The study was also completed in one small area of Canada and thus may not be representative of experiences outside of this population, however the pilot nature of this research laid the methodology foundations for their later research.

While these studies focus on experiences in Canada and Australia and thus may not be representative of CYP's experiences of FASD in different countries, the findings consistently position relationships as central in shaping and mediating educational experiences, with a gap to explore this further in different contexts.

Lack of Teacher Knowledge and Support. A common challenge highlighted in literature, is limited teacher knowledge of FASD and associated implications (Green et al., 2014; Sanders & Buck, 2010; Watson et al., 2013) which can shape these CYP's educational experiences. Skorka et al. (2020), conducted a critical review of literature exploring the experiences of CYP (aged 5-18) with FASD and their families and impacts on daily functioning across school, home and the community. Eleven papers were included and coded to identify themes. Inadequate school support was identified and parents reported frustrations regarding staff's limited understanding of CYP's needs, particularly their responses to behaviour, resulting in communication breakdowns and inappropriate support. Limited teacher knowledge was also highlighted by Duquette et al. (2007). Teachers were identified as a factor which inhibited school persistence for adolescents with FASD, due to not implementing provision, lacking knowledge and being unsympathetic as they did not believe these CYP struggled to complete work.

Similar findings regarding teacher knowledge were identified in UK research exploring adolescents lived experiences of FASD across home, school and community contexts. Eodanable et al. (2024) used photovoice methodology and semi-structured interviews with eight adolescents (mean age=14.5). Participants identified labels for photos and used codes of focus (e.g., what, who, where) to develop categories, the researcher then conducted IPA of transcripts, developing two themes. 'Adolescents living with FASD' captured the breadth and variation of challenges alongside supportive measures experienced by these CYP. 'Supports and coping with FASD' captured educational adaptations. Adult support was crucial, particularly from Teaching Assistants (TAs), however participants had a contrasting view of teacher support, feeling dismissed and teachers focusing on the pace of the curriculum rather than support. Due to teachers' limited knowledge, experiences supporting FASD and assumptions of disability, one participant felt the need to teach their

teacher how to support their needs related to FASD. Despite this, teachers often maintained an expert role, dismissive of CYP's suggested adaptations. These findings highlight how limited teacher knowledge and adaptation can shape experiences and perceptions of school, contributing to a scarcity of literature as the first UK-based published research exploring the experiences of adolescents with FASD across home, school and community. Moreover, using participatory methods is a strength as non-verbal strategies can empower CYP to share their voice and have autonomy in research, pertinent for CYP with FASD whose cognitive challenges may limit participation (Overmars-Marx et al., 2018). Participants were diverse in relation to school placement and care status, but were all from white ethnic backgrounds, thus findings may not reflect the experiences of CYP with FASD from different ethnicities. Consideration of how societal and cultural factors may shape educational experiences of CYP with FASD is pertinent given estimated prevalence rates of FASD are much higher in developing countries, such as 28% in South Africa (May et al., 2018), echoing the principles of Bronfenbrenner's bioecological perspective in understanding experiences (Bronfenbrenner & Morris, 2006).

While teacher knowledge has been explored in adolescent samples, (Duquette et al., 2007; Eodanable et al., 2024) similar findings were reflected across preschool, elementary, secondary and post-16 contexts. Ryan and Ferguson (2006a) explored the diagnostic process and experiences of professionals and families of five CYP (aged 3-19) with FASD from Alaska, over a three-year qualitative study. Data represented a subset of their larger data set exploring later life outcomes for CYP with FASD (Ryan & Ferguson, 2006b), thus these were the same participants at a younger age. Data was collected through semi-structured interviews with various stakeholders, observations (400+ hours) of school, home and professional settings, alongside analysing documents. Three themes were identified. 'On, yet under the radar' highlighted the invisible nature of FASD observed across home and school, despite increased societal awareness of FASD in Alaska. One teacher suggested these CYP go under the radar as their needs do not present as the greatest in class. While research suggests teachers can be reluctant to believe CYP's presenting needs (Duquette et al., 2007), these findings suggest needs may go undetected due to the 'hidden' nature of FASD, alongside other CYP presenting with more overt needs (Millar et al., 2017). Thus, attributing these challenges solely to teacher knowledge may risk oversimplification. Moreover, Ryan and Ferguson's (2006a) findings suggest adaptations are dependent on experience, becoming embedded in practice for experienced teachers, identifying they do not overtly treat CYP with FASD differently. Less experienced teachers echoed not doing anything differently, though

this did not hold the same meaning, as these teachers became frustrated by the need to make adaptations. These findings highlight the importance of teacher training to ensure teacher confidence and consistency supporting these vulnerable CYP. A culture of blame on teachers is unhelpful. Instead, a meta perspective is needed to consider how exosystem factors, like limited funding for training and societal knowledge of FASD (Bronfenbrenner & Morris, 2006) can shape teachers' confidence knowledge and reliance on experience-based strategies.

Literature suggests CYP with FASD navigate educational environments shaped by a complex interplay of classroom practices, relationships and teacher knowledge. While individualised support and positive relationships can be protective, experiences are inconsistent. Moreover, much of the existing research is based on small samples outside of the UK and there remains limited research focusing on how CYP experience these factors within UK secondary education settings. This highlights a need for research which centres CYP's voice, to better understand how school-based factors shape their experiences.

2.2.2.2 The Home Context. The educational experiences of CYP with FASD are also shaped by interactions within the home context, like support and advocacy from caregivers, reflecting the microsystem. This section therefore explores how these interactions shape these CYP's educational experiences. Some elements also reflect the mesosystem, such as interactions between parents and supporting services, explored in greater depth later in this review.

Parents as Advocates. Within literature, CYP highlight family support as central in predicting educational experiences (Duquette et al., 2007; Stade et al., 2011). Within Duquette et al. (2007) research, parental support strongly contributed to persistence in secondary school, with five of eight participants noting their parents as the reason they remained in school. Parents not only provided academic support, but also emotional support and advocacy. Parents spoke of "battles" (p.587) with healthcare professionals in receiving an accurate diagnosis for their child and with educational professionals in relation to school placement and classroom adaptations. Parents were knowledge-disseminators, informing teachers and professionals about support needed, thus parental advocacy was the strongest predictor of school persistence. While this study highlighted parents as protective for these CYP within education, their sample was limited to adoptive parents who had adopted CYP at a young age. Therefore, the research has limitations to generalisability due to its Canadian context, alongside the perspectives of birth parents and caregivers adopting CYP at a later stage not being included, whose experiences and ability to advocate may vary.

Similar findings regarding parental support and advocacy were highlighted by Stade et al. (2011) in Canada, exploring CYP's experiences of living with FASD. Twenty-two participants with FASD (aged 6-18) completed multiple in-depth interviews, analysed using Colaizzi's method (descriptive phenomenological approach), to understand how CYP make sense of their experiences. Three overarching themes encapsulated participants' experiences: knowing their disability, feeling alone-feeling supported and overcoming the disability. Support received from caregivers (biological, kinship, adoptive and foster), was central to CYP's experiences. While the research focused on day-to-day life experiences rather than specifically educational experiences, the unstructured nature of interviews allowed participants to explore pertinent areas. Given that all participants commented on the significance of parental support across home, healthcare and education, parental advocacy appeared central to these CYP's experiences. The research has strengths in including CYP of various ages, who commented on their current experiences, avoiding limitations of retrospective accounts noted previously. Moreover, their inclusion of CYP who remain with their biological parents ($n=3$) and relatives ($n=2$) provides valuable insights, since aforementioned studies were limited to adoptive or foster families (Duquette et al., 2007). While relevant to Canada, these findings add nuanced understanding suggestive that parental advocacy is key for both adopted CYP and those living with biological relatives.

Although research highlights the positive impacts of parental support for CYP with FASD, literature also highlights overreliance on parental advocacy and knowledge (Domeij et al., 2018; Wilson et al., 2024). Within their scoping review of studies exploring lived experiences of individuals with FASD, Wilson et al. (2024) highlighted lack of knowledge and support as a major challenge. Parents felt they needed to advocate for their child (biological or adoptive) to ensure they are understood and supported, sharing knowledge to counteract professionals' knowledge. Professionals acknowledged feeling unprepared and unsupported to help CYP with FASD, relying on caregiver knowledge. This was particularly pertinent in education settings to ensure learning was within CYP's abilities. Studies were predominately conducted in Canada ($n=36$), likely reflecting earlier diagnostic guidelines' comparative to the UK and support for research, thus the findings may not reflect experiences outside this context, with only four UK studies included. Moreover, some participants self-reported FASD, reflecting diagnostic challenges, therefore caution is needed when comparing findings with those from individuals with confirmed diagnoses. Despite this, findings highlight a substantial gap in knowledge and support for these CYP, with over reliance on

parental knowledge. Moreover, the limited UK-based research highlights a need for greater understanding of the lived experiences of CYP with FASD within UK contexts.

Literature highlights how home-based factors and interactions shape CYP's experiences across contexts. Within Bronfenbrenner's framework, these factors form part of the microsystem, and some reflect the mesosystem (e.g., home-school relationship), where limited professional knowledge can result in overreliance on parental advocacy. However, CYP's voices remain underrepresented, particularly in the UK, highlighting the need to explore how CYP understand their experiences shaped by interactions across broader systems.

2.2.3 Mesosystem

This section considers how interactions between microsystems, reflecting the mesosystem, influence CYP's educational experiences. Particularly highlighting the role of home-school relationships in shaping the outcomes for CYP with FASD (Bronfenbrenner & Morris, 2006; Poth et al., 2014).

Home-School Relationship. Home-school relationships built on trust have positive implications for support provided, parental views of school and thus educational experiences. Contrastingly, fragmented home-school relationships can adversely impact CYP's educational experiences (Job et al., 2013; Griffiths, 2022). Job et al. (2013) exploratory research highlighted the importance of home-school relationships in supporting CYP with FASD. Through focus groups and interviews with teachers, administrators, caregivers and professionals, the researchers explored the need for collaboration, considering successes and challenges, to understand how to facilitate positive working relationships. Findings highlighted the importance of mutual respect in fostering collaboration and communication between home and school. While some educators valued open communication, many parents felt their views were overlooked, whereas educators emphasised respect for their professional expertise. A need for greater honesty and transparency was identified, though collaboration was hindered by perceived parental disengagement, with parental experiences of stigma and judgement creating barriers to collaboration. While the findings are limited to experiences in Canada, limiting applicability outside this context, they highlight the importance of collaborative home-school relationships which indirectly shape CYP's educational experiences. Moreover, their triangulation of multiple perspectives is a strength, contributing to a limited research base exploring teacher perspectives relating to FASD. While CYP's

views were not included, their awareness of the home-school relationship may be harder to identify due to being separate from these interactions.

Similar findings highlighting the importance of home-school relationships were highlighted by Poth et al. (2014), who explored the experiences of CYP with FASD and influences of classroom practices from the perspective of teachers, administrators, allied professionals and caregivers. Data from eleven focus groups and three interviews were analysed, generating three themes. Home-school relationships built on trust were central to CYP's success and promoted consistent approaches across settings. Educators highlighted the need to be sensitive to families' experiences raising a child with FASD and caregivers highlighted the need to feel heard and respected. Similarly to Job et al. (2013), including multiple perspectives was a strength in triangulating accounts, though perspectives were restricted to Canada, limiting generalisability. While there are limitations of adopting focus groups in relation to information participants are willing to discuss in group contexts, measures were taken to reduce this, and the findings offer valuable insight to understanding these CYP's educational experiences as multifaceted and shaped by interactions at the mesosystem.

The importance of home-school relationships was further highlighted in the UK context by Griffiths (2022), who explored the views of parents (8 adoptive, 1 foster carer) regarding FASD and education, alongside implications for EPs. Using semi-structured interviews analysed through thematic analysis, four overarching themes highlighted the complexity and individuality of CYP's needs, with a need to understand CYP both as an individual and an individual with FASD. Parents highlighted the importance of viewing behaviour as communication, particularly in education settings which were reported as challenging. Relationships were key in fostering belonging. Parents valued communication and collaborative home-school relationships, however there was overreliance on parents to facilitate this. Home-school relationships lacking shared responsibility resulted in distrust and limited support. These findings highlight the need for improved awareness of FASD, particularly among educational professionals, with over-reliance on parents as knowledge-disseminators. While the sample was limited to one region of the UK and does not capture birth parents' perspectives, the research contributes valuable insights of caregivers to limited UK research exploring FASD and education. The findings suggest home-school relationships are central to caregivers' experiences supporting CYP with FASD, and thus may also shape CYP's educational experiences, with a need to consider how CYP themselves interpret mesosystem interactions.

2.2.4 Exosystem

The exosystem reflects interactions which CYP are not actively involved, but which indirectly shape their experiences (Bronfenbrenner & Morris, 2006). For example, Poth et al. (2016) highlighted the impacts of financial constraints of schools', impacted by government policy in the exosystem, on support received by CYP with FASD in school. This section therefore explores how factors like social care systems and education policies can shape educational experiences.

Social Care. In his narrative account of his experiences as a teacher, foster carer and virtual school head, Roberts (2015) highlights FASD may be far more prevalent among care-experienced individuals than in the general population, with unvalidated estimates suggesting 30-90% of care experienced individuals are affected to some degree. Moreover, for CYP with FASD in foster care, the complexity of their needs often results in multiple placements and placement disruption (Skorka et al., 2020). Therefore, while external to CYPs' immediate environment, the social care system can impact CYP's experiences through custody arrangements and care placements.

Ryan and Ferguson's (2006a) aforementioned three-year qualitative study, exploring the diagnostic process and experiences of professionals and families with five CYP with FASD from Alaska, highlighted these CYP's social care experiences. Majority of CYP were in the care of foster or adoptive parents, had experienced multiple placements and social care involvement throughout their lives. Participants also experienced frequent transitions within family networks, dependent on parental bereavement and caring abilities. The researchers highlighted through their longitudinal observations that frequent experiences of living transitions resulted in risks of falling through cracks of support services, suggesting social care experiences can have broader implications for these CYP's experiences. Moreover, placement instabilities experienced by these CYP likely disrupts other areas like changes in school placements, highlighting how experiences at the exosystem can influence educational experiences at the microsystem.

Exclusion and Behaviour Policies. Caregivers report concerns that expectations of education systems, often exceed the abilities of CYP with FASD (Sanders & Buck, 2010). Due to lack of physical features and spiky developmental profiles, the first indications of FASD may present through behaviours, which can result in exclusions when met with well-intended, but ineffective behaviour strategies (Carrick & Hamilton., 2023). Streissguth et al. (2004) highlight the high prevalence of disrupted school experiences among four-hundred

and fifteen CYP with FAS or FAE (61%). Furthermore, their earlier research exploring secondary disabilities experienced by CYP with FASD (Streissguth et al., 1996), highlighted 60% of participants had been suspended, expelled or dropped out of school. Challenges related to inattention, not completing work, behaviour and difficulties with peer relationships. Although dated, their research alongside wider literature, suggests these issues have persisted for decades. This highlights the need to explore how CYP interpret their experiences of exclusion, alongside considering how barriers and facilitators to inclusion may be addressed to reduce associated risks.

Within Duquette et al. (2007) study exploring the experiences of eight adolescents and their persistence in school, although most participants wanted to succeed and complete school, seven of the eight CYP had been suspended, with one participant experiencing at least twenty-five suspensions. Similarly, in Duquette et al. (2006) earlier research, almost all participants experienced disruptive school experiences. Although experiences differed, commonalities included suspension for “defiant behaviour” (p.223), movement to specialist classes and parental withdrawal from school due to behaviour escalation. Roberts, (2015) highlighted limited awareness of FASD among educational staff, particularly regarding reasons behind presenting behaviours, can result in CYP with FASD being labelled as disruptive, defiant and lazy and faced with punitive approaches. Similar findings were identified by Salmon and Beutow (2012) mixed-methods design exploring the daily challenges and experiences of fourteen individuals (aged 14-37) with FAS or FAE in New Zealand; many participants had left school or been expelled for their behaviour. These CYP often appeared stubborn and unmotivated but struggled to cope with the overwhelming sensory input of school environments. Roberts (2015) further detailed that due to the cognitive needs associated with FASD like poor memory and organisational skills, punitive approaches often do not have the intended outcome, resulting in cycles of sanctions without CYP developing understanding of appropriate behaviours. CYP with FASD also have difficulties with impulsivity, therefore behaviours which appear intentional are often driven by alcohol-related neurodevelopmental differences (Roberts, 2015). Therefore, there is a need for educational professionals to reframe expectations from ‘won’t’ to ‘can’t’ (Roberts, 2015), to avoid risks of exclusion and disengagement with education.

Bronfenbrenner’s framework supported consideration of external, though influential systems on these CYP’s educational experiences which are multi-faceted. Literature highlights how social care experiences can result in instability, alongside inflexible behaviour

policies shaping CYP's experiences of inclusion, driven by limited understanding of needs associated with FASD (Bronfenbrenner & Morris, 2006).

2.2.5 Macrosystem

Adopting Bronfenbrenner's framework helped conceptualise how macrosystem factors like societal stigma and parental blame can indirectly shape these CYP's educational experiences (Bronfenbrenner & Morris, 2006).

Stigma and Blame. Reedman et al. (2024) conducted a systematic review of research exploring the school experiences of CYP with FASD and their teachers, highlighting the stigma faced by these CYP and their families, parental blame (Mukherjee et al., 2013; Wilson et al., 2024) and educators' limited awareness and understanding of FASD (Duquette et al., 2007; Eodanable et al., 2024; Ryan & Ferguson, 2006b). While relationships and flexible approaches were identified as supportive in shaping educational experiences (Duquette et al., 2007; Hammond, 2021), stigma impacted societal bias and discrimination, particularly related to gender, substance use and race. In Canada, FASD is often misperceived as an 'indigenous only' issue, leading to disproportionate blame and judgement towards indigenous mothers as promiscuous and irresponsible, rooted in longstanding systemic racism (Choate & Badry, 2019; Wilson, 2018). The review also highlighted stigma is intensified by narratives framing FASD as preventable, positioning mothers as responsible and accountable for their child's outcomes and costs of support (Kendall-Taylor & Fond, 2017). The researchers highlight that blame-focused discourses commonly ignore systemic factors contributing to PAE like poverty, trauma, access to care and support. Moreover, framed within a world view of neoliberalism which emphasises individual responsibility, disability can be viewed as something needing 'fixing'. However, FASD support is lifelong and focused on building skills, given that there is no cure. Such long-term, systemic support requires investment and can create adverse societal stigma towards the FASD community. This systematic review and the findings, particularly those regarding indigenous populations in Canada, have limited generalisability to different societies and cultures. However, the research highlights the societal stigma faced by this community as a result of macrosystem factors like cultural ideologies, government policy and political climates. Such factors are likely to indirectly shape CYP's experiences in education, such as adults' understanding, availability and investment in support.

Wilson et al. (2024) highlighted similar findings regarding stigma experienced by CYP with FASD and their families, through their aforementioned scoping review exploring

the lived experiences of individuals with FASD. Findings highlighted the challenges and rewards of raising a child with FASD, with caregivers reporting their experiences of stigma from professionals in healthcare and education, and the general population. Adoptive and biological carers felt misunderstood, blamed for their child's behaviour and stigma impacted caregiver burden. In contrast, biological parents felt stigmatised for being responsible for their child's difficulties, while many mothers are not aware of the implications of alcohol consumption during pregnancy. Stigma and blame contributed to negative caregiver and professional interactions at the mesosystem level, creating barriers to support and shaping CYP's experiences within microsystems. Families often reached crisis point before receiving help, reflecting policy and service limitations. The findings highlight the far-reaching impact of societal stigma on the experiences of CYP with FASD and their families, which likely impact educational experiences.

Together, these findings highlight the persistent stigma surrounding FASD and its impact on CYP and their families across contexts and from multiple perspectives. This reinforces the multifaceted nature of CYP's experiences and the influence of broader systems in shaping such experiences. The findings also highlight underrepresentation of CYP's views in research, particularly in the UK, highlighting the need to explore how CYP make sense of their experiences within contexts shaped by stigma and parental blame.

2.3 Conclusions and Research Aims

This review has critiqued research exploring the experiences of CYP with FASD across various contexts, though focused primarily on educational experiences and CYP's perspective. Recognising development is dynamic and reflects bi-directional interactions between individuals and their environment, perspectives of relevant stakeholders such as teachers, professionals and caregivers are also considered (Bronfenbrenner & Morris, 2006) to better understand how CYP's experiences are shaped by broader systems within which they are situated. The review highlights the implications of living with FASD, alongside the significant challenges education presents for CYP with FASD. The review further highlights how such difficulties are not widely understood, supported or recognised by professionals or society as a whole, with a need for greater awareness and support across education, healthcare and society.

The inclusion of research conducted outside of the UK, primarily in Canada, reflects a gap in research specific to the UK-context, particularly that which elicits CYP's perspectives. This differentiation is important given that the UK educational system significantly differs

from other countries, particularly in relation to rigid primary-secondary transitions, frequent transitions between teachers, structured national curriculum and greater emphasis on independence (Roberts, 2015). Through their systematic review of thirty-nine studies exploring school experiences of CYP with FASD and their teachers, Reedman et al. (2024), highlight a significant lack of research which includes perspectives of CYP with FASD (only two studies engaged directly with CYP), despite school being consistently reported as a primary stressor. Moreover, research primarily focuses on identification, incidence, prevalence and diagnosis of FASD, or caregiver perspectives, with limited focus on the lived experiences of CYP in educational contexts (Domeij et al., 2018; Knorr & McIntyre, 2016).

At the time of the review, there was only one UK-based, published study (Eodanable et al., 2024) exploring the lived experiences of adolescents with FASD across home, school and community. While this study did not focus solely on educational experiences, findings provided insights into the difficulties faced by adolescents with FASD across contexts and demonstrated meaningful inclusion of these CYP within research. The researcher is aware of an unpublished doctoral thesis exploring primary-aged children's experiences of school belonging (Hammond, 2021), which provided useful insights relative to primary school contexts. Thus, there exists a gap in research exploring the educational experiences of CYP with FASD in secondary school or post-16 education in the UK context. Secondary school experiences are of particular relevance for this population, due to noted shifts in these CYP's abilities to cope with the increased, complex demands in secondary school, despite coping in primary school (Roberts, 2015). Alongside this, adolescences with FASD are underrepresented in research (Flannigan et al., 2021; Reedman et al., 2024; Skorka et al., 2020).

Chapter Three: Empirical Paper

3.1 Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a complex, lifelong neurodevelopmental condition caused by prenatal alcohol exposure (PAE), which can impact physical, emotional and cognitive development. While awareness is developing, there is need for greater understanding, recognition and support across healthcare, education and society. UK literature exploring the educational experiences of CYP with FASD is sparse, but highlights experiences of educational challenges, with school reported as a primary stressor. Research primarily focuses on caregivers' perspectives, with a lack of research eliciting CYP's views. This qualitative research therefore addresses a knowledge gap, as the first UK study to explore the educational experiences of young people with FASD in secondary settings, learning from CYP's experiences, rather than indirectly through others' accounts. Semi-structured interviews were conducted with four CYP (3 males, 1 female; aged 12–13), analysed through seven-stage Interpretative Phenomenological Analysis (IPA). Interviews incorporated visual resources to support accessibility, reflecting the spectrum of needs associated with FASD. IPA gave value to participants' individual experiences and meaning-making, alongside exploring convergence and divergence across accounts (Eatough & Smith, 2017), reflected through five Group Experiential Themes (GETs): Adults as Shaping Safety, Trust and Access to Learning, Reliance on Trusted Peers to Navigate Learning and Social Interactions, School Ethos Shaping Experiences of Inclusive Practice, Making Sense of Academic Challenges and Sensory Support as Fundamental to Educational Experiences. The study adds to the limited UK evidence base, highlighting these young people's educational experiences as multifaceted and how they make sense of school through relationships, trust, peer support, sensory safety, academic self-concept and perceptions of school ethos. Notably, participants rarely referenced or expressed frustration towards their diagnosis highlighted in prior research from others' perspectives. The findings highlight implications for educational professionals, inclusive of Educational Psychologists (EPs), alongside suggested future directions of research.

3.2 Introduction and Legislative Context

FASD is an umbrella term, which describes the range of developmental differences which can occur when a fetus is exposed to alcohol during pregnancy (Chudley et al., 2005; Ryan & Ferguson., 2006a). The prevalence of FASD is difficult to determine due to reliance on self-reported alcohol consumption alongside limited research, though is estimated to be 1.8-3.2% in the UK (McCarthy et al., 2021). This is higher than the estimated prevalence of autism and down's syndrome combined, yet FASD is consistently under resourced, misunderstood and stigmatised (Choate & Badry, 2019; Westrup, 2013). Families have to navigate inconsistent and limited assessment and diagnostic services (Carrick & Hamilton, 2023), which intensified in 2022 when Suffolk's FASD centre closed due to funding challenges, leaving one remaining funded support centre in Surrey (BMA, 2016; NO-FAS, 2022). Moreover, professionals often lack knowledge of FASD and there is limited consideration for these individuals' lived experiences (Howlett et al., 2019; Mukherjee et al., 2015). In 2019, SIGN introduced the first UK national clinical guidelines for CYP prenatally exposed to alcohol, incorporated in NICE guidelines in 2022, a step towards standardised terminology, but these are still in the early stages of consistent implementation.

The extent and severity of effects of PAE on the developing fetus are dependent on the volume, frequency and pregnancy stage (Mattson et al., 2001), with associated facial features observed in only 10% of cases (Brenna et al., 2017; Millar et al., 2017). While effects are not homogenous, studies highlight commonalities in implications of PAE on brain development (BMA, 2016), impacting regions supporting memory, attention, language development, processing speed and visual-spatial abilities (Hendricks et al., 2018; Kodituwakka, 2007). Individuals with FASD are often described as having 'spiky' developmental profiles, due to the variations in strengths and needs (Blackburn et al., 2012; Henshaw, 2012). These differences can make identification of FASD more challenging and can have implications for accessing and managing educational environments and learning (Chudley et al., 2005; Millians, 2015).

For CYP with FASD, educational experiences can be challenging due to the cognitive, behavioural and social impacts of PAE (Duquette et al., 2006; Knorr & McIntyre, 2016; Poth et al., 2014). Such difficulties are reflected in 61% of CYP with FASD experiencing disrupted school experiences, with high suspension and exclusion rates (Duquette et al., 2007; Steissguth et al., 1996, 2004). Often, these CYP's needs' first present through their behaviour which can be misunderstood and viewed as disruptive (RCY, 2021).

Therefore, there is a need to consider the root cause of presenting behaviour (e.g., brain development), alongside reframing expectations (Malbin, 2004).

Given the considerable time spent in education and difficulties faced by these CYP, it is unsurprising that school is reported as a primary stressor by CYP and their caregivers (Job et al., 2013; Millar et al., 2017; Skorka et al., 2020). While societal knowledge of FASD is limited (Mukherjee et al., 2012; Reedman et al., 2024), lack of teacher knowledge about FASD is frequently referenced within literature (Sanders & Buck, 2010; Watson et al., 2013). In 2012, the All-Party Parliamentary Group (APPG) for Looked After Children and Care Leavers reported recommendations to raise attainment, inclusive of training to improve teaching staff's understanding of and ability to manage areas like trauma, attachment and FASD, highlighting professionals' limited understanding. In 2015, the APPG for FASD was established to raise awareness. Their report highlighted CYP with FASD have difficulties managing school environments, becoming home-schooled, with limited staff awareness reported as a prominent issue (APPG, 2015). Limited staff knowledge can result in overreliance on parental advocacy to support these CYP to navigate school (Domeij et al., 2018; Stade et al., 2011; Wilson et al., 2024), with caregivers acting as knowledge-disseminators to counteract professionals' understanding (Duquette et al., 2007; Griffiths, 2022).

3.3 Current Research

UK literature exploring the educational experiences of CYP with FASD is sparse, with research conducted primarily in the USA or Canada, where differing education systems make cross-system comparisons challenging. Currently, only two studies have elicited the voice of CYP with FASD in the UK. Although not focusing solely on educational experiences, Eodanable et al. (2024) explored eight adolescents' (aged 12-19) with FASD experiences across home, school and community. Using online photovoice methods, analysed using IPA, the findings highlighted the breadth of the impacts of living with FASD, emotional dysregulation relating to FASD, the need for adjustments in education, developed coping strategies and teachers' lack of knowledge and experience. The research demonstrated how participatory methods helped capture these CYP voices, contributing to our understanding of adolescent's experiences across contexts.

A doctoral thesis by Hammond (2021) explored primary-aged (aged 7-10) CYP's educational experiences of belonging, using a mosaic approach and IPA. All participants felt they belonged in their schools, attributed to four overarching themes: 'School Ethos and

Sense of Community’, ‘Relatedness to Peers’, ‘Staff Attributes and Teaching Practices’, and ‘Myself as a Learner’. The research’s solution-oriented lens, framed within what works, highlighted ways schools may support CYP with FASD. Moreover, the research demonstrated how participatory methods can support these CYP to share their views, moving away from deficit-orientated research commonly associated with FASD. However, the study’s generalisability is limited by its primary-aged focus, all participants attending mainstream settings and being adopted.

Through their systematic review of thirty-nine studies exploring school experiences of CYP with FASD and their teachers, Reedman et al. (2024), highlight a significant lack of research which includes CYP’s perspectives, despite school consistently reported as a primary stressor. They highlight an “immediate need for further research to address the challenges and experiences of students with FASD at school” (Reedman et al., 2024, p.8). Similarly, literature reviews exploring the lived experiences of CYP with FASD highlight research typically focuses on caregivers’ perspectives, with an identified lack of literature directly exploring CYP’s views (Domeij et al., 2018; Flannigan et al., 2021). As Skorka et al. (2020) highlight, little is known about the lived experiences of CYP with FASD, with a considerable gap in research exploring successes and taking a strengths-based lens, and a need to include CYP and their families in such research (Flannigan et al., 2021). Prior UK research which includes CYP with FASD has focused on primary-aged students (Hammond, 2021) or explored experiences across multiple contexts (Eodanable et al., 2024). Therefore, the educational experiences of adolescents with FASD in the UK have not yet been explored in-depth. This age range is important, as adolescence involves biological, social and cognitive changes and the impacts of such changes can become evident in home, school and communities (Skorka et al., 2020, 2022).

3.4 Educational Psychology

Given the educational and social vulnerability of CYP with FASD (Carpenter, 2011; Mukherjee et al., 2013), it is highly likely EPs will support CYP from this population. Despite this, EPs lack knowledge of FASD (Blackburn, 2010a), and their contributions often relate to caregivers feeling listened to, rather than EPs secure understanding of FASD (Griffiths, 2022). While, EPs have a unique knowledge base across education and healthcare, with extensive knowledge of special educational needs and child development (Roffey et al., 2018), there appears a gap in knowledge about FASD. Gathering in-depth accounts of the

educational experiences of CYP with FASD may therefore be beneficial for EPs to support their understanding, inform approaches and provision in practice.

3.5 Research Aims and Rationale

As aforementioned, no research has explored the secondary educational experiences of CYP with FASD in the UK. The research therefore aimed to address this gap, as the first UK study to focus solely on the secondary educational experiences of young people with FASD, seeking to learn from the meaning they give to their experiences rather than indirectly exploring their views through others' accounts. As stated in the United Nations Convention on the Rights of the Child (1989), CYP have the right to express their views freely in relation to matters affecting them. Additionally, research suggests opportunities to share one's voice can be therapeutic and foster feeling valued (Elmir et al., 2011; Nordentoft & Kappel, 2011). Drawing on Lundy's (2007) model of participation and Hart's (1992) ladder of participation, the research therefore aimed to provide these CYP space to share their views, using participatory approaches to support their inclusion and acting upon information shared through presenting the findings.

Greater knowledge and awareness of FASD aimed to enhance understanding of how to support these CYP in secondary school, alongside raising awareness of FASD more broadly (Dow et al., 2020), as current research highlights limited understanding among professionals and society. The research also hoped to provide insights into what these CYP find supportive in secondary school, contributing to a limited evidence base which draws on a strengths-based lens in exploring these CYP's experiences (Van Schalkwyk & Marais, 2017). It is also hoped the research can be a stepping stone to informing support and provision for CYP with FASD in schools.

As noted by Roberts, (2015), while not all CYP with FASD have SEND, gaps in attainment between these CYP and their peers extends with age and there is a noted shift in students' ability to cope with the increased and complex demands in secondary school. Moreover, adolescents with FASD are commonly underrepresented in research (Flannigan et al., 2021; Reedman et al., 2024; Skorka et al., 2020), supporting the rationale for focusing on secondary aged students.

3.6 Research Question

The following research question was explored: What are the educational experiences of young people with a diagnosis of FASD in UK secondary education settings?

3.7 Methodology

3.7.1 *Ontology and Epistemology*

To conduct rigorous research, researchers must consider the philosophical underpinnings and thus position of the research (Remenyi et al., 2011). Ontology and epistemology are philosophical assumptions rooted in the nature of reality and knowledge (Braun & Clarke, 2022; Daniels & Alston, 2023). Ontology is concerned with the nature of reality, what is possible to know and what is considered ‘real’ (Snape & Spencer, 2003). Epistemology, derived from the Greek word ‘epistme’ which means knowledge (Kivunja & Kuyini, 2017), focuses on the nature of knowledge; what is meaningful knowledge and how is it possible to generate (Richards, 2003). This research adopts an interpretivist theoretical perspective, focusing on exploring subjective constructions of the social world and how CYP with FASD give meaning to, and interpret their educational experiences (Bhattacharjee, 2012; Cuthbertson et al., 2019). This perspective aligned to the purpose of the research in gaining a deeper understanding of the phenomenon of school experience, within the population of CYP with FASD in their unique social context, rather than producing generalisable findings (Creswell & Poth, 2016).

The research was situated from an ontological position of relativism, which highlights reality is multiple, co-existing and constructed through social processes (Ashton et al., 2020). Relativism therefore refutes the principles of ontological realism, which suggests an objective, independent reality or ‘truth’ which can be objectively measured (Cuthbertson et al., 2019). In contrast, relativism suggests there is no singular ‘reality’, rather what is perceived as ‘real’ is dependent on the subjective perspective of the individual experiencing it (Willig, 2016). The researcher therefore sought to explore the multiple realities and interpretations of CYP with FASD, and their constructions of the phenomenon of educational experiences (Cuthbertson et al., 2019).

The research was situated from an epistemological position of social constructionism, highlighting knowledge is socially constructed through experience, mediated by culture and language (Braun & Clarke, 2022; Burr, 2024; Kelly, 2017). Social constructionism refutes the principles of positivism which suggests knowledge is generated from the application of scientific methods and empirical evidence, thus the researcher and research are deemed to be separate (Braun and Clarke, 2022). In contrast, social constructionism acknowledges the interplay between the researcher and social world; the researcher’s subjective perspective and interpretation on the social world plays a role in the research, recognising complete

detachment from the research is not possible (Burr, 2024; Burr & Dick, 2025). By adopting an epistemological position of social constructionism, the research aimed to explore how CYP with FASD give meaning to their educational experiences, within their unique social contexts (Burr, 2024).

3.7.2 Qualitative Methodology

Aligning with the researcher's ontological and epistemological position, a qualitative research design was implemented (Willig, 2016). Unlike quantitative designs which focus falsification of theory, qualitative research is concerned with meaning and how participants make sense of their experiences, aligning with the aim of exploring these young people's educational experiences in secondary school (Pietkiewicz & Smith, 2014). Qualitative designs have also been utilised successfully in prior research exploring the experiences of young people with FASD (Eodanable et al., 2024; Hammond, 2021; Skorka et al., 2021). Specifically, this research followed an Interpretative Phenomenological Analysis (IPA) (Smith et al., 2022). IPA aligns with the research aims and interpretivism paradigm, allowing the researcher to explore elements of experience which cannot be observed like thoughts, values, feelings and perspectives and acknowledging discovery of knowledge is shaped by the relationship between the researcher and subject (participant) (Larkin et al., 2006; Wellington & Szczerbinski, 2007).

3.7.3 Interpretative Phenomenological Analysis (IPA)

IPA is a qualitative approach, which has become a more popular methodology within psychological research (Hefferon & Gil-Rodriguez, 2011; Pietkiewicz & Smith, 2014). IPA is grounded in detailed exploration and examination of how people make sense of, and give meaning to their experiences (Smith et al., 2022) and assumes humans are actively involved in interpreting their environment and experiences (Pietkiewicz & Smith, 2014). IPA aims to explore how people make sense of their experiences of a shared phenomenon, such as experiences in secondary school, interpreting accounts to deepen understanding (Alase, 2017; Smith et al., 2022). The researcher recognises qualitative insights are relevant to the participant sample, considered the 'expert group' for whom the phenomenon is meaningful (Oxley, 2016), and findings are not intended to be generalisable. Such limitations are widely acknowledged in IPA research, and findings can contribute to broader understandings of the phenomenon (Oxley, 2016). IPA originated from Husserl's work, seeking to understand contexts and meanings of lived experience (Alase, 2017). Phenomenology, Hermeneutics and

Idiography form IPA's theoretical underpinnings (Smith, 2017), outlined below and considered throughout the research.

3.7.3.1 Phenomenology. Phenomenology is the philosophical study of subjective experiences of particular phenomenon, seeking to explore and describe how individuals perceive, interpret and make sense of their experiences (Eatough & Smith, 2017; Smith et al., 2022). Husserl, one of the earliest phenomenological philosophers, focused on the study of 'being' (Hefferon & Gil-Rodriguez, 2011), breaking away from early 20th-century positivist approaches and perspectives at the time. Husserl suggested understanding experience requires intentionally considering each particular thing in its own right to attend to the experience we take for granted; we must "go back to the things themselves" (Smith et al., 2022 p.8), referring to things as content of the consciousness (Smith et al., 2022). Therefore, Husserl suggests we should attempt to put to one side or bracket assumed or pre-existing knowledge about a phenomenon, to focus on our perception of the experience of the phenomenon. Heidegger, a student of Husserl's, considered Husserl's phenomenology to be too abstract and difficult to apply in practice because bracketing interpretations of the world is unattainable (Oxley, 2016; Tuffour, 2017). Heidegger argued humans are positioned in a world of objects, relationships, culture and language (Smith et al., 2022) which we cannot be meaningfully detached from (intersubjectivity). Therefore, our interpretation and perspective are always in relation to something and the closest way to understand phenomena is through interpretation (Oxley, 2016), discussed further below in relation to hermeneutics.

Research providing CYP with FASD a voice is scarce. Thus, the phenomenological underpinning of IPA allowed the researcher to value each individual account and explore participants unique interpretations of their secondary educational experiences.

3.7.3.2 Hermeneutics. Hermeneutics is the second philosophical assumption of IPA, which is the study of interpretation or meaning (Tuffour, 2017), which is deemed as fluid and consistently open to new interpretation, insights and revisions (Smith et al., 2022). Although phenomenology and hermeneutics were initially two discrete philosophical movements, Heidegger highlighted our access to experiences of a phenomenon is through interpretation (Smith et al., 2022) and that experiences and meaning are intertwined (Tuffour, 2017). It is assumed things (e.g., experiences) have visible but also hidden meanings, which emerge in IPA through the researcher's immersion in data, participants' world and interpretation (Oxley, 2016).

The hermeneutic cycle refers to the relationship and inter-dependency between the parts and whole, when seeking to make sense of experience; our understanding of the parts,

can only be understood through our understanding of the whole and vice versa (Willig, 2017). IPA analysis is therefore an iterative process whereby the researcher moves back and forth to analyse data, in a meaning-making process (Oxley, 2016; Smith et al., 2022).

Heidegger highlighted how a reader or analyst (e.g., the researcher) brings prior experiences, assumptions and preconceptions, known as fore-conception, to the new situation (e.g., phenomenon explored). Therefore, while the focus should be on exploring the new situation (e.g., phenomenon), it is recognised that the researcher's own lived experiences will impact their examination of participant's lived experiences (Smith et al., 2022), referred to as the 'double hermeneutic' (Smith & Osborn, 2015). Thus, interpretation is happening at the researcher and participant level; the researcher is making sense of participants making sense of their experiences (Tuffour, 2017). It is therefore essential that the researcher is reflective throughout about what they bring to the research, which may emerge further through the interpretation process (Oxley, 2016).

3.7.3.3 Idiography. The third philosophical assumption is idiography, which is concerned with in-depth analysis of individual cases, "the particular" (Smith et al., 2022, p.24), within unique contexts (Pietkiewicz & Smith, 2014; Smith et al., 2022). Idiographic approaches are committed to the depth of analysis, as well as understanding how certain phenomenon (e.g., educational experiences) have been understood from participants' perspective in their unique contexts. Therefore, value is given to each case independently, then possible transferability of findings from a group is explored through identifying convergence and divergence in cross-case analysis, instead of a focus on generalisability (Hefferon & Gil-Rodriguez, 2011; Oxley, 2016). IPA therefore aligns with small participant samples, who share common experiences and characteristics (Oxley, 2016). Idiographic approaches contrast traditional nomothetic approaches within psychology, which prioritise universal claims and generalisable findings. However, idiographic insights can extend nomothetic understanding, aligning with the hermeneutic cycle of understanding the part, to make sense of the whole (Oxley, 2016; Smith et al., 2022).

IPA's idiographic focus in the current study, provides insight into how a purposely selected homogenous sample (young people with FASD) make sense of their educational experiences, rather than aiming for generalisable findings (Smith et al., 2022). IPA therefore enabled attention to individual experiences, while also exploring convergence and divergence across cases, contributing to broader understanding of the topic (Larkin et al., 2006).

3.7.3.4 Validity. Due to its philosophical underpinnings, qualitative research cannot be examined in the same way as quantitative research (Yardley, 2017). Therefore, the quality,

value and validity of this qualitative research are demonstrated through four principles: sensitivity to context, commitment and rigour, transparency and coherence, impact and importance (Yardley, 2000, 2008). Table 3 identifies how these were addressed in the research (Yardley, 2017). This framework was chosen to evaluate the research, as recommended by Hefferon and Gil-Rodriguez (2011) for demonstrating validity in IPA studies.

Table 3

Addressing the Four Principles in Yardley's (2017) Framework for Validity and Quality

Principle	Research considerations
Sensitivity to Context	High-quality qualitative research requires sensitivity to context, including theory and literature (Yardley, 2000). This was addressed through a comprehensive literature review, which identified gaps and informed the research design. Recognising the role of language, interactions, and culture in meaning-making process of experiences of phenomena, reviewing literature and professional engagement supported consideration of the socio-cultural context of FASD (Yardley, 2000). This informed an accessible design, using flexible methods to include diverse needs and amplify CYP's voice ethically (Hart, 1992). Sensitivity to context was further reflected in offering participant choice (e.g., visuals, caregiver presence) and maintaining awareness of broader issues like stigma, changing language, and the high prevalence of care experiences throughout the research process, design and implementation.
Commitment and Rigour	Commitment and rigour involve in depth engagement with the research topic through data collection and in depth analysis of the phenomenon (Yardley, 2017). This was demonstrated through immersion in the data, prolonged engagement with analysis, and data collection methods designed to get close to participants lived experiences. Regular supervision was key during analysis to ensure sufficient interpretation and that the researcher's claims reflected participants' accounts. Rigour was strengthened through purposive sampling to achieve a relatively homogeneous sample and participants checking transcript accuracy following interviews. Although it is recognised that triangulation of data from various sources (e.g., CYP, parents, school) can enhance depth

	of understanding (Yardley, 2000), this did not align with the researcher values of prioritising CYP's voice, who are underrepresented in research.
Coherence and Transparency	Transparency and coherence require clear links between data and interpretation (Yardley, 2017). This was achieved by maintaining alignment between the research paradigm, methodology, and research question, derived from the literature review, and by grounding analysis in participant quotes to demonstrate how data links to the research question and interpretation. The researcher also provides detailed explanation of data collection and analysis, providing examples to support transparency of the process and interpretation (see appendices). Reflexivity is central to transparency (Yardley, 2000, 2008) and was maintained through supervision, a reflective diary, and discussions with professionals and peers also completing IPA. This enabled the researcher to consider and make explicit, how their beliefs, values and practices may impact the research (Braun & Clarke, 2013).
Impact and Importance	For research to be valid, findings should generate useful knowledge which has some influence on the belief or actions of others (Yardley, 2000). The research intended to amplify CYP's voice in matters affecting them (United Nations, 1989, BERA, 2024), and raise awareness of FASD in education, addressing identified gaps in understanding and support. Exploring what may be supportive in school within semi-structured interviews, aimed at offering practical implications, which is of interest across systems given the long-term risks associated with FASD (Streissguth et al., 2004). Findings are particularly relevant for EP practice, where knowledge gaps persist (Blackburn, 2010a), and aim to contribute to wider socio-cultural change by challenging assumptions that CYP with FASD cannot meaningfully engage in research through gathering their views ethically and in accessible formats.

3.7.4 Participants

3.7.4.1 Sample and Recruitment. A purposive sampling strategy was used to gather information-rich cases within a limited sample (Palinkas et al., 2013) and to ensure there was a reasonable degree of homogeneity (Smith et al., 2022). Purposive sampling involves

intentionally selecting participants, based on characteristics relevant to the research questions, identified through inclusion criteria (Table 1).

Table 1

Inclusion Criteria

Participant Inclusion Criteria	Justification
(1) Confirmed FASD diagnosis, Including FASD with or without sentinel facial features, FAS, FAE, pFAS, ARND and ARBD.	Diagnostic criteria and terminology reflect SIGN and NICE guidelines, acknowledging evolving language and complexity in diagnosis. Participants needed to have an FASD diagnosis to ensure sample homogeneity and ethical practice, though the diagnostic challenges around FASD are recognised alongside exclusion of CYP without a diagnosis.
(2) Attending UK education setting at the time of data collection, in Years 8-11.	Based on guidance from professionals, Year 7 students are excluded due to transition-related adjustments and post-16 students to avoid reliance on retrospective accounts, given FASD-related memory difficulties. Recruitment was broadened to include specialist settings and units to increase recruitment.
(3) Aware of their diagnosis, confirmed through pre-inclusion discussions with families.	To ensure adherence to ethical practice.

As outlined by (Smith et al., 2022), there is no right sample size for IPA as the number depends on several factors such as the degree of commitment analysis, richness of accounts and organisational factors, which should be considered on a study-by-study basis (Smith et al., 2022). Aligning with IPA's idiographic focus, the focus should be on fewer participant accounts examined at greater depth, rather than shallow descriptive analysis of many participants (Reid et al., 2005). While Smith et al. (2009) earlier edition recommends four-ten participants for IPA research due to the competing demands of professional doctorates, their later edition suggests typical numbers of interviews in doctoral research range from six-ten and multiple interviews can be completed with the same participants (Smith et al., 2022). What is key is that IPA requires a small sample size, with reasonable homogeneity, who can provide detailed reflections; the focus is on quality and not quantity (Reid et al., 2005; Smith et al., 2022). Thus, the researcher aimed to recruit a minimum of four participants, while also considering the hard-to-reach participant sample.

To address challenges recruiting vulnerable populations (Dow et al., 2020), the researcher established connections with professionals in the field, specifically a clinical psychologist and member of the National Organisation for FASD who agreed to act as gatekeepers. Gatekeepers shared recruitment resources via websites, social media and within their professional networks. The researcher also shared recruitment resources (Appendix D) on platforms commonly used by EPs (e.g. LinkedIn) and within their professional network. To support participants to understand the study before providing consent, in line with common cognitive challenges associated with FASD, a video explaining the research process was included in the information sheet. This was intended to help participants know what to expect and was appropriate to ensure their informed consent (Smith et al., 2022).

3.7.4.2 Participant Characteristics. Four CYP with a diagnosis of FASD, aged 12-13 took part in the study (Table 2). All participants were adopted and two (Lily and Thomas) were siblings. IPA involves a sample with reasonable homogeneity and for whom research aims and questions are relevant, and homogeneity varies from one study to the next (Smith et al., 2022). The participant sample can be considered homogeneous in relation to all of the young people having a diagnosis of FASD and all currently attending a UK secondary educational setting. While this was not part of inclusion criteria, participants were also homogeneous in relation to being adopted, likely reflecting high prevalence of care experiences among this population. This additional shared characteristics reflects broader patterns within wider literature exploring the educational experiences of CYP with FASD, where many studies disproportionately include adopted or fostered children, with biological families often not represented in participant samples. Therefore, much of what is currently understood about young people with FASD and their experiences, is shaped through the lens of adoption. This has implications for how the findings of such research should be interpreted, as the experiences and perspectives of adopted young people likely differ from those living with birth families, particularly in relation to attachment, identity and caregiver dynamics. This is reflected upon further in the reflective chapter of this research.

As aforementioned, recruitment was initially restricted to mainstream settings, though was extended to include specialist settings and units due to complexities recruiting this hard-to-reach participant population. While it is recognised that variation in settings attended reduces homogeneity, as highlighted by Smith et al. (2022), researchers need to be pragmatic, reviewing recruitment as it occurs and adapting inclusion criteria or the approach if there are recruitment challenges. Moreover, within small samples, the researcher can be more selective

about which factors or homogeneity are most important (Smith et al., 2022); which in this research was having a diagnosis of FASD and attending a UK secondary education setting.

Table 2*Participant Characteristics*

Pseudonym	Gender	Diagnosis	Year Group	Age	Type of Setting	Level of Support	Parental/Care Status	Length of Interview (minutes)
Josh	Male	FAS without sentinel facial features	8	12	Mainstream	EHCP	Adopted	68
Oscar	Male	FAS without sentinel facial features	9	13	Specialist	EHCP	Adopted	46
Lily	Female	Partial FAS	8	12	Specialist	ECHP	Adopted	52
Thomas	Male	Partial FAS	8	12	Mainstream	SEND Support	Adopted	60

3.7.5 Data Collection

3.7.5.1 Semi-Structured Interviews. Data was collected through semi-structured interviews (SSI), commonly used within IPA (Smith et al., 2017) and effective in capturing rich personal and collective accounts (Bloomberg & Volpe, 2016). This was key given the scarcity of prior research which prioritises the voice of CYP with FASD and explores their lived experiences. Aligning with advice from Smith et al. (2022), the researcher developed a SSI schedule (Appendix E) which included open-ended questions, different question types (e.g. descriptive, evaluative, contrast), prompts and follow-up questions to deepen discussions (Braun & Clarke., 2013; Dempsey et al., 2016). The SSI schedule was discussed and reviewed in supervision and following university feedback. The SSI provided an overall guide for the interview process, while also offering opportunities to build rapport and flexibility for participants to discuss areas pertinent to their experiences (Alase, 2017; Oxley, 2016; Smith et al., 2022), maintaining a balance between guiding participants and being led by their experience (Hefferon & Gil-Rodriguez, 2011). Aligning with phenomenology, this flexible structure supported the researcher to, as far as possible, put aside their preconceptions and be receptive to participants' reality and construction of their experiences (Oxley, 2016). Framed within positive psychology and a solution-oriented lens, interviews explored what supports CYP with FASD in education, with an appreciation that varying experiences may arise (Smith et al., 2017). Interviews were conducted between September-December 2025, ranging in length from 46-68 minutes.

The researcher was conscious of the hard-to-reach nature of the participant sample and therefore interviews were conducted and transcribed virtually using Microsoft Teams to widen recruitment. In deciding this approach, the researcher considered ethical factors such as digital literacy, digital poverty and ensuring participants were in a safe environment for the interview. All participants completed the interviews at home, aligning with guidelines that this setting should be comfortable and familiar to the participant (BPS, 2020). Participants were offered that their caregiver could be present if this was their preference, to manage the complexities and challenges of virtual interviews (Smith et al., 2022).

3.7.5.2 Accessible Resources. IPA assumes participants can use language to articulate their experiences. Therefore, the researcher had a key role in adapting questions to be appropriate to participants' needs to support them to share their experiences (Eatough & Smith, 2017). To accommodate the diverse cognitive needs associated with the FASD (Duquette et al., 2006), the

researcher offered creative, person-centred visual resources like scaling, blob classroom and card sorting activities within the interview, reducing language demands and enhancing accessibility (Rogers & Boyd, 2020; Sevón et al., 2023) (Appendix F-H). Using participatory approaches can increase engagement and empower individuals (Reid et al., 2021), pertinent for individuals with disabilities who are often excluded from research (Sevón et al., 2023). Ensuring the process was accessible for all participants was a value which underpinned the research and was paramount in ensuring CYP with FASD were meaningfully included (BERA, 2024). The diversity of needs associated with FASD as reflected in the literature, were also reflected within the participant sample; some participants did not require visual supports whereas others relied on visuals to scaffold their responses, with Thomas and Lily needing adaptations most to articulate their experiences. Prior to the interview, the researcher also emailed participants caregivers a drawing sheet (Appendix I) to reflect a mosaic approach and offer an alternative format for participants to share their experiences (Clark, 2017). However, no participants felt this was needed. While these visual resources were not formally analysed, they supported discussions within interviews, particularly to scaffold participants responses when struggling to share their views. They are also referred to within the analysis to enrich understanding of participants' experiences. The first participants' parent requested a list of potential questions to prepare their child, therefore, this was replicated with all participants to support preparation and accessibility.

3.7.6 Data Analysis

Data was analysed following Smith et al. (2022) seven-stage IPA; participant's accounts were analysed individually, then cases were cross-analysed to identify convergence and divergence. While the process is presented here in steps, IPA is an iterative and inductive cycle (Smith, 2007). Transcripts generated via Microsoft Teams were checked for accuracy by the researcher, then by CYP and caregivers if they chose to via email (Appendix J). Initial reflections were recorded after each interview in a research diary, aiding later reflexivity.

3.7.6.1 Step One: Reading and Re-reading. This step involves the researcher immersing in the data to attempt to enter the participant's world, remaining open to new insights (Oxley, 2016). It includes repeated listening to audio recordings and re-reading transcripts, so the participant becomes the focus of analysis, alongside noting initial, impactful reflections (Smith et al., 2022).

3.7.6.2 Step Two: Exploratory Noting. The second stage involves noting anything of interest through examining language and semantics within the transcript at an exploratory level. This supports further emersion in data, considering how the participant understands, describes and interprets their educational experiences, generating a comprehensive collection of notes. Exploratory notes were descriptive (content of what was said), linguistic (exploring language used and how this contributes to meaning making) or conceptual (asking questions of the data to consider overall concepts of the participants' experience) (Smith et al., 2022). The researcher organised this in a table, with transcripts alongside exploratory notes and experiential statements (Appendix K).

3.7.6.3 Step Three: Constructing Experiential Statements. This stage involves consolidating exploratory notes into experiential statements which reflect the key features while retaining complexity (Appendix K). Experiential statements reflect the essence of participants' lived experiences as interpreted by the researcher. The process marks a shift from working with the transcript to working with exploratory notes in producing experiential statements, reflecting the hermeneutic cycle by moving from the whole to a collection of parts (Oxley, 2016; Smith, 2007; Smith et al., 2022).

3.7.6.4 Step Four: Searching for Connections Across Experiential Statements. This stage involved mapping experiential statements to identify how they fit together, focusing on those most relevant to the research question and setting aside less pertinent material. The researcher manually organised printed statements (with transcript page numbers), cutting and clustering them on a large surface to explore interconnections (Appendix L). This process was revisited multiple times to remain open to alternative groupings and ensure they reflected participants' accounts (Smith et al., 2022). Reflecting the double hermeneutic, the clusters represent the researcher's interpretation of participants' meaning making, with an acknowledgement that alternative interpretations are possible, supported through ongoing reflexivity and keeping a research diary.

3.7.6.5 Step Five: Naming Personal Experiential Themes (PETs), Consolidating and Organising into a Table. This stage involved naming clusters of experiential statements to form Personal Experiential Themes (PETs). It became evident that some clusters overlapped and shared similar experiential meanings, therefore were grouped to reflect sub-themes of the PET. PETs are 'personal' as they operate at the individual level, 'experiential' as they reflect

participants' lived accounts, and 'themes' as they represent the researcher's process of bringing together statements, rather than representing single entities. After naming PETs, a table was developed linking PETs and sub-themes to experiential statements and verbatim transcript extracts with page references (Smith et al., 2022; Appendix M).

3.7.6.6 Step Six: Continuing the Individual Analysis of Other Cases. This process was repeated for each transcript as interviews were completed over the three-month data collection period. In line with IPA's idiographic focus, each case was analysed individually, supported by natural gaps between interpretation. While prior cases may influence interpretation, this was managed through ongoing reflexivity and systemically following steps 1-5 for each case (Smith et al., 2022).

3.7.6.7 Step Seven: Working with PETS to develop Group Experiential Themes (GETs) Across Cases. Once all transcripts were analysed individually and PETs were developed, the final step involved identifying convergence and divergence across PETs to generate Group Experiential Themes (GETs). Analysis is not intended to produce a generalisable group 'norm', rather the researcher is attempting to highlight areas of shared and differing experiences across participants (Smith et al., 2022).

PETs and subthemes were printed and mapped across a large surface to consider areas of similarity or difference at the highest level of organisation (e.g., PETs). Some themes emerged readily, while others required an iterative, dynamic process of looking closely at subthemes and experiential statements (sometimes transcripts to check meanings), to consider possible interconnections. This resulted in some PETs being separated through subthemes and merged to reflect the higher order level of analysis through the GET. GETs were named to reflect the experience at the group level, organised into a table (Appendix N-O)

3.8 Ethical Considerations

Ethical approval was granted by the University of East Anglia (UEA) Ethics Committee in June 2025 and re-approved following amendments to include specialist settings in August 2025 (Appendix P). The research was conducted in accordance with the British Educational Research Association guidelines (BERA, 2024), BPS Code of Human Research Ethics (2021) and HCPC Standards of Conduct, Performance and Ethics (2024). Respect for participants' privacy and dignity was a priority (HCPC SoCPE, 1.1). As highlighted by Smith et al. (2022),

ethical practice is embedded throughout research and is a dynamic process which requires monitoring, particularly during data collection and analysis.

3.8.1 Informed Consent and Right to Withdraw. Caregivers expressed their interest in their child/the child they care for taking part in the research by contacting the researcher via email. The researcher first asked caregivers to confirm their child was aware of their FASD diagnosis, before sharing the parental and child information sheets and consent forms outlining information about the research, ethical considerations, anonymity, rights to withdraw, and data storage (BERA 9; BPS CoHRE 4.1) (Appendix Q). Adapted versions of the child information sheet (inclusive of a video explaining the process) and consent form was also shared to support the diverse cognitive needs associated with FASD (BERA 23; BPS CoHRE 4.4; HCPC SoCPE 2.3, 2.4) (Appendix R). This enabled participants to consider their voluntary participation and what the research would involve, before providing informed consent (BERA 8; BERA 24; BPS CoHRE 4.1; HCPC SoCPE 1.4) by completing the consent forms (one parent, one CYP) and sending them to the researcher. Dual-consent accounts for cognitive challenges and vulnerability of CYP with FASD and potential parental presence during the interview if this was participants preference as identified in the consent form. This option also considered BPS (2020) guidance recommending caregiver presence when using online platforms. The parental information sheet and consent form clearly outlined that parental views would not be collected, and their role was to support the CYP.

At the start of the interview, the researcher clarified the research aims, structure, reaffirmed consent for recording, offered time for questions and outlined safeguarding parameters (BERA 48; HCPC SoCPE 5.2, 7.3). Participants' consent was reaffirmed at the beginning and throughout the interview, highlighted as good practice by Smith et al. (2022). Participants were reminded at the beginning and throughout, of their rights to withdraw at any time during the interview and up to the point of anonymisation of transcripts (see below) (BERA 31; Smith et al., 2022).

3.8.2 Confidentiality and Anonymity. Data was managed in accordance with the UEA Research Data Management Policy, General Data Protection Regulation (GDPR) and Data Protection Act 2018; data was stored securely on a password-protected laptop (HCPC SoHRE 5.1) and will be destroyed following viva completion (BERA 39, 45, 46). Transcripts were fully anonymised to ensure confidentiality, removing personal or identifiable information (e.g.,

school, friends mentioned etc.) and each participant was given a pseudonym. At the end of the interview, caregivers were emailed the transcript and offered the opportunity to review this for accuracy with the young person (Smith et al., 2022); two families completed this. While confidentiality of participants data was an utmost priority, the researcher acknowledges an ethical tension in sharing the transcript with caregivers for review, when the young people had been assured their views would remain confidential and many did not request caregiver presence during the interview. Despite this, it was not ethical to contact the young people directly and therefore the transcripts had to be shared via caregiver contact details. This required careful balancing of the young people's rights to confidentiality and ensuring their accounts were accurately represented within the transcripts.

3.8.3 Duty of Care and Debriefing. Consideration was given to the vulnerability of research with children (BPS CoHRE 4.4), complexity of FASD and associated cognitive challenges (Dow et al., 2020). While the research posed no intended harm, the researcher recognised vulnerable groups are at increased risk of experiencing harm from research processes and took extra steps to reduce risk (Hurst, 2008; HCPC SoCPE 6.1, 6.2). Participants were offered movement breaks and opportunities to ask questions throughout (Coons & Watson, 2013) and reminded of their voluntary participation (BPS 2018; Dow et al., 2020). Using skills developed as a Trainee Educational Psychologist, the researcher monitored withdrawal signs, consistently reaffirming consent through wellbeing check-ins (BPS CoHRE 4.7)

The interview schedule was framed within a positive psychology lens, though recognised the potential of sensitive topics which are stigmatising or emotional emerging (Alexander et al., 2018), particularly given literature highlighting the difficulties these CYP can experience in education. Participatory research can enrich understanding of the topic (Cargo & Mercer, 2008; Jagosh et al., 2012), however it is recognised there is a need to balance identifying strengths and the real-life experiences of navigating life with FASD (Flannigan et al., 2021).

Evidence of DBS and access to support resources, (e.g., charities), were provided to further safeguard participants (BPS CoHRE; Dow et al., 2020). The interview concluded with asking participants if there was anything deemed relevant to their experiences which was not discussed (Smith et al., 2022) and debrief forms were shared with caregivers via email (Appendix S).

3.9 Findings

Aligning with IPA's idiographic underpinning and to remain close to participants' individual experiences (Oxley, 2016), this section first presents an overview of the individual analysis of each participants' account through participant profiles. Subheadings reflect Personal Experiential Themes (PETs) from stage four of the analysis. Verbatim quotes are italicised, followed by transcription page number (e.g., p.2). Participant profiles are intended as a summary, with accounts explored in greater depth through Group Experiential Themes (GETs). A thematic map of PETs for each participant is presented in Appendix T.

Following this, cross-case analysis and GETs are presented, developed through exploring convergence and divergence across PETs (Smith et al., 2022). This process moving from the part (participants experience) to the whole (patterns across cases) reflecting the hermeneutic cycle, is not intended to present a norm of participants' experiences, rather to highlight areas which participants have shared or differing experiences (Smith et al., 2022).

3.9.1 Participant Profiles

3.9.1.1 Josh. Josh is 12-year-old boy in Year 8, attending a mainstream secondary school in Northern England. Josh has FAS without sentinel facial features and is adopted. Josh has an EHCP, however his adoptive mother identified support can be limited and inconsistent. Josh did not use visual supports, other than scaling.

Importance of External Support and Advocacy. Through making sense of his experiences, Josh appeared to use comparisons, with awareness his experiences likely differ from his peers, describing himself as *“not your average child”* (p.7). Despite awareness of his needs, Josh had difficulty seeking support, identifying *“I don't get the help I need”* (p.7). Josh relies on external support and advocacy in navigating school, such as support from attuned peers to access learning, providing *“a hint or two...to get me going”* (p.5) and peers who *“remind me which lesson I'm in”* (p.10). Josh also values support from Teaching Assistants (TAs), though identified this as inconsistent, needing *“a lot more TAs in a lot more lessons”* (p.4) to make school more positive. While adult support was valued, inconsistencies in staff's approaches, *“all the TAs say things in different ways”* (p.4), resulted in confusion. Josh also appeared to rely on parental advocacy to navigate school, however this was highlighted through his mother's contributions, which were not formally analysed and considered a subtheme.

Externalising Difficulties in Learning and Sustaining Attention. Josh spoke of difficulties managing the learning environment and engaging, describing he “*cannot sit in a chair for more than an hour for the life of me*” (p.4), suggestive he views some expectations as unachievable. Josh often attributed his difficulties, particularly inattention, to factors outside of his control such as his FASD and environmental factors. Josh was easily “*distracted*” by “*students, people outside the window, random sounds*” (p.1), naming these distractions to “*fall under me FASD*” (p.1). Peers were also a source of distraction, “*the idiots that...I thought at first were class clowns but they’re not*” (p.11), expressing his frustration through his language. Josh recognised he finds peers’ behaviour frustrating, though often behaved in similar ways, presenting with limited control; “*I might sound a bit rich saying this, but people not shouting out...I can’t say that too much because I do that*” (p.11). Josh’s behaviours and responses presented as impulsive, “*the idea goes into my head, and I can’t stop my mind from saying it*” (p.15). Josh also experienced difficulties processing and recalling information, making sense of his experiences through visualisation and metaphor, describing his brain as a “*bookshelf*” (p.13) with limited capacity. He also described difficulty holding in mind information, “*I will have a question, and I put my hand up, and then I’ll have another question, but I don’t want to be listing the 1000 questions*” which became a cyclical experience “*over and over and over*” (p.13).

Disconnect Between his Abilities and Expectations, Impacting Self-Concept. Josh alluded to possible disconnect between his abilities and schools’ expectations, which impacted his self-concept and confidence, referring to himself as “*no good with that*” alongside the pace of learning meaning he “*can’t really keep up sometimes*” (p.13). Josh showed awareness that he likely finds school more challenging than his peers, though felt tension when he experienced difficulty in areas he perceives he should be confident in; “*there’s the questionable lessons that I think am I really supposed to be struggling with this one*” (p.2). Josh also made comparisons between his abilities across contexts, resulting in a disconnect in his skills across environments; “*we’ve got music and that’s one of the...lessons I struggle most with, which is pretty confusing for me because I’ve been doing, you know, music...two years*” (p.2). Confusion and self-criticality resulted in a “*weird cycle*” and heightened emotions, “*I get anxious and then I get angry at myself and then I just go into full on meltdown*” (p.15). His awareness of his difficulties was not met with appropriate adjustments and support such as school not having “*the right equipment*” (p.3). Josh also noted how equipment adaptations are not made to suit his needs

which was “*very confusing because I’m...left-handed...then I have to play right-handed*” (p.3). Josh appeared to perceive that others think negatively about additional supports, justifying it wouldn’t “*be completely cheating*”, “*I still understand where to put me punctuation and all that*”, which may reflect broader experiences of inclusion in school (p.3).

Supportive Strategies, Tailored to Individual Needs. It was important for Josh that support was tailored to his needs. Josh benefited from clear, explicit communication, like teachers asking, “*do you understand?*” rather than “*are you ok?*” (p.3). Josh also benefited from a slower pace of learning and visual demonstrations; “*showing me through it...she won’t just describe it to me*” (p.14). Adult check-ins and reassurance were also supportive, “*check if I’m like you know, on the same page...which is sometimes literally...that’s a big helper*” (p.12). Josh spoke about the importance of sensory regulation like using “*fidgets*” (p.15). He described his sensory diet “*gives me brain that boost...It’s kind of like when you recharge batteries, power you up again...I feel like normal*” (p.15). His use of metaphor describing his brain like a battery supports him to articulate and make sense of his internal experiences. Also, his use of “*normal*” reflects a sense of difference to his peers when his sensory needs are not met, making navigating school more challenging. Josh also highlighted the importance of sensory spaces, describing his ideal sensory space, tailored to his interests; “*a little den, maybe like some books because I love books...sensory snacks and like music...lights...sometimes my phone...no shouting or anything, just silence*” (p.16).

Importance of Structure and Predictability. Josh highlighted the importance of structure, “*I like a routine*”, predictability and feeling “*organised*” (p.7) in supporting his experiences. When lacking structure, Josh struggles to navigate situations such as experiencing conflict of needing a break, alongside difficulty navigating unstructured times like breaktimes, “*after 5 minutes I just I go into the, what do I do?...10 minutes just standing there*” (p.9). He also had difficulties articulating his views to adults when encountering experiences outside of his routine; “*She thought that I was going to go on the bus because that’s what I normally do*” (p.16). While Josh highlighted his preference for structure and routine, he recognised there are aspects outside of his control which can be unpredictable. For example, the school bus is “*15 minutes late every day*” (p.8), describing it as a “*miracle*” (p.6) to be on time. The bus being late impacted Josh’s morning routine and ability to “*actually get to our lessons*” noting “*we can’t teleport*” (p.8), suggestive he perceives some expectations as impossible, due to factors outside of his control.

This sense of predictability was reflected in Josh's preference for practical, concrete learning, *"the practical, the theory, you know how things work"* (p.1), over abstract concepts like religion, *"I do like to question things...I have given our RE teacher a bit of a run for his money...we never really know. We're all just making...hypotheses"* (p.6). Josh highlighted his difficulties with abstract concepts in maths like algebra, *"I will give up when we start putting letters into a lesson about numbers"* (p.6), presenting rigidity in his thoughts and disliking change, *"I don't know if I'm old fashioned, but I think that's how it [algebra] works"* (p.12).

Systemic Factors Shaping Educational Experience. Josh was reflective about systemic factors impacting his experiences, and his understanding of school wide processes appeared to impact his interpretation of such experiences. Changes in school structures impacted the support Josh received, like restrictions accessing sensory spaces since becoming an academy; *"So if you've, if you've been upset in like the last 10 minutes of the lesson, you're going to wait 20 minutes to actually go"* (p.3). This created tension with his desire for accessible support when needs arise, like *"calming strategies and things like that and not having to wait 20 minutes"* (p.15). Josh's experiences highlighted consistency of support appeared related to teacher experience and knowledge, particularly about how FASD may impact his learning. This was shaped by his experiences of not *"really getting the proper...help"* (p.15) and limited consideration for his views such as when interventions were removed because he *"got better at them"*, although he felt they were *"helping with me confidence and things like that"* (p.15). Josh was the only participant who spoke of how settings' reputations in supporting SEND and inclusion can impact placement decisions and he *"might have to move"*. This was influenced by family members experiences, *"it's a family thing at [local mainstream]"*, appearing to make sense of his experiences through comparison to other's experiences.

3.9.1.2 Oscar. Oscar is a 13-year-old boy in Year 9 attending a specialist setting in Eastern England and has an EHCP. Oscar has FAS without sentinel facial features and is adopted. Oscar's setting supports SEMH needs through a nurturing approach, physical activities, therapeutic support and an adapted curriculum. Oscar previously attended a mainstream secondary school from Year 7-8, therefore offered a unique, comparative account of his experiences between settings, offering hopeful insights of what has supported him. Oscar chose not to use visual supports.

Trusting Adult Relationships Shaping Attuned and Consistent Support. Oscar commonly referenced the importance of staff availability in making support feel possible, *“there’s so many LSAs”, “always free for to...have a chat with or, you know, you ever needed help”* (p.3), *“always someone to talk to if I like ever feel sad or angry”* (p.5). Oscar placed importance on staff attuned to students’ needs and skilled in their approach, knowing *“how to handle it”,* supporting feelings of safety, *“staff are so good before that happens, they know...so nothing ever happens”* (p.5). Staff in his current setting were perceived as *“nice”* (p.3) and passionate, attributing this to the reason they got their jobs; *“got their job because they understand kids, just like me”* (p.9). His use of *“just like me”* highlights a sense of relatedness, which appears important in navigating school. Oscar also noted how consistency in adults, having the *“same teachers”* is important, to *“get to know them”* (p.8). Consistency was also supported by the settings’ overall approach, as students access *“the same hub”* rather than *“go from year two to year three in a different class”* (p.8).

Support Tailored and Adapted to Students’ Needs. Oscar highlighted provision *“based around me”* supports him to feel *“a lot more comfortable there than my other school”* (p.1). This was also supported by resources tailored to individual preferences; *“you can choose whatever book you want to read...if you want to order a book that you really like, they would order it for you”* (p.6). Oscar further highlighted the need for support to be flexible and adapted to students’ needs, finding rules in mainstream *“a lot stricter”,* in particular *“uniform was quite strict”* which impacted *“my sensory”* (p.1). This contrasted his current experiences where *“you can wear whatever you want...long as it’s appropriate of course”* (p.1), suggesting an agreed sense of flexibility within broader boundaries. Flexibility around completing learning also supported Oscar’s experiences, *“you can skip it. You don’t have to do it, but you just have to do something”* (p.7). This was reflected in staff being *“pretty free”* and students seeking support when needed; *“if you ever needed space from the classroom, you can go up to one of them and ask can we go for a walk or can we go for a drive”* (p.2). Through his comparative account across settings, Oscar noted the importance of staff availability on feasibility of adjustments, with *“a lot of staff”* supporting him to *“do it in a quiet room”* (p.7). Though, in mainstream, *“of course, they didn’t have enough staff to really take you into another room and say, do you want to do this in a quieter room?”* (p.7) suggesting limited staff is a barrier to adaptations and support, presented as the expected experience in mainstream settings.

Difficulties in Lessons and Supportive Strategies. When making sense of his learning experiences, Oscar anchored his understanding through comparing his experiences between settings. Oscar was reflective about how his behaviours in his previous setting of mixing “*with the wrong group*” were not necessarily supportive, noting “*it didn’t go great*” (p.3). Peers were a source of distraction, “*rude classmates...just always trying to drag my attention away from the class...trying to get me in trouble...it wasn’t a good like atmosphere to try and learn*” (p.7), recognising the influence of external factors on his experiences and engagement. The meaning Oscar gave to his experiences, such as being distracted, appeared influenced by his view of the environment. For example, in his current setting he noted “*It’s not as loud, although we do have a kid what’s very loud*”, describing this peer as a “*funny guy*” and “*chatterbox*” (p.8). This directly contrasted his view of distracting peers in his mainstream setting, labelled as “*rude*” (p.7), highlighting how environmental factors shaped his perception of his peers and interpretation of his experiences.

While some difficulties were attributed to external factors, Oscar recognised his challenges sustaining attention; “*I find sitting still on a chair watching someone, say, do this, do that, do that. I find that really hard*” (p.5). Oscar identified he “*couldn’t handle that*” (p.5) suggestive the attentional demands of learning were overwhelming, and inattention was outside of his control rather than a conscious choice; “*I couldn’t focus on them. It was just too much*” (p.7). Oscar would “*zone out*” and found it easier “*saying yes*” (p.5), struggling to advocate for his difficulties, which resulted in challenges keeping up with the pace of learning. Aligning with his attention difficulties, Oscar preferred practical activities, “*I really like cooking*” (p.6), demonstrating a sense of achievement creating an end product; “*just really like satisfying that you made something you can eat*” (p.7). Oscar also prefers learning in short bursts, interspersed with breaks, wanting to get learning “*out of the way*” to complete more desirable activities like “*play football, you can have a break and then you back in*” (p.2).

Sense of Community and Affiliation Impacting Motivation to Engage. Oscar made direct comparison to his setting feeling “*like another home*” (p.9), “*I really fit in and I feel at home*” (p.1). This suggests a strong sense of belonging and feeling valued within the school community, supported by a nurturing approach, “*everyone’s giving you fist pumps, everyone’s saying hi*” (p.4) and providing wrap around care; “*they do the best breakfast*” (p.2). A sense of autonomy and “*freedom*” (p.5) was important in supporting affiliation and students “*all get a*

table and...a proper spinny office chair” (p.3), creating sense of ownership. Oscar highlighted feelings of relatedness to peers in his current setting, which *“helps kids like me with FASD”* (p.1), presenting FASD as part of his identity. Oscar’s current peers are *“much more mature and everyone understands everyone else”* (p.3), with mutual understanding that *“everyone of course, has their own needs”* (p.4), which appeared to support a sense of relatedness and mutual understanding. This contrasted his experiences at a *“normal school”* where they *“don’t really understand other people”* (p.3), presenting heightened awareness of differences between his experiences and perception of typical experiences. Moreover, social opportunities with relatable peers were supportive in establishing a sense of belonging, as staff put *“everyone together and try and socialise everyone”* alongside enjoying social times, *“because I get to sit with my friends”* (p.3). Oscar contrasted this to his experiences in mainstream, spending lots of time *“walking around on my own”* and *“everyone was proper like bullies”* (p.9).

Approaches to Managing Behaviour Impacting Safety, Motivation and Belonging.

Oscar commonly made comparisons between punitive approaches in mainstream and restorative approaches in his current setting, which shaped his experiences. Oscar found *“detentions...quiet, it was awkward”* which made him *“feel horrible and it scares me...it doesn’t make me want to go into school”* (p.4). This contrasted experiences of *“educational consequences”* in his current setting, which support students to explore *“how that’s happened or how we can resolve it”* (p.4). Oscar highlights how his experience of relational approaches, positively impacted his overall school experiences, *“it works”* when students *“know they can’t really get badly told off, so they feel more themselves”* (p.4). This was reflected in him stating there is nothing he would change about his setting. In contrast there is *“a lot”* (p.7), he would change about his previous setting; laughter following this suggested the level of change needed would be significant, later noting *“there’s just so much, everything would be changed”* (p.8).

Rules, restrictions and inflexibility appeared to impact Oscar’s motivation and engagement. Within his independent setting there appeared acceptance that rules were needed to support safety; *“they have a security wand. You get wanded down, you get a pat down and then you go into the school”* (p.7), suggesting his interpretation of rules is shaped by environmental factors. His current setting also has rules about *“one person in the toilet”* at a time, however in mainstream *“there were loads of people in the toilets”* resulting in *“bullying...cause there’s no one to see it”* (p.9). When rules did not make sense to Oscar, he struggled to follow them, *“I was*

allowed a fidget to it, but there's rules about it...I don't think the rules about fidgeting like, what's wrong with fidgeting" (p.5). His interpretation and acceptance of rules were shaped by environmental factors and perception of whether rules kept him safe, though simultaneously shaped his overall perception of school.

Overall Approach, Curriculum and the Physical Environment. Oscar preferred smaller class sizes and having *"more staff than children"*, usually with *"one teacher...two LSAs"* (p.5). He *"didn't like the big classrooms with all the kids, I'd rather be in a classroom with like three to four kids"* (p.8). Sport was also central to his current experiences, with a *"a big field to play football"* and variety of sporting opportunities, *"it could be tennis, it could be ping pong, it could be any sport"* (p.2), supporting emotional regulation and opportunities for social interactions. Oscar referenced *"football is like therapy"* (p.1), highlighting the impact of physical activity on his regulation and overall experiences. Regulatory spaces were also central to accessing school successfully, such as the *"sensory room"* and *"each hub has a corner for sensory"*, supporting him to feel *"comforted"* (p.7).

A slow and staged transition into his provision supported his familiarity and success; *"they'll come out with you...you won't go straight into [current setting]. They'll first start introducing you into it, and then they'll take you out to...meet all the staff"* (p.7). This was supported by a nominated outreach teacher, *"personal, like to you"* and time to build a trusting relationship through low demand activities, *"they'll go out with you and get like tea, if you like tea or a coke...you can even go to McDonalds"* (p.8). Oscar's setting also promotes autonomy and skills to equip students for post-16 transition, *"they support you with your journey to getting into college and the transition into college"* (p.1).

3.9.1.3 Lily. Lily is a 12-year-old girl in Year 8, attending a specialist setting in Northwest England. Lily has partial FAS (pFAS) and is adopted. Lily's setting supports primarily SEMH needs, focusing on a nurturing and individualised approach in small classes with high student-teacher ratios.

Lily struggled most to articulate her views, requiring support of participatory approaches. Lily generally answered questions succinctly, and demonstrated reluctance or difficulty sharing information, often stating *"don't wanna do that question"*, (p.5) when asked to elaborate. Lily at times communicated through her dog; *"If I put [dog's] arm up, that means yes. If I leave it down, that means no"* (p.2), suggestive that communicating indirectly about her experiences may feel

safer or illuding to potential language needs. Once visual supports were introduced, Lily appeared more able to respond directly, “*Yes, my hand now [instead of the dog]*” (p.4), highlighting the importance of adapting approaches to support accessibility. Despite difficulties articulating her views initially, Lily was able to share her experiences in school.

Challenges Experienced at School. Lily’s overall dislike of school was highlighted by rating school a 3/10 through scaling (Appendix F). She described school as “*horrible*”, attributed to “*everything*” (p.6) rather than specific aspects. This could relate to difficulties articulating her views, though her description reflected her overall account of her experiences, such as her academic challenges shaping her experiences. Within a card sorting activity discussing aspects which make school harder, Lily identified ‘understanding’ as the “*the worst one, the worst one*” (p.5), with her language and repetition reflecting her level of difficulty. Maths was particularly challenging, struggling with “*the work...algebra*” (p.8). Lily identified other areas she disliked, reflecting her strong feelings through her language, “*I hate PSHE and RE*” (p.3). She described lessons she does not like as “*Boringggg*” (p.4), which may relate to difficulty articulating why, though may reflect strong dislike and difficulty engaging. During the blob classroom (Appendix G) activity, Lily chose the below blob to represent her in lessons she dislikes, noting this reflected “*sadness*” (p.13).

Figure 4

Blob Chosen by Lily to Represent her Experiences in a Lesson she Dislikes

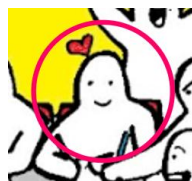


Lily also alluded to difficulties navigating social times and interactions, preferring to be “*alone*” (p.11). When shown the blob classroom, Lily noted “*there’s too many people there*” (p.12) suggestive busy environments can be overwhelming, or perhaps this image does not reflect her experiences of smaller classes in her setting.

Supportive Adults and Fun in Learning as Protective. There were aspects of school which Lily enjoyed, “*drama...english, maths*” (p.3), choosing the blob below to represent her in lessons she enjoys, identified as “*happy*” (p.12).

Figure 5

Blob Chosen by Lily to Represent her Experiences in a Lesson she Enjoys



Lily identified drama as her favourite subject, attributed to being it “*fun*” (p.3). Lily also enjoys practical learning, “*soon we are doing a fire experiment*”, “*we're turning 5 different colours*” (p.3). Lily often spoke about interactive games and platforms within learning, identifying “*playing Kahoot and Bluekit*” as the best parts of her day, which “*everyone plays*” (p.3). This suggested a sense of relatedness and low-pressured environments positively shape her experiences. Support from familiar, trusted adults who are consistently accessible appeared important, describing she likes “*two teachers that stay in there most of the time. Miss X who is always with us and Miss X which isn't with us all the time because she's the drama teacher*” (p.9). The importance of adult relationships was reflected in her desire for autonomy and a voice in decisions around staff employment, presenting student-staff relationship and teachers' approach as central to her experiences; “*Maybe let the children when people are hiring, let the children look because we're not...because we're the ones being taught by them*” (p.9). Lily highlights how broader decisions impact her experiences and therefore, this is an area she would change to make school more positive.

Support for Sensory and Emotional Regulation Shaping Educational Experience.

Lily's frequent reference to her sensory experiences suggested the school environment placed significant demands on her sensory processing needs and actively shaped her experiences. Lily repeatedly identified school uniform as “*not comfy*” (p.6), placing this under the category ‘does not make school positive’ in the card sorting task (Appendix H). Lily expressed preference to “*be in comfy clothes and wearing pyjamas*” (p.6). Access to spaces to support her regulation and opportunities for movement were also important, like the “*drama room, which is right outside the room*” “*it's just so big, so I can do cartwheels in it*” (p.7). Her choice of the drama room, which is her favourite subject, suggests a sense of familiarity is important in supporting

regulation. Lily noted how her setting does not have a designated sensory space, but *“there was in lower primary”* which she can *“sometimes”* access as the settings are connected, *“two schools combined into one”* (p.7). Lily’s aforementioned desire for autonomy and voice was further highlighted in her description of what may improve school. Lily frequently used *“letting me”*, which appear to reflect limited autonomy within constraints of school rules, such as *“letting me go home when I want to”* (p.6) and *“letting us be in comfy clothes and wear pyjamas”* (p.2). Lily also had awareness of supportive resources at home, *“crafting”* (p.1), and technology such as her *“iPad”* or *“laptop”* (p.10), though she experiences limited autonomy and voice regarding resources she can use in school, *“no, I’m not allowed. I wish I was”* (p.12).

3.9.1.4 Thomas. Thomas is a 12-year-old boy in Year 8, attending an all-boys mainstream setting in Northwest England. Thomas does not have an EHCP, so receives support at universal SEND support. Thomas has partial FAS (pFAS) and is adopted. Lily is Thomas’ sister. Thomas chose to use visual supports.

Friends as Protective, Peers as a Source of Distraction and Annoyance. Opportunities for peer interactions positively shaped Thomas’ experiences, *“I like it because then I can see my friends and play football”* (p.3). While Thomas enjoys social times, he can be vulnerable to unkind comments from peers, particularly relating to appearance; *“mean to me because of my height, so it makes it harder [to make friends]”* (p.2), highlighting how challenging interactions can shape broader experiences of social inclusion. Thomas relied on advocacy of his friends to navigate school and interactions who *“stand up and say just leave him alone”* (p.3), identified as one of the few things supporting his experiences. Thomas attributed some difficulties engaging to *“people in my lessons really annoy me”* (p.3), presenting limited control over this. Thomas chose the blob below to represent him in a good lesson.

Figure 6

Blob Chosen by Thomas to Represent his Experiences in a Lesson he Enjoys



Thomas shared *“the teacher puts me at the back on my own”* and accessing his own workstation which creates physical separation from peers is supportive; *“it’s easier for me to sit*

there when no one's annoying me", (p.8), though suggests learning challenges attributed to peers' behaviour adversely impacted social inclusion. Thomas appears motivated to learn though experiences barriers to his engagement, *"we barely ever get any work done"* making him feel *"annoyed because I want to learn"* (p.9). Thomas made a distinction between the his friends and peers' intentions, suggesting his interpretation of his experiences depends on relationships and can shape peer perceptions, *"my friends do it as a joke, but other people do it on purpose"* (p.8).

Academic Strengths, Difficulties and Reliance on Adult Support. Thomas experienced success in areas of the curriculum, naming *"maths"* as his favourite subject, *"I find it really easy"* (p.1). *"PE"* is also an area he enjoys, and which supports his wellbeing, with a variety of opportunities, *"swimming, football, athletic things and use the gym"* (p.2). Thomas received merits for his work such as *"golden tickets"* but did not rely on this recognition, *"it doesn't make me feel anything, I don't need it"*.

Thomas also experienced academic challenges, finding some work *"a bit tricky but I get the help if I need it"* (p.13), with difficulties initiating tasks, *"spelling...I don't know how to start"* (p.1). His academic challenges shaped his view and confidence as a learner *"with Geography...flags into countries I'm fine with, but anything else I can't do"* (p.5) suggesting perceived limits to his abilities. Adult support appeared central to successfully accessing learning, *"help with my spellings and they put sentence starters so I can start in"* (p.1), identifying *"a bit more help trying to understand"*, *"maybe a teacher sits next to me, helping me with my spellings...giving me some examples"* (p.5), as areas which would improve school.

Support from Familiar, Attuned Adults as Protective. Adults were central to accessing learning, perceived in a helping capacity when experiencing challenges, *"when I struggle. I put my hand up and wait for my teacher to come and help me"* (p.9), reflected through his choice of blob below.

Figure 7

Blob Chosen by Thomas to Represent his Experiences Asking for Help



His enjoyment in lessons and support provided appeared dependent on relationships with staff, *“depends who’s teaching me”*, enjoying lessons when teachers are *“kind and they help me if I need help”* (p.12). Thomas also highlighted the importance of consistency in staff and approaches, although experienced frequent changes in teachers, adversely impacting his learning, *“I got confused because we have different teachers quite a bit...I just can’t keep track of what we’re doing and the work”* (p.10), reflecting his experiences through his choice below.

Figure 8

Blob Chosen by Thomas to Represent his Experiences of Confusion in Lessons



Despite the importance of adult support, Thomas experienced disconnect between his perception of adults’ helping role and support received; *“I tell the teacher and they never do anything”*. Thomas appeared to navigate difficulties by attributing trust to certain members of staff, *“my head of year...I trust them more than my teachers”* (p.4). Adult advocacy appeared central to successfully accessing school and shaped his perception of staff, *“the head of years will sort it, but the teachers don’t sort it”* (p.4). Thomas identified *“if the teachers...dealt with what was happening in class”*, *“letting the teachers deal with things and helping me”* and *“the teachers letting me be able to tell them what’s happening”* as aspects which would improve his experiences. This suggests his current experiences are shaped by limited advocacy and feeling dismissed, though he perceives adults as central to accessing school.

Sensory Overwhelm and Regulation Strategies. The school environment was experienced as overwhelming, and *“too noisy”*, impacting his sensory regulation and physical discomfort, *“it really hurts my left ear”* (p.6). Within the card sorting activity, Thomas identified *“it’s too loud when there’s large groups”* (p.13), suggesting busy environments contribute to sensory discomfort. Thomas’ experiences of sensory overwhelm, impacted his ability to seek support *“not when its loud in the classroom”* (p.9) and engage in learning, presented as a persistent difficulty attributed to peers’ behaviour, *“Everyone is just shouting all the time...we*

Figure 9

Blob Chosen by Thomas to Represent his Experiences Seeking Regulatory Support

barely ever get any work done” (p.9). Thomas developed strategies to cope with environmental overwhelm, *“stand outside sometimes...calm down...have a minute out because of how loud it is”* (p.9), *“walk up and down the corridor”* (p.10), represented by his choice below.



Regulatory spaces appeared to support him to manage the school environment, particularly when dysregulated like *“the hive”*, *“to calm us down...if we’re upset or annoyed”* accessing *“fidget toys and timers”* (p.10). Outdoor space and physical activities were also important in supporting regulation, developing strategies to limit the time he spends in environments which cause discomfort; *“I eat my lunch and then go straight out to play football, so I’m in there for like 2 minutes”* (p.13).

3.9.2 Cross-Case Analysis: Group Experiential Themes (GETs)

Five GETs and seventeen sub-themes emerged from the data (Table 4); ‘Adults as Shaping Safety, Trust and Access to Learning’, ‘Reliance on Trusted Peers to Navigate Learning and Social Interactions’, ‘School Ethos Shaping Experiences of Inclusive Practice’, ‘Making Sense of Academic Challenges’ and ‘Sensory Support as Fundamental to Educational Experiences’. Each GET and related subthemes are outlined below, as well as verbatim quotes to capture participants’ experiences and remain close to data. Themes are presented separately but it is important to highlight themes are interrelated and overlapping, reflecting the hermeneutic cycle and need to look to the whole to understand the parts, and the parts to understand the whole (Smith et al., 2022). Quotes are presented as follows:

- Verbatim quotes are italicised, followed by pseudonyms and transcription page number (e.g., (Josh, p.2)).
- Contextual information is presented in brackets (e.g., *[pause]*).
- Ellipsis (...) indicates omitted speech, which was not relevant to include as it did not add to understanding (e.g., follow-up questions).
- Where necessary to support understanding, the researchers’ contributions are presented using “R:”.

- Caregiver views were not gathered, however some caregivers were present during interviews to support participants. Caregiver comments which provide context to participants responses are presented (e.g., *Josh's mother*:).

Table 4*Overview of GETs and Subthemes***GET 1: Adults as Shaping Safety, Trust and Access to Learning**

- Trusting adults as a foundation for safety, support and being understood
- Adult presence providing sense of safety and consistent access to support and adaptation
- Staff's perceived knowledge and understanding shaping support provided
- Predictability and familiarity in adult relationships as key in navigating learning and school

GET 2: Reliance on Trusted Peers to Navigate Learning and Social Interactions

- Peers as a source of distraction, frustration and unkind behaviour
- Peers as a source of support and advocacy
- Navigating unstructured times and social aspects of school

GET 3: School Ethos Shaping Experiences of Inclusive Practice

- Relatedness with peers and staff supporting feelings of belonging
- Rules and punitive approaches shaping perceptions of school, self and staff as approachable
- Need for flexible support, tailored to individual needs
- Desire for increased autonomy

GET 4: Making Sense of Academic Challenges

- Difficulties sustaining attention, engaging and retaining information
- Academic difficulties impacting confidence, view of self and ability to advocate for support
- Preference for learning which is fun and practical
- Supportive approaches in lessons

GET 5: Sensory Support as Fundamental to Educational Experiences

- Sensory processing needs and supportive strategies
- Access to regulatory spaces

3.9.2.1 GET 1: Adults as Shaping Safety, Trust and Access to Learning

This GET explores how adults were key in shaping experiences, though the nature of support varied, highlighting the importance of trust, staff availability, perceived experience, staff-student relationships, consistency and predictability.

Table 5

Prevalence of Subthemes Related to ‘Adults as Shaping Safety, Trust and Access to Learning’

Participant	Trusting Adults as a Foundation for Safety, Support and Being Understood	Adult Presence Providing Sense of Safety and Consistent Access to Support and Adaptation	Staff’s Perceived Knowledge and Understanding Shaping Support Provided	Predictability and Familiarity in Adult Relationships as Key in Navigating Learning and School
Josh		✓	✓	✓
Oscar	✓	✓	✓	✓
Lily	✓			✓
Thomas	✓	✓	✓	✓

Trusting Adults as a Foundation for Safety, Support and Being Understood. While experiences varied, Thomas, Oscar and Lily highlighted the importance of building relationships with staff in navigating the cognitive demands and unpredictability of school. Thomas and Oscar placed importance on staff being kind and helpful:

“All the staff is really nice” (Oscar, p.3)

For Thomas, staff attributes and his relationship with them impacted his overall view of teachers and enjoyment of lessons:

“Depends who’s teaching me...I’ve got a good science teacher...They’re very kind and they help me if I need help” (Thomas, p.12)

Similarly, Oscar’s relationships with teachers were important, preferring time to build a relationship with one staff member:

“I like having the same teachers...you can get to know them and then get to know them more...you don’t just switch every teacher and have to get to know them, then get to know them, you get to know one teacher and that’s the teacher that teaches you” (Oscar, p.9)

Oscar's use of *"get to know them and then get to know them more"* suggests relationships with teachers develop overtime, with consistency enabling deeper understanding beyond surface level.

Lily's desire for agency and voice in staffing decisions reflected the importance of student-staff relationships in shaping her experiences:

"Maybe let the children when people are hiring, let the children look because...we're the ones being taught by them" (Lily, p.9)

Lily's use of *"we're the ones"* highlights her heightened awareness of how staffing decisions shape her experiences.

The importance of trust and feeling heard was highlighted by Thomas, who's experiences led to him identifying staff in authority positions as trustworthy:

"I just trust them [head of year] more than my teachers" (Thomas, p.4)

"I know they they'll sort it the head of years will sort it, but the teachers don't sort it" (Thomas, p.4)

In contrast, Oscar perceived all staff in a positive light, as they are approachable and provide a sense of safety:

"I must say there, there's no teachers that I don't like...I like all of them and I can go to because I feel safe around every single one...I find it really comforting" (Oscar, p.9)

Participants' emphasis on staff who are trustworthy, kind and attuned to their needs suggests relational attunement is central in shaping their educational experiences.

Adult Presence Providing Sense of Safety and Consistent Access to Support and Adaptations. Availability, or scarcity, of adult support shaped whether support felt possible, predictable and responsive. Some experienced support from Teachers and Teaching Assistants:

"I have both [TAs and teachers]" (Thomas, p.1)

"Normally we have one teacher, we have two LSAs" (Oscar, p.3)

Josh identified additional, familiar adult support as something which would improve his experiences, emphasising the importance of adult support in navigating the cognitive demands of school:

"If I had like one TA for me lessons, just so...I understand a bit better and then I can you know focus more" (Josh, p.4)

"For that I'd need a lot more TAs in a lot more lessons" (Josh, p.4)

Josh's repeated use of "*a lot more*" conveys a perceived discrepancy between support he receives and what he needs, suggestive existing TA support is useful, though insufficient.

Josh demonstrated awareness that adult support was dependent on attainment due to limited staff capacity, thus systemic constraints impacted his learning experiences:

"The SENCo has put where...I've not done so well on my end of year test. That's what we put the TAs. But that means I've only got TAs for english and science" (Josh, p.4)

Oscar also highlighted how limited staff capacity impacted feasibility of adjustments in learning:

"Then of course, they didn't have enough staff to really take you in another room and say, do you want to do this in a quieter room? [pause]. They didn't have enough staff to monitor that" (Oscar, p.8)

Oscar's use of "*of course*" emphasises limited staff availability to provide additional support became commonplace in his mainstream setting. His experiences of limited staff availability in mainstream school impacted his sense of safety, making sense of his experiences through comparison:

"Anything can happen and no one will know...I got into this fight, and no one knew...then I jumped over the fence. No one knew, until I got home and my mum had to text them. No one knew...I think it's bad that they don't know if anything happened because if it was a serious thing...dangerous...no one would know" (Oscar, p.5).

Oscar's repetition of "*no one knew*" highlights a sense of isolation in his experiences within mainstream when difficulties occurred, navigating situations independently due to perceiving he could not rely on staff. In contrast, increased staff availability and accessibility in Oscar's current setting supported adaptations and co-regulation:

"There's so many LSAs, like always free for you to, like, have a chat with or...you ever needed help" (Oscar, p.3)

"I have always someone to talk to if...I ever feel sad or angry, I can always go up to a friend or a teacher and just say I'm feeling quite angry, can we go walk or can we talk and then it just when you get it out. It feels so much better" (Oscar, p.5)

Staff capacity also shaped feelings of safety and containment:

"I feel much more safe [in independent setting] and I feel like because in [previous setting] there's so many kids and so less staff" (Oscar, p.5)

Adult support was experienced not only as an additional resource but as fundamental to accessing learning, regulation support, shaping whether school was experienced as unsafe and unpredictable, or safe, containing and attuned to needs.

Staff's Perceived Knowledge and Experience, Shaping Support Provided. While experiences varied, Josh, Oscar, and Thomas spoke of their perception of staff experience and knowledge and how this impacted their experiences; for Josh, this related to lack of understanding of FASD.

Josh's mother: "apparently, he [teacher] wasn't aware that Josh needed processing time or that it was part of his FASD and not just Josh...procrastinating"

"Oh, right, yeah" (Josh, p. 14)

In contrast, Oscar perceived staff understanding as a strength, attributing this to the reason they acquire their jobs:

"I just feel like they're really trustworthy and they got their job because they understand kids, just like me" (Oscar, p.9)

Oscar's reference to *"just like me"* also highlights a sense of relatedness to his peers, suggestive of mutual understanding of needs and strengths.

Oscar's perception of staff's understanding and knowledge was reflected in his confidence in their ability to manage situations, attune to students' needs and offer support before situations escalate:

"Staff are so good before that happens, they know. So, they'll take the person...go for a walk, let's go get some food and take it away from the other person. So, nothing ever happens...it's never been that bad...because the staff know how to handle it" (Oscar, p.5)

Oscar's experiences contrasted Thomas', who described a mismatch between his expectation of teachers to manage situations and his experiences; an area he would change to improve school:

"Teachers sorting things out that happen in the lesson...would make me feel much happier" (Thomas, p.7)

This subtheme appears interrelated to earlier subthemes, particularly 'Adult Presence Providing Sense of Safety and Consistent Access to Support and Adaptation'. When adult support was readily available, this shaped positive perceptions of staff knowledge. In contrast, mainstream settings with limited staff capacity may limit staff's ability to develop understanding

of individuals' needs, adversely impacting perceptions of staff experience and knowledge. This suggests contextual factors like staffing and resourcing, actively shaped the meaning participants gave to their perception of adults and thus their educational experiences, sense of safety and access to learning.

Predictability and Familiarity as Key in Navigating Learning and School. All participants described the importance of consistency and predictability in adult support, in shaping their experiences.

For Lily, consistency in adult support was key to navigating lessons, preferring support from familiar adults, though demonstrating awareness of restrictions to staff consistency due to differing roles in school:

"My two teachers that stay in there most of the time. Miss X who is always with us and Miss X, which isn't with us all the time because she's the Drama teacher" (Lily, p.4)

Oscar, who also attends a specialist setting, highlighted the importance of reduced transitions between year groups which provided consistency:

"It's not like you go from year two to year three in a different class from different class, from different classroom...It's normally in the same hub" (Oscar, p.9)

In contrast, for Thomas and Josh who attend mainstream settings, experiences of changes in teaching staff or approaches were frequent, creating confusion and uncertainty in lessons and difficulties meeting expectations:

"Yeah, sometimes I got confused because we have different teachers quite a bit...I just can't keep track of what we're doing and the work" (Thomas, p.10)

"TAs say things in different ways. So, when I get used to one TA saying something one way I've got another one...I've got trying to figure out what they mean" (Josh, p. 4)

Josh' use of *"trying to figure out"* highlights learning is experienced as confusing when staff are unpredictable in their approach and language, creating barriers to accessing lessons.

Thomas' experiences of inconsistencies in support also varied between staff members, with some teachers appearing to make presumptions about his needs and support required, which may reflect the hidden nature of FASD:

"It depends who it is...some teachers will help me, but some teachers and students say don't help him because he knows it all [pause] when I don't!"

Here, Thomas' statement of "*when I don't*" highlights his frustration of the disconnect between others' perception of his abilities and his experiences of academic challenge, which are not met with consistent support.

Participants highlight the importance of predictability and consistency in adult approaches, though experiences varied both between and within participants' accounts. When faced with inconsistencies, school was experienced as challenging and confusing.

3.9.2.2 GET 2: Reliance on Trusted Peers to Navigate Learning and Social Interactions

This GET relates to how participants' interactions with peers shaped their educational experiences, both positive and negative.

Table 6

Prevalence of Subthemes Related to 'Reliance on Trusted Peers to Navigate Learning and Social Interactions'

Participant	Peers as a Source of Distraction, Frustration and Unkind Behaviour	Peers as a Source of Support and Advocacy	Navigating Unstructured Times and Social Aspects of School
Josh	✓	✓	✓
Oscar	✓		✓
Lily			✓
Thomas	✓	✓	✓

Peers as a Source of Distraction, Frustration and Unkind Behaviour. Josh, Oscar and Thomas spoke of challenging interactions with peers, sharing frustrations that peers were a source of distraction, impacting engagement and ability to meet expectations and creating unsupportive learning environments.

"I had quite a few...rude classmates and they were just always trying to drag my attention away from the class and trying to get me in trouble, and it didn't help...it wasn't a good like atmosphere to try and learn" (Oscar, p.8)

Thomas positioned himself as motivated to learn, but his ability to engage was undermined by factors outside of his control, particularly distractions from peers. His frustration appeared to stem from not only being distracted, but a sense of injustice that he wants to engage but experiences barriers to doing so:

"We barely ever get any work done and don't do anything...Annoyed because I want to learn" (Thomas, p.9)

Josh recognised at times he can mirror distracting behaviours of his peers, though expressed ambivalence, with awareness of his limited control of such behaviours and simultaneous frustrations when others behave the same. Presenting this as outside of his control may help him make sense of his experiences by separating his intentions from those of his peers:

"I might sound a bit rich saying this, but people not shouting out...I can't say that too much because I do that" (Josh, p.14)

Josh's experiences of his peers being distracting shaped his overall perception of his classmates. The meaning given to such experiences shifted overtime, from peers as funny, to disruptive. This contrast appeared to reflect Josh's desire to engage in learning and thus attempts to separate himself from his peers who are disruptive:

"Distracting people...the idiots that...I thought at first were the class clowns. But they're not" (Josh, p.11)

Oscar's comparative account noted his experiences of distractions, though highlighted how environmental factors like class sizes shaped his experiences:

"I didn't like the big classrooms with all the kids. I'd rather be in a classroom with like three to four kids, like I am at the moment which I find...much more better because it's not as big distractions. It's not as loud" (Oscar, p.8)

Peers were also a source of unkind behaviour and negative influence on participants, making school more challenging to navigate. Oscar attributed adverse experiences in mainstream to the influence of peers, while also recognising his role in these interactions. Oscar reflected on his retrospective experiences in his previous setting, illuding to attempts to distance himself from an earlier version of himself, which may not reflect his current experiences:

"I mixed with the wrong group in my other school, everyone was a bit immature, and it didn't go great" (Oscar, p.4)

Thomas' experiences of unkind behaviour appeared repetitive, impacting his overall experiences of inclusion:

"People are mean to me, so it makes it harder" (Thomas, p.2)

"They're always pulling faces at me, telling shut up and going like...[signals hand pushing down] at me because of my height...makes me quite annoyed." (Thomas, p.3)

Thomas made a clear distinction between the playful intentions of friends, and disruptive intentions of peers, presenting a sense of injustice alongside protection for his friendships:

“My friends do it as a joke, but other people do it on purpose” (Thomas, p.8)

Thomas described strategies to navigate peer-related difficulties, like physical separation:

“The teacher puts me at the back on my own [pause] Cause...lots of people annoy me.

So, it’s easier for me to sit there when no one’s annoying me.” (Thomas, p.8)

Thomas’ use of *“put me”* suggests this support is initiated by staff, rather than self-directed, presenting with limited autonomy though acceptance this is supportive.

Peers as a Source of Support and Advocacy. Josh and Thomas spoke of the importance of friends in supporting them to access school. For Josh, this related to supporting his engagement and understanding in lessons. The level of support provided appeared dependent on whether they were close friends attuned to his needs, though suggests some reliance either way on peer support:

“Sometimes they’ll [peers] ...give me like a hint or two to...get me going. But then sometimes they’ll just, you know, get on with your own work” (Josh, p.5)

“He like it reminds me which lesson I’m in because me brain fuzzes and [friend] learned when me brain fuzzes because I do a specific face...sometimes [friend] has to physically just go [mimics poking] for me to realise and then I come back” (Josh, p.11)

Josh uses literal explanations to make sense of his academic experiences, such as *“fuzzes”* likely reflecting experiences of confusion or cognitive overload. *“Come back”* suggests Josh’s mind may drift from learning, needing reminders to stay on task.

In contrast, Thomas spoke of the importance of his peers in navigating school, placing value on peers advocating for him in social interactions, identified as one of the only things that supports his educational experiences:

“Some of my friends stand up and say just leave him alone” (Thomas, p.3)

“My friend’s standing up for me...that’s really it” (Thomas, p.6)

This not only highlights Thomas’ experience of friendship as a protective factor but also challenges interacting with students who he doesn’t have a relationship with, highlighting his socially vulnerability.

Navigating Unstructured Times and Social Aspects of School. Participants experienced difficulties navigating social interactions or social times in school, highlighting

potential social vulnerability. Josh experienced conflicting feelings of recognising he needed a break, alongside difficulty navigating unstructured times independently.

“I do enjoy having a break, but after 5 minutes I just I go into the, what do I do...10 minutes just standing there” (Josh, p.3)

Similar to Josh’s experiences, Lily’s account suggested her difficulties with social interactions have developed a preference of being alone, increasing social isolation:

R: “if you're having a good day, would you be on your own”

“Alone [pause] yeah”

R: “is it easier to be on your own?”

“Yeah” (Lily, p.11)

Lily’s clear distinction between times on the playground being ok and not good, may reflect her tolerance of unstructured times, rather than actively enjoying them.

R: “How do you find it when...you're on the playground? [Lily signals ‘ok’ sign with hand] Good?”

“Does this [making ok signal] look like this [making a thumbs up]?”

R: “Oh, sorry...Is that ok?”

“Yeah”

R: “What makes it OK? What could make it better?”

“Don't wanna do that question” (Lily, p.5)

Lily’s withdrawal may reflect difficulties articulating her views or discomfort sharing information about areas she finds challenging. In line with her preference for being alone, her experiences suggest unstructured times may be overwhelming, and while she navigates this as best she can, it is not a positive aspect of school.

Similarly, Oscar’s experiences in mainstream school were shaped by difficulties forming peer relationships, particularly with older or intimidating peers, contributing to social isolation and vulnerability. Oscar’s reliance on familiar, trusting relationships to navigate social environments presented as a coping strategy, though intensified difficulties and isolation.

“I had not many friends, I was hanging around with my sister's friends, and my sister fell out a lot with her friends, so I was always taking sides...I never had a really close friend...I was walking around on my own. Or just run...I never played football...because

it was just too scary. Everyone was proper like bullies, and everyone was bigger than me” (Oscar, p.10)

Oscar’s use of “*everyone*” generalises his negative social interactions, reflecting limited relatedness to peers and experiencing social situations as intimidating and isolating. Oscar appears to separate himself from the wider school community, suggesting limited feelings of belonging. In contrast, Oscar’s current setting is experienced as socially supportive as staff facilitate interactions:

“They [staff] just do it, so you do make friends, they put everyone together and try and socialise everyone” (Oscar, p.3)

“Lunches, I really like it because I get to sit with my friends and it's really easy to make friends, everyone's really nice in there” (Oscar, p.3)

“You always get to see your friends whether you like it or not...you can always go out of the hub to...another hub where your friends are and just say hi” (Oscar, p.7)

His use of “*I really like it*” contrasts his social experiences in mainstream school, highlighting a shift in the meaning-making of his social interactions. This was reflected through moving from “*everyone*” to “*friends*”, suggesting increased feelings of belonging and connection. His account suggests social experiences are not solely impacted by within-child factors but also by environmental factors, with increased structure enabling positive interactions.

Thomas shared commonalities in his experiences, highlighting the importance of friendships in navigating unstructured times and contributing to positive school experiences:

“I like seeing my friends” (Thomas, p.4)

“I got to play football with my friends” (Thomas, p.2).

Unlike Oscar’s difficulties making friends in mainstream school, Thomas finds social interactions easier to navigate, supporting his inclusion:

“I've got quite a lot...They're all new friends” (Thomas, p.2)

While social experiences varied and were shaped by individual and environmental factors, they did not align with the setting type, as participants attending the same type of setting (e.g., mainstream or specialist) reported markedly different experiences. This suggests social experiences in education are shaped by interacting individual and systemic factors, with adverse experiences impacting the meaning given to such experiences.

3.9.2.3 GET 3: School Ethos Shaping Experiences of Inclusive Practice

This GET explores how various elements contributed to settings overall ethos and approach, which shaped participants' experiences of inclusion and sense of community in school.

Table 7

Prevalence of Subthemes Related to 'School Ethos Shaping Experiences of Inclusive Practice'

Participant	Relatedness and Mutual Understanding Supporting Feelings of Belonging	Rules and Punitive Approaches Shaping Perceptions of School, Self and Staff as Approachable	Need for Flexible Support, Tailored to Individual Needs'	Desire for Increased Autonomy
Josh	✓	✓		✓
Oscar	✓	✓	✓	✓
Lily	✓		✓	
Thomas		✓	✓	

Relatedness and Mutual Understanding Supporting Feelings of Belonging. Three participants spoke about how experiences of relatedness in terms of activities, shared needs, and mutual understanding fostered a sense of inclusion.

"Everyone plays it" (Lily, p.2)

"Everyone, of course, has their own needs" (Oscar, p.4)

"It's a great school because it helps kids like me with FASD" (Oscar, p.1)

Oscar's use of *"like me"* suggests he feels a sense of belonging in his setting and such experiences influence his overall perception of school. His use of *"of course"* highlights a sense of acceptance of difference, resulting in school experienced as inclusive and a space he feels he belongs. Oscar's sense of relatedness was extended to adults in school, attributed to a shared experience of neurodivergence:

"Even some of the teachers I think have ADHD" (Oscar, p.10)

In contrast, Josh's experiences suggested a limited sense of inclusion and acceptance of differences, with heightened awareness of comparisons to his peers' and need to justify adaptations:

“They've not got the right equipment to use it...I can say it, but...I've still got to say, like the punctuation figure. So, it's not completely cheating. I still understand where to put me punctuation and all that” (Josh, p.3)

Oscar contrasted his sense of relatedness and mutual acceptance of difference in his current setting, to prior experiences in mainstream:

“If you're having a bad day...everyone has a bad day, but no one takes it out on each other” (Oscar p.5)

“Everyone in [current setting] is much more mature and everyone understands everyone else...but a normal school, should I say, they don't really understand other people, other people's needs and stuff, so it's hard to make friends and harder to chat to people” (Oscar, p.4)

Participants' experiences suggest when there is mutual understanding of differing needs, school is experienced as safe, accepting and inclusive, though in absence of this, educational experiences are characterised as isolating and feeling misunderstood. Oscar's use of “*normal school*” suggests heightened awareness that his experiences in a specialist setting are not the typical approach. Given his prior experiences in a “*normal*” setting were challenging, Oscar has perhaps internalised this by perceiving his needs to not align with what is accommodated and accepted in a mainstream environment, creating a sense of othering further impacting belonging.

Rules and Punitive Approaches Shaping Perceptions of School, Self and Staff as Approachable. Oscar, Josh and Thomas noted their experiences of behaviour management approaches and how this impacted their experiences and wellbeing.

Thomas' frustration of unjust sanctions reflected feeling targeted by peers, and a sense of separation and difference from his peer group:

R: “How do they make you feel when you get those [sanctions]?”

“Sad and annoyed because I never did anything...It's people in my class...they blame it on me” (Thomas, p.13)

Josh's fears of sanctions impacted his ability to advocate for his needs, and seek adult support, attempting to complete tasks independently:

“You know the teacher gets, you know, aggravated like shout...I don't like that and it's just really difficult...then I feel even more pressured to not put my hand up, because if I say something wrong, then I'm going to be in a bit of what do do” (Josh, p.5).

His feelings of “*even more pressure*” suggest his experiences are already reliant on adult support to access learning, though when adults become punitive, the barriers to accessing learning are intensified. His account also suggests accessing support is reliant on his self-advocacy, rather than adults being attuned to support needed.

Josh’ awareness of adult hierarchies and fear of doing wrong resulted in unsafe situations like being on the road with limited awareness of danger, highlighting how staff approaches can result in perceptions of staff as unapproachable, impacting students’ ability to self-advocate:

“I’m thinking I might have to go round because if this is the assistant head teacher, I don’t want to get in trouble. So, I just listened and tried to go on the road” (Josh, p.16)

For Oscar, punitive approaches and rigid rules when he attended mainstream significantly impacted his motivation to engage in lessons and attend school. Throughout his account, experiences of punitive responses presented as a catalyst to his placement change:

“Personally detentions, I didn’t like it. It was quiet. It was awkward...if they shout at you, it makes me feel...horrible and it just scares me and it doesn’t make me want to go into school...it makes me be scared of the school and don’t want me to go to school. But with [current setting], let’s say I want to go to school” (Oscar p.4)

“I really, really, really, really didn’t like running and you didn’t have a choice unless you had a...note saying he can’t run, you had to run...I ended up bunking in the toilets and trying to hide....It wasn’t good and it didn’t make me want to do it...it didn’t want to make me get to school so. But with [current setting], let’s say you can...skip it. You don’t have to do it, but you just you have to do something like colouring or word search” (Oscar, p.7)

Oscar’s demonstrated awareness that his approach to managing challenging situations wasn’t necessarily positive, though was a coping strategy to navigate an environment he found challenging. His comparative account suggests increased autonomy and flexibility of expectations has shaped his educational experiences as safe, enjoyable and motivating, which contrasts his prior experiences characterised by fear, avoidance and inflexibility. This difference in his experiences was supported by restorative approaches to challenges, through educational consequences and co-regulation from attuned adults, not only impacting motivation but also his self-concept and students’ ability to be themselves:

“With a real school, you either go to detention, you get told off, you get shouted at. What personally makes me feel bad about myself, and I don't like that...with my school now you get an educational consequence...you just get, either chatted to and just say why that's happened or how that's happened or how we can resolve it...or you go out, get some food and talk about what happened. And that's all” (Oscar p.4)

“You never get a detention, you'll never get any of that...it works because...that's how everyone feels their self in the school...as they know, they can't really get badly told off, so they feel more themselves” (Oscar p.4)

Similarly to subthemes aforementioned, Oscar's use of “*real school*” highlights heightened awareness of his experiences differing from mainstream settings and may denote consciousness that his experiences do not match societal expectations of typical educational experiences. Oscar's use of “*it works*” highlights a sense of buy in and agreement with the behavioural approach. Moreover, “*everyone feels their self*”, implies his prior educational experiences did not foster a safe environment to express himself, highlighting the impact behaviour approaches can have on students' feelings of safety.

Need for Flexible Support, Tailored to Individual Needs. Participants highlighted desire for adaptable and flexible support, though experiences varied, dependent on multiple factors like staff availability, systemic decisions, and settings' broader approach. When support was adapted, school was experienced as accessible, positively shaping educational experiences:

“I like that it's based around me and that I just feel a lot more comfortable there than what my other school” (Oscar, p.1)

Interrelated to other subthemes, feasibility of adjustments was shaped by adult availability:

“They have a lot of staff to take you to another room” (Oscar, p.8)

Accessibility was also shaped by environmental aspects of learning such as flexibility in groupings to ensure provision aligns with students' strengths and needs, positively shaping educational experiences:

“If you didn't like that hub, you can change into other hubs...when I first started in a hub...I didn't not like it, but it didn't suit me. It was too easy. So, we go into a different hub” (Oscar, p.9)

In contrast Josh's experiences of limited reasonable adjustments resulted in school experienced as unclear, adversely impacting his engagement and ability to navigate school:

"It's very confusing because I'm... I'm left-handed...then I have to play right-handed instruments" (Josh, p.2)

Josh expressed confusion regarding rules and restrictions introduced since the setting became an academy, limiting access to regulatory spaces and reducing flexibility of support highlighted how broader systemic decisions can shape educational experiences:

"So...if you've been upset in like the last 10 minutes of the lesson, you're going to wait 20 minutes to actually go" (Josh, p.3)

Josh identified *"calming strategies and things like that and not having to wait 20 minutes"* (Josh, p.15), as an area which would improve school for him, highlighting the adverse effects of inflexibility of support on his experiences of regulation in school.

Broader systemic decisions not only impacted Josh's experiences and whether support felt possible, but had broader implications for placement decisions:

Josh's Mother: "For him to be struggling I find it hard to understand? But if he's not getting the support, then"

"We might have to move" (Josh, p.5)

Josh' use of *"have to"* implies limited autonomy, reflecting how settings' approaches to adjustments and flexibility of support can shape educational experiences and placement decisions.

Desire for Increased Autonomy. Participants highlighted how autonomy shaped educational experiences. Lily repeatedly noted her desire for greater autonomy in decisions which impact her experiences, though she currently experiences restrictions to this:

R: "Is there anything else that's not very good about school?"

"Uh, not being able to leave the classroom" (Lily, p.6)

R: "What helps makes things easier when you're in the classroom?"

"Crafting...this bag helps...craft...I'm not allowed [to take it to school]. I wish I was" (Lily, p.14)

Lily's use of *"not allowed"* and *"not being able"* highlights her limited autonomy and voice, alongside teachers' determining support, despite her awareness of what may be

supportive. Her desire for greater agency was reflected through “*I wish*”, presented as a hope, though not likely a reality based on her experiences.

Similarly, Thomas noted how having a voice in school would reduce experiences of feeling dismissed:

“Maybe the teachers letting me be able to tell them what's happening” (Thomas, p.4)

In contrast, Oscar’s setting appeared to promote student autonomy wherever possible, creating a sense of responsibility and supporting students to advocate for support. Greater autonomy characterised his experiences as accessible and flexible:

“They're pretty free...if you ever needed space from the classroom, you can go up to one of them and ask can we go for a walk or can we go for a drive or can we go to Tesco's and then we'll go shop or walk on the field” (Oscar, p.2)

“You got the freedom of just saying, can we go out and we're out. In the other school, you'd never be allowed to go out. The whole day sitting on your bum, on the chair, listening” (Oscar, p.6)

Similarly to Lily and Thomas’ language, Oscar’s use of “*allowed*” highlights limited autonomy and reliance on adults to access support in mainstream. In contrast, his current experiences are characterised by “*freedom*” through increased autonomy, reflecting how sense of autonomy can support self-advocacy and positively shape educational experiences. Moreover, use of “*we*” suggests feelings of togetherness shaped through co-regulation from attuned staff.

3.9.2.4 GET 4: Making Sense of Academic Challenges

This GET refers to participants’ meaning making of their experiences of academic difficulties, which commonly related to inattention, engagement and retention, preferring practical learning tasks. Participants offered suggestions of changes which would be supportive in learning.

Table 8

Prevalence of Subthemes Related to ‘Making Sense of Academic Challenges’

Participant	Difficulties Sustaining	Academic Difficulties	Preference for	Supportive
	Attention, Engaging	Impacting Confidence,	Learning which is	Approaches in
	and Retaining	View of Self and Ability	Fun and Practical	Lessons
	Information	to Advocate for Support		

Josh	✓	✓	✓	✓
Oscar	✓	✓	✓	
Lily	✓	✓	✓	✓
Thomas		✓		✓

Difficulties Sustaining Attention, Engaging and Retaining Information. Josh, Oscar and Lily's experiences of academic difficulties relating to inattention and engagement adversely shaped aspects of their educational experiences. While Thomas experienced distractions in class, his interpretation of his experiences aligned most with the subtheme noting peers as a source of distraction and therefore is explored above, though highlights how subthemes are interrelated.

While Lily did not explicitly mention difficulties sustaining attention, her dislike for certain subjects and difficulties engaging were highlighted through emotive language, and repetition:

"I hate PSHE and RE...they're just boring lessons...Boringggg" (Lily, p.4)

Josh demonstrated heightened awareness of his difficulties, experiencing constant environmental distractions, suggesting inattention creates additional barriers to learning:

"I get distracted and all that...students, people outside the window. Random sounds. Lots of, you know, things that fall under me FASD the things that distract" (Josh, p.1)

Josh's reference to *"fall under me FASD"* suggests he attributes difficulties to factors outside of his control, which present as a way to accept challenges experienced. Moreover, his account suggests difficulties are multiple, and therefore he experiences daily implications which he associates with FASD. His limited sense of control was further highlighted by viewing aspects as learning as not possible, creating tension with his desire to learn:

"I cannot sit in a chair for...more than an hour for the life of me" (Josh, p. 7).

Here, *"for the life of me"* reflects him feeling incapable of meeting expectations, presenting difficulties as outside of his control, to perhaps diminish feelings of responsibility which may impact his self-concept.

Josh used visualisation and metaphor to make sense of his experiences and articulate internal processes he experiences, suggestive he has limited capacity for information and therefore too much information is overwhelming, impacting his engagement:

“It’s kind of like a bookshelf with a bin on top of it. If I just keep piling up my ideas, the original one will fall...into a bin and then I can’t remember it...It’s a less confusing way to explain it” (Josh, p.13)

Josh’s visualisation also suggested his thoughts are constant and overwhelming, creating cycles of determining which information is useful to share to support him to access learning:

“The thing with my brain is I’ll have a question, and I put my hand up...then I’ll have another question, but I don’t want to be listing the 1000 questions...it’s used over and over and over” (Josh, p.13)

Alongside discussing how his needs associated with FASD impact his experiences, Josh attributed some of his difficulties to ADHD, further externalising his difficulties perceived as outside his control:

“I’ve got ADHD...I get distracted a lot forgetting things and all that sort of thing and yeah low focus. But then we got me some...tablets. One of them were an absolute nightmare. The other one were an absolute lifesaver” (Josh, p.11)

Josh’s contrasting descriptions of medication as both a “lifesaver” and “nightmare” highlight the influence of external supports on his experiences and may reflect tendency to locate difficulties outside of his control, through reliance on external supports.

Similarly, Oscar’s presented his difficulties with attention as outside his control:

“I find sitting still on a chair watching someone, say, do this, do that, do that. I find that really hard” (Oscar, p.6)

“I feel like if I had to do the lessons I had to do, I couldn’t. I couldn’t focus on them. It was just too much” (Oscar, p.8)

His repetition of “I couldn’t” reflects Oscar limited perceived control, presenting inattention not as a conscious choice, rather an area he finds extremely challenging. Much like Josh, Oscar attributed and made sense of some difficulties through his ADHD. Externalising his difficulties may reflect attempts to reduce self-blame, perceiving challenges as outside his control:

“Whole day sitting on your bum, on the chair, listening...watching the whiteboard...I just couldn’t handle that...especially because I got ADHD. I’m always moving” (Oscar, p.6)

Here, “especially” suggests engaging in lessons is already challenging, though his ADHD and associated implications, create additional barriers to engagement.

Oscar recognised adjustments which supported his attention, though experienced rules as confusing and frustrating, likely as he perceived his behaviours to be outside his control and therefore struggles to understand how he may adhere to expectations:

"I was allowed a fidget to it, but there's rules about it...I don't think the rules about fidgeting...what's wrong with fidgeting...I just find it a bit mean that you can't fidget"

(Oscar, p.6)

Academic Difficulties Impacting Confidence, View of Self and Ability to Advocate for Support. Participants' academic difficulties shaped their confidence, ability to ask for help and view of themselves. This contrasts experiences in the prior subtheme as rather than attributing difficulties as outside of their control, difficulties appeared internalised.

Lily's difficulties understanding significantly impacted her learning experiences:

"Nooo, the worst one, the worst one"

R: "The worst one...should I guess?...understanding?"

"How do you know?" (Lily, p.6)

While the researcher used asked *"what makes school trickier?"*, Lily's language choice and repetition of *"the worst"* implies her understanding is an area which significantly shapes her educational experiences, characterised as challenging and inaccessible.

While Thomas identified learning strengths, he also perceived learning as unattainable, highlighting limited confidence and reliance on support:

"It's my spelling...I don't know how to start or something" (Thomas, p.1)

"With Geography...I struggle on like flags into countries I'm fine with, but anything else I can't do" (Thomas, p.5)

Like Lily and Thomas, Josh identified challenging areas of learning, with particular difficulties keeping up with the pace of lessons:

"I'm no good with that. It takes me like 5 minutes to write a sentence...I go like that. [modelling 'pecking' action on keyboard]" (Josh, p.2)

"I'm not a good typer or writer...I'll be going p-h-y-s-i-c-s, right now I want you to write [modelling what teachers say] and then it just keeps going...Then I'm a bit stuck...I can't really keep up sometimes" (Josh, p.13)

Josh's language "*no good*" and "*I'm not good*" highlights how his academic challenges not only shape his experiences but also his perception of himself, adversely impacting his confidence and suggesting such experiences are internalised.

Josh's academic challenges were experienced as cyclical and ongoing, impacting his emotional wellbeing and ability to engage:

"It's a weird cycle because if I can't do something. I get anxious and then I get angry at myself and then I just go into fall on meltdown" (Josh, p.15)

Josh demonstrated heightened awareness of difference, interpreting his experiences through positioning himself comparative to others and perceived norms, reflecting a mismatch between his experiences and what he perceives as typical:

"I'm not your average child" (Josh, p.7)

Josh experienced tension between his self-perception of strengths and lived experience of difficulty, further using comparison to shape his interpretation:

"There's the questionable lessons that I think am I really supposed to be struggling with this one" (Josh, p.2)

Josh also made sense of his experiences through comparative experiences outside of school, creating confusion and self-doubt when experiences did not align across contexts:

"We've got music and that's one of the...lessons I struggle most with, which is pretty confusing for me because I've been doing, you know, music...two years...yet I still...don't understand it" (Josh, p.2)

While Josh demonstrated awareness of his academic challenges, he experienced difficulties advocating for support, perceiving the level of support needed would limit resources for others. He appeared to position himself as a burden, understanding his experiences through comparison to his peers. Consequently, he adopted copying strategies, working independently to minimise perceived impacts on others, protecting peers from experiencing similar difficulties:

"I'm like very confused [pause] but I don't want to ask for help...from the main teacher 'cause...they're teaching and I don't wanna intrude...It's hard to explain because I don't want them like using up all the time after me when other students might also need the help...I don't want them to be confused as well" (Josh, p.5)

Similarly, Oscar experienced heightened awareness of his difficulties in learning, like keeping up with the pace of learning and feeling behind which impacted his confidence, shaping learning as unattainable and overwhelming with difficulty advocating for support:

“I normally zone out on something and then when they ask...Oscar are you going to do it?...I find saying yes, like a lot easier to say no when they get through to the whole conversation about it. So, I just say yes, it sorts it and I never get my work done...then I can never get to the next lesson because I'm always trying to finish the work off before the end of the lesson...I found it a lot stressful” (Oscar, p.6).

Oscar appeared to have developed coping strategies to temporarily alleviate pressure, alongside not wanting to become further behind. His academic challenges and awareness of difficulties appeared to impact his view of himself as a learner, shaping his overall educational experiences.

Preference for Learning which is Fun and Practical. Learning made to be fun, or which offered practical activities, positively shaped participants experiences, reflected across three participants’ accounts who attended various settings. Oscar’s experiences of learning being fun characterised learning as accessible, tailored to individual needs, providing a sense of achievement:

“I don't actually mind it because they put it in a way that it's fun...give you a set of tasks...Work it out in a way what's fun for you, and they can break it down to really small bits” (Oscar, p.3)

“I find cooking really fun...cooking something you can eat just really like satisfying” (Oscar, p.7)

A sense of fun was facilitated not only by activities but also adults’ approach, shaping a supportive and safe learning environment, with a reduced sense of power hierarchies:

“I really like cooking like full stop but especially cooking with the teachers because they make it really fun...every single teacher always comes out of flour on their head or flour on them because the students just throw the flour at them, what they completely allow and just take it as a joke” (Oscar, p.7)

Lily frequently mentioned how interactive platforms and practical activities were central to her school experience, identified as the best parts of her day. Similarly, Josh preferred

practical activities. Such opportunities characterised learning as low-pressure, interactive and engaging:

“Playing Kahoot and Bluekit” (Lily, p.3)

“Actually, I like science more...soon we are doing a fire experiment...we're turning 5 different colours” (Lily, p.3)

“Like the practical's, the theory, you know how things work” (Josh, p.1)

Josh's enjoyment for practical activities and understanding how things work appeared to relate to difficulties understanding abstract concepts like religion, therefore making sense of his experiences by comparing challenges to areas he feels confident in:

“I do like to question things...I have given our teacher a bit of a run for his money... We're all just making...hypotheses...predictions so I like that” (Josh, p.6)

Supportive Approaches in Lessons. This subtheme captures participants suggestions of changes which would support their experiences, drawn from their prior experiences and meaning-making processes. For Josh, clear, explicit communication and avoidance of ambiguous language would support him to access learning.

“Do you understand Josh? [demonstrating what staff would say]. That's the main one” (Josh, p.5)

Josh also finds it supportive for adults to check his understanding and provide reassurance, suggesting he sometimes experiences confusing and cannot follow expectations independently:

“Check if I'm like you know, on the same page...Which is sometimes literally...that is a big helper” (Josh, p.12)

Staff slowing the pace of learning, checking his understanding and using visual demonstrations would also be supportive, relating his interpretation to experiences in other areas of his life:

“Slow down and make sure I understand...show me through.... it's kind of like if [gymnastics teacher] is telling me how to do a tuck front, she won't just describe it to me. She'll get someone to actually do it so I can see how to do it...I like...a physical example” (Josh, p. 14)

Technology was identified as supportive in other environments, though was not accessible in school, highlighting how environmental factors shaped Josh's educational experiences and the need for accessible, tailored support:

"They've not got the right equipment to use it [speech to text]" (Josh, p.3)

Thomas identified additional adult support and examples as supportive, suggesting reliance on additional support, although current mismatches between support provided and perceived need:

"Maybe a teacher sits next to me...helping me with my spelling...giving me like some examples" (Thomas, p.5)

Josh would find additional processing time supportive, suggesting he currently experiences frustrations keeping up learning resulting in tasks becoming less meaningful:

"People not shouting out...the answers...because I'll be thinking about it...then if somebody helps out the answer and...I keep figuring it out and I figure out it is that answer, it feels a bit pointless at that point" (Josh, p.14).

3.9.2.5 GET 5: Sensory Support as Fundamental to Educational Experiences

Table 9

Prevalence of Subthemes Related to 'Sensory Support as Fundamental to Educational Experiences'

Participant	Sensory Processing Needs and Support Strategies	Access to Regulatory Spaces
Josh	✓	✓
Oscar	✓	✓
Lily	✓	✓
Thomas	✓	✓

Sensory Processing Needs and Support Strategies. The school environment and associated sensory inputs appeared central to participants' regulation and ability to navigate the environment and learning. Lily and Oscar highlighted the discomfort of school uniforms and desire for flexibility:

"I used to go [previous secondary school], it was a lot stricter you had to wear uniform. But with this school, you can wear whatever you want...Long as it's appropriate, of

course...I found uniform quite strict and I didn't like the tie because it was a clip and my sensory” (Oscar, p.1)

Oscar’s account suggests he may perceive his prior setting to prioritise conformity to the rules, rather than adapting approaches to meet his needs, using comparison to his current experiences to make sense of his retrospective experience. Lily’s dislike for the school uniform appeared key in shaping her experiences and her repeated reference to pyjamas highlighted how her sensory discomfort actively shapes her educational experiences:

“Not comfy...Put uniform on this one on don't like, with school [pointing to ‘does not make school positive’ during card sorting] ...Letting us be in comfy clothes and wearing my pyjamas in school” (Lily, p.6)

Lily’s use of “letting us” suggests she experiences limited agency; while identifying uniform flexibility as something which would improve school, she experiences rigidity in rules, which she does not perceive to meet her needs.

Thomas’ experiences were characterised by auditory discomfort, though his frustrations appeared attributed to peers’ intentional behaviour, demonstrating how sensory discomfort may impact peer perceptions:

“Classroom is too noisy... It hurts my left ear a lot...It's nearly all the time...everyone's always screaming” (Thomas, p.6)

Thomas developed strategies to manage his sensory discomfort, relying on self-advocacy:

“I get to stand outside sometimes to [pause] calm down...have a minute out because of how loud it is...I ask, could I please have a minute out 'cause it's too loud and they say yes” (Thomas, p.9)

Josh did not detail specific sensory experiences, but spoke about various approaches to support his sensory regulation, some of which were influential while others were counterproductive:

“Sometimes I get too distracted by the fidgets, and I don't do my work, and I don't pay attention anyway” (Josh, p.15)

“Yeah...it [sensory diet] just gives me brain that boost [pause] It's kind of like when you recharge batteries, power you up again...I feel like normal” (Josh, p.7)

Josh’s metaphor of “recharging batteries” suggests his capacity for sensory input is finite, and school is an environment which places significant demands on his sensory needs.

Regulatory supports are presented as necessary, rather than optional, to support Josh's capacity to navigate his educational experiences. Moreover, his reference to "*normal*" positions his experiences of sensory discomfort as different to his peers, and such experiences may present an additional challenge in school. Josh's repetition of "*normal*" was also reflected through experiences of co-regulation; "*people can like, you know, help me, you know, like, go back down to normal level*" (Josh, p.15), further highlighting feelings of difference, suggesting sensory supports allow him to temporarily experience what he perceives as the expected experience.

Access to Regulatory Spaces to Support Sensory Needs. All participants' settings had sensory spaces or rooms which participants could access to varying degrees, though all participants found this supportive:

"There was in lower primary... Yeah [responding to whether she is allowed to access the sensory room], sometimes...it's good" (Lily, p.7)

"The Hive...it's to calm us down...we go there if we're upset or annoyed...they've got fidget toys and timers" (Thomas, p.10)

Josh highlighted how sensory spaces tailored to his needs could foster feelings of safety, and improve his educational experiences:

"A little den, maybe like some books because I love books...sensory snacks and like music and things like that and yeah lights...sometimes my phone...no shouting or anything, just silence... you know teddies" (Josh, p.16)

Oscar's setting provided a dedicated sensory room and sensory spaces in classrooms, suggesting support is actively provided and normalised. Oscar's account suggests he experiences sensory spaces as a physically and emotionally containing, which provide autonomy:

"They have a sensory room...each hub has a corner for sensory, but there's a whole other hub just a whole sensory [pause] sofas, boxing bags, fidgets, loads of fidgets, carpets, bean bag, blankets...you can...do your work in there, you can lay on the sofa. I find it really cosy...they got all the lights on the ceiling... It's really cool" (Oscar, p.8)

Physical activity was also central to participants regulation. For Lily it was important to access a familiar and easily accessible space:

"Drama Room, which is right outside the room...It's just big, so I can do cartwheels" (Lily, p.7)

For Oscar, physical activity supported regulation by providing breaks from learning and a method of exerting emotions. This was presented as embedded in the settings' approach and provided in line with students' preferences, avoiding feelings of difference:

"You can go play football, you can have a break and then you go back in and it's normally English...once you have that you go play football, have a break" (Oscar, p.3)

"I personally really like the gym, so it's like my happy place. I like getting all the anger out in the boxing bags" (Oscar, p.5)

When describing his educational setting, Oscar highlighted sport as central to his provision and experiences:

"It just really helps me because for a lot of kids, football is therapy...For me, I never really liked football, but when I joined there because football is quite a big thing...I started to like football and they're very supportive of what you like" (Oscar, p.1)

Oscar's reference to football as therapy suggests sport is central to his emotional regulation. Notably, this reflects a shift in his interpretation overtime; although football was not initially perceived as supportive, the environment and culture of the specialist setting appear to have shaped his understanding of helpful strategies. This suggests environmental factors actively shape how participants experience and make sense of regulatory support, implying regulatory support may be less about the activity itself and more about the shared social experience embedded in the settings' culture.

3.9.3 Summary of Findings

Across the five group experiential themes, participants educational experiences were shaped by the interplay between adult support, peer relationships, school ethos, academic challenges and sensory supports. Adults played a central role in shaping participants' experiences of secondary school, with trust, kindness and relational consistency helping the young people feel safe, understood and able to access learning. Limited staff availability and inconsistent approaches often created confusion or left the young people feeling unsupported, while predictable, familiar adults supported regulation, confidence and a sense of containment. Overall, participants' accounts suggest that attuned, knowledgeable and consistently available adults were fundamental to whether school felt safe, manageable and responsive to their needs.

Peers were also key in shaping participants educational experiences. Peers often made learning and social experiences more challenging, with the young people experiencing

distractions, unkind behaviour and difficulties navigating social interactions, which consequently shaped their experiences of inclusion and belonging. At the same time, for some participants, trusted friends played an important, protective role in navigating school, providing support in learning and advocacy when social challenges arose. Social experiences varied widely, shaped by both individual needs and environmental factors, such as contrasts between social experiences at mainstream and independent settings. Despite this variation, the findings highlight these young people's social vulnerability, difficulties navigating unstructured times and forming friendships, alongside the importance of supportive peer relationships.

Settings' overall ethos and approach shaped participants' experiences of inclusion and the sense of community within school. Mutual understanding and shared experiences helped some participants feel a strong sense of belonging and inclusion, particularly in settings where differences were recognised and accepted among both peers and adults. In contrast, experiences of punitive behaviour approaches and inflexibility of rules within mainstream settings resulting in participants feeling fearful, misunderstood and unable to advocate for their needs, adversely shaping overall perceptions of school and themselves. In contrast, experiences of restorative approaches to challenges focusing on co-regulation, positively shaped motivation, self-concept and participants ability to be themselves. Across accounts, flexible support and opportunities for autonomy were key to making school feel safe, inclusive and responsive to their needs.

Participants educational experiences were also shaped by academic challenges and the meaning given to these difficulties. Participants described significant difficulties sustaining attention, engaging in lessons and retaining information, often experiencing distractions, cognitive overload and challenges keeping up with the pace of learning and meeting expectations. While some academic challenges were attributed to factors outside of their control, some challenges appeared internalised, impacting participants' confidence, view of themselves as learners and ability to advocate for support. Learning often felt most accessible when it was practical, fun or broken down clearly, and when adults used supportive approaches such as checking understanding, slowing the pace and providing visual or practical examples.

Finally, participants' sensory processing needs shaped how they experienced school, with discomfort from uniforms, noise and other sensory inputs affecting regulation and engagement. Sensory supports such as quiet spaces, fidgets, physical activity and dedicated sensory rooms were described as essential in helping participants feel calm and able to learn, presented as them

temporarily experiencing what they perceived as a typical school experience. Across accounts, flexible access to regulatory spaces and activities made school more manageable, with a need for spaces and support to be tailored to individual needs. Moreover, environmental factors such as the culture surrounding regulatory activities shaped participants' perceptions of what supported their regulation, thus positively shaping their overall educational experiences.

3.10 Discussion

This section discusses the findings in relation to the research question, situated within broader literature exploring the educational experiences of CYP with FASD. Implications, limitations and directions for future research are considered.

This research explored the educational experiences of young people with FASD in UK secondary education settings, using a qualitative approach, aiming to address; *What are the educational experiences of young people with a diagnosis of FASD in UK secondary schools?* To explore participants' interpretations of their educational experiences, semi-structured interviews with four adolescents were analysed using seven-stage IPA (Smith et al., 2022), generating five GETs and seventeen sub-themes.

Findings highlighted the diverse spectrum of needs, strengths and educational experiences and such variation echoes prior UK research eliciting the voice of CYP with FASD (Eodanable et al., 2024). Participants' ratings of school ranged from 3/10 (Lily), 7/10 (Thomas and Josh), to 10/10 (Oscar, when attending specialist setting), illustrating this variation. Experiences were not solely determined by the type of setting (e.g., mainstream or specialist), as Oscar and Lily's experiences differed greatly despite both attending specialist settings. While many subthemes reflect the microsystem (Bronfenbrenner & Morris, 2006), likely because of the focus on eliciting CYP's voices, the findings suggest CYP's interactions with broader systems shape their interpretation of their educational experiences. Therefore, participants' experiences were multifaceted, complex and shaped by multiple interacting factors. Despite heterogeneity in participants' experiences, cross-case analysis highlighted convergence and divergence.

3.10.1 RQ1: What are the educational experiences of young people with a diagnosis of FASD in UK secondary education settings?

The focus of the research was to explore the educational experiences of young people with a diagnosis of FASD in UK secondary education settings, reflected across all five GETs.

Adults as Shaping Safety, Trust and Access to Learning. Adults were central in shaping how participants navigated and experienced school, described as fundamental to accessing learning, supporting regulation and fostering safety. While experiences varied, participants highlighted the importance of support from kind, attuned adults with whom they could develop trusting relationships, shaping enjoyment of lessons and flexibility of support. This aligns with existing literature across multiple perspectives, including CYP (Eodanable et al., 2024; Skorka et al., 2022) teachers, administrators, professionals and caregivers (Poth et al., 2014).

When participants felt their views were not considered and teachers made presumptions about ability, they associated trust with staff in senior leadership roles. This reflects Eodanable et al. (2024) findings, whereby adolescents with FASD felt dismissed by teachers, which negatively impacted perceptions of staff. In contrast, in the current research, one participant perceived support as consistent across all staff. This echoes Hammond's (2021) findings that primary-aged CYP with FASD did not associate positive staff qualities with hierarchies, instead these were evident across school. This contrast suggests individual factors shape how support is experienced across settings, though highlights the importance of CYP feeling heard, understood and supported in facilitating trust. The findings reinforce the importance of student-staff relationships for CYP with FASD, though extends literature by foregrounding adolescents' perspectives, emphasising relational factors not only as beneficial, but foundational to engagement, regulation and access to support.

Participants' experiences demonstrated how adult presence shaped the extent to which support and co-regulation felt possible, impacting feelings of safety. When adult support was limited and capacity was stretched, school was experienced as unsafe, confusing and inflexible, presented as the expected experience in mainstream settings. In contrast, higher adult ratios enabled attuned, relational support, thus school was experienced as safe, containing and responsive. This contrast highlights how systemic constraints like staff capacity can shape CYP's interpretation of their experiences and overall perception of school. The importance of staff availability was reflected in participants' desire for increased adult support, particularly from TAs, aligning with findings positioning "adult support as a central educational adjustment" (p.8) (Eodanable et al., 2024). The current findings extend existing research by indicating adolescents with FASD not only recognise systemic factors influence adult support, such as staff capacity,

but such awareness shapes experiences of relational support, overall educational experiences and broader perceptions of school. This reinforces the importance of conceptualising support not only as interpersonal but as a relational process embedded within broader systemic constraints, which can be understood through Bronfenbrenner's framework (Bronfenbrenner & Morris, 2006), emphasising how microsystem experiences are shaped by wider systemic influences. This is key to consider in the UK context, with education systems facing limited funding (macrosystem) and staff retention challenges (Bronfenbrenner & Morris, 2006; Institute for Fiscal Studies 2025). Thus, while the findings reinforce the importance of adult support, there is tension between identified need and systemic constraints impacting implementation.

Participants' experiences were also impacted by perceptions of staff knowledge and experience, influencing in-class and broader support. Consistent with perspectives of parents, (Sanders & Buck, 2010; Watson et al., 2013) professionals (McCormack et al., 2022; Ryan & Ferguson, 2006a) and CYP (Eodonable et al., 2024), the findings highlighted limited staff understanding of how FASD presents in school and inadequate support, which adversely impacted experiences (Duquette et al., 2007). In contrast, when staff were perceived as knowledgeable and experienced, school was experienced as safe and containing. Such perceptions appeared interrelated across subthemes, relating to systemic factors, as greater staff availability enabled more responsive, attuned support, impacting perceptions of staff's understanding and experience. Notably, the findings suggest awareness of teachers' limited knowledge is not limited to caregivers as highlighted in literature but is recognised by CYP and shapes their interpretation of experiences, highlighting a need for greater teacher training.

Participants emphasised the importance of consistency and predictability. While prior research highlights the importance of predictability and structure for these CYP in navigating daily activities (Skorka et al., 2022) and within classrooms from teachers' perspectives in Alaska (Poth et al., 2014), this research contributes the perspectives of adolescents in the UK. Moreover, while consistency in environmental adaptations is important (e.g., visual timetables) (Eodonable et al., 2024), the findings emphasise the importance of consistency in adults' approaches and language. Inconsistencies in adult support, particularly when needs were not immediately visible, led to frustrations, reflecting assumptions about ability and parental frustrations that staff often do not believe their child has a disability due to the hidden nature of FASD (Duquette et al., 2007). The current findings suggest such frustrations are not isolated to caregivers but are shared

by CYP and shape their educational experiences. Therefore, the findings suggest consistency in adult approaches and communication is key in supporting these CYP to successfully access learning.

Reliance on Trusted Peers to Navigate Learning and Social Interactions. Peers were key in shaping participants' educational experiences across learning and social environments. Participants often attributed difficulties sustaining attention to peers' behaviour, which resulted in getting into trouble, difficulties engaging and preference for smaller classes. Participants positioned themselves as motivated to learn, but framed peers' behaviour as barriers to engagement, leading to frustration and positioning these difficulties as beyond their control. Such frustrations adversely shaped perceptions of peers and thus broader social experiences and inclusion. Interestingly, the same behaviours were characterised differently depending on whether peers were considered friends, suggesting interpretation of social experiences are influenced by relationships and trust. These findings which attribute participants' inattention to peers' behaviour, contrasts Knorr and McIntyre (2016), where participants' frustrations with inattention stemmed from difficulty understanding lessons, resulting in disagreements with staff and frustration towards their FASD diagnosis, rather than towards peers. Therefore, while attention and working memory difficulties for CYP with FASD are well documented in literature, (Blackburn, 2010a; Martinez-Cengotitabengoa et al., 2023; Mattson et al., 2011), these findings contribute a unique perspective which suggests participants attributed inattention to external factors (e.g., peers) rather than cognitive challenges or their diagnosis. Thus, these CYP's needs cannot be understood in isolation, as classroom experiences may have wider implications for social inclusion, crucial given these CYP's social vulnerability (Duquette et al., 2006, 2007).

Consistent with existing literature highlighting the supportive role of peers for CYP with FASD in navigating everyday activities (Skorka et al., 2022) and educational experiences (Duquette et al., 2006, 2007; Hammond, 2021), participants also experienced peers as a source of support and advocacy. This related to support in learning from attuned peers and peer advocacy during social interactions, highlighting participants' social vulnerability and reliance on peers to navigate educational contexts. Reliance on peers within learning echoes Hammond's (2021) research in primary school contexts, whereby one participant identified his peers as more supportive in learning than teachers. The importance of peers in navigating school also reflects

Brenna et al. (2017) case study whereby a young person with FASD proposed a peer support system which offered non-judgmental support, preferring to share his challenges with peers than adults. The current findings extend understanding by foregrounding adolescents' experiences in secondary schools in the UK, reinforcing the importance of peers in navigating learning, and further extending understanding by identifying peer advocacy as key in also navigating social aspects of school.

While some participants highlighted the importance of peer interactions in shaping educational experiences, most described difficulties navigating social interactions, contributing to feelings of isolation and adversely impacting belonging. This aligns with literature highlighting difficulties with peer interactions and social challenges among adolescents with FASD (Duquette et al., 2007; Eodanable et al., 2024) and parental concerns regarding social vulnerability (Griffiths, 2022). Participants appeared to rely on familiar relationships to navigate social contexts, though this could inadvertently reinforce isolation when difficulties arose. Participants experienced intimidation and bullying, and some generalised these experiences and perceptions to peers more broadly, exacerbating isolation and shaping negative perceptions of school. Such experiences of bullying have been highlighted from the perspectives of CYP, parents and adults' retrospective accounts (Duquette et al., 2007; Duquette & Orders, 2013; Knorr & McIntyre, 2016; Sanders & Buck, 2010). However, the current findings suggest the meaning adolescents give to their experiences of social challenges can have detrimental impacts on broader perceptions of school and inclusion. Notably, participants' reflections changed over time, highlighting the role of environmental factors, such as staff facilitating opportunities for interactions, in shaping social experiences. This extends existing literature by emphasising how systemic factors can actively support social inclusion, rather than positioning social interaction difficulties within the individual.

School Ethos Shaping Experiences of Inclusive Practice. Experiences in secondary school were shaped by settings' ethos, which consequently shaped inclusion and belonging. Such experiences were influenced by multiple factors, like relatedness to peers and staff, acceptance of difference, approaches to managing behaviour, flexibility of support and autonomy.

The importance of relatedness and mutual understanding was reflected through shared experiences and needs, not only among peers but also supporting adults, alongside acceptance of differences and support required. In the absence of mutual understanding of difference,

educational experiences were characterised as isolating with difficulties forming friendships, accessing learning and feeling misunderstood. One participant's justification of learning adaptations mirrors Hammond's (2021) findings, whereby participants' justification of support presented as consciousness of how external intervention may be perceived. Participants' heightened awareness of difference was reflected in perceptions their needs did not align with a "normal school", aligning with Knorr and McIntyre's (2016) research in Canada; the theme "I don't fit in" reflected participants awareness of difference, difficulties with friendship and limited belonging, leading to frustrations towards their diagnosis. Adolescents with FASD in Eodanable et al. (2024) UK research, also demonstrated awareness of difference, though there was not a consensus of this being positive or negative. The current findings extend understanding by highlighting participants' awareness and interpretation of difference, shaped by environmental and social factors; mutual understanding and relatedness supported participants' sense of inclusion and belonging, whereas heightened awareness of difference not met by acceptance, flexibility and understanding adversely impacted experiences. Moreover, a novel finding was participants' sense of relatedness to adults as well as peers, suggesting their sense of belonging extends across the school community. While prior research highlights CYP's experiences of not fitting in, the current findings shift away from deficit-focused research, offering lived experiences of how acceptance of difference, shared needs and experiences can positively shape educational experiences of belonging, social interactions and peer perceptions. This suggests secondary settings should foster a sense of inclusion through making adaptations and difference accepted as the 'norm', alongside the importance of supporting CYP to identify people (peers or adults) they can relate to in school, to positively shape their experiences.

Behaviour management approaches were central in shaping participants' experiences. Punitive strategies and sanctions negatively impacted participants' self-concept, ability to advocate for support and motivation to attend school, suggesting such approaches may be experienced as disengaging and create barriers to educational experiences. This aligns with parental frustrations regarding behaviour policies for CYP with FASD (Griffiths, 2022) and literature highlighting that these CYP are often labelled as disruptive and face punitive approaches, without consideration for underlying needs (Roberts, 2015; Salmon & Beutow, 2012). The current findings extend literature by foregrounding adolescents' perspectives, highlighting these frustrations are not only experienced by caregivers, but are meaningfully

experienced by CYP themselves and behaviour approaches actively shape whether educational experiences are characterised as safe and motivating, or threatening and rigid. Importantly, accounts of restorative approaches and co-regulation illustrate how alternative practices can foster positive experiences, though participants' heightened awareness of such approaches differing from "normal school" suggests their experiences are rare. Nonetheless, the findings highlight a need for behaviour policies which prioritise relational, flexible approaches, reframing expectations from 'won't' to 'can't' considering reasons behind behaviours (Roberts, 2015).

Flexibility and adaptation emerged as central in shaping inclusive practice. Participants valued tailored support, including access to alternative spaces and in-class adjustments. Such flexibility was more evident in specialist settings, whereas mainstream environments often involved barriers to accessibility like unsuitable equipment and restrictions accessing regulatory support. For some, limited flexibility contributed to considering changing setting. These findings highlighting the importance of flexible support, align with findings in primary contexts (Hammond, 2021) and parental accounts (Griffiths', 2022), though extend literature by presenting perspectives of adolescents and highlighting the broader impact of inflexibility on placement decisions and engagement.

Participants expressed desire for greater autonomy, particularly related to regulatory support, uniform and flexibility in activities. This aligns with Hammond (2021), who found positive experiences of agency in learning and regulation in primary settings. However, the current findings highlight participants' desire for greater autonomy, but limited experiences of autonomy, extending understanding of adolescents' experiences by suggesting autonomy may decline as CYP progress through education. Moreover, some participants appeared reliant on adults to access support, whereas others experienced greater autonomy which supported self-advocacy in seeking learning and regulatory support. As highlighted by Poth et al. (2014), allowing students with FASD choice supports development of personal identities and independence, equipping them for life. Alongside the current findings, this suggests providing increased autonomy may positively shape learning experiences and is particularly important to consider in secondary schools in preparation for later independence.

Making Sense of Academic Challenges. Aligning with research highlighting the cognitive difficulties associated with FASD (Blackburn, 2010a; Dalen et al., 2009; Eodanable et al., 2024; Millians, 2015), participants described their experiences of academic challenges in

secondary school. This is unsurprising given the complex cognitive demands of learning (St-Clair Thompson & Gathercole, 2006), and diagnostic criteria for FASD emphasising impairments across three or more neurodevelopmental areas inclusive of cognition, academic achievement, memory, attention and executive functioning (SIGN, 2019). However, a novel contribution of the current findings lies in how participants made sense of these challenges.

Participants often perceived difficulties as outside their control, reflected through attributing challenges to implications of diagnoses like FASD and ADHD, which presented as reducing self-blame. Some aspects of learning, like prolonged sitting, were presented as unmanageable, resulting in frustration, impacting enjoyment of lessons and perceptions of school. This relates to Knorr and McIntyre (2016), whereby adults' retrospective accounts highlighted difficulties with attention alongside academic challenges resulted in participants getting into trouble and frustration towards their diagnosis. In contrast, the current research offers a novel insight, suggesting participants were not frustrated with their diagnosis, rather diagnosis provided justification for their experiences, allowing them to externalise their difficulties to reduce blame and perceived agency.

In contrast, some academic challenges were internalised, affecting confidence, self-concept and seeking support. This was reflected through participants' heightened awareness of difference, feeling like a burden, and comparing their experiences to perceived norms and their experiences across contexts. As a result, academic challenges shaped not only educational experiences, but also how participants viewed their abilities, which resulted in characterising school as challenging and inaccessible. This suggests possible internalisation of stigma associated with FASD, negatively impacting self-esteem, identity and self-efficacy (Wehmeyer, 2014, 2020). When tasks felt beyond their capabilities, motivation decreased and some found it easier to comply than seek support. This aligns with self-determination theory and the role of competence on motivation (Ryan & Deci, 2020), where repeated difficulties can reduce engagement and confidence. These findings also reflect caregivers' concerns that educational expectations often exceed CYP's abilities (Sanders & Buck, 2010) and that academic challenges can lead to getting into trouble, reduced self-esteem and confidence (Salmon & Buetow, 2012). Extending existing literature, the findings highlight how academic challenges not met with support can shape educational experiences and self-perceptions. From a social model perspective (Oliver, 2013), this underscores the role of environmental factors in shaping what is experienced

and interpreted as a challenge and the importance of making learning accessible to support cognitive needs, wellbeing and confidence.

When learning was fun and practical, educational experiences were shaped as accessible, low-pressure and engaging, reflected through enjoyment in practical activities and staff taking a playful approach which reduced power dynamics. This somewhat aligns to Hammond's (2021) findings which identified opportunities for play as central to supporting belonging in primary-aged students with FASD. The current findings contribute a unique perspective of adolescents, aligning with commonly reported strengths in practical skills and visual strengths for CYP with FASD (Blackburn, 2010a; Brenna et al., 2017), extending literature by highlighting how opportunities for practical learning drawing on strengths, can positively shape these CYP's educational experiences.

Participants also highlighted strategies which would be supportive, offering a unique strengths-based perspective and hopeful insights. These included explicit communication, adult check-ins, processing time, visual examples, scaffolding and technology. This aligns with accommodations proposed in postsecondary settings by CYP (Duquette & Stodel, 2013), inclusive of smaller classes, computers, 1:1 support, chunking information, breaks and reducing sensory overload. In the current findings, strategies were commonly suggested by participants in mainstream settings, potentially reflecting gaps in available support interrelating to prior subthemes like staff availability. Participants made sense of what would be supportive through comparing experiences across contexts, further highlighting how environmental factors shape educational experiences as challenging or accessible.

Sensory Support as Fundamental to Educational Experiences. Participants' educational experiences appeared significantly shaped by sensory needs, reflected through participants' experiences of sensory discomfort related to noise and tactile inputs (e.g., uniform), alongside limited autonomy and flexibility. Participants presented with limited capacity for sensory input, with secondary school as an environment which places significant demands on sensory processing. These findings reflect literature highlighting CYP with FASD can experience greater sensory processing difficulties (Du Plooy, 2017) and difficulties engaging with high levels of sensory stimuli in school environments (Skorka et al., 2020). While sensory processing difficulties experienced by CYP with FASD are documented across home (Eodonable et al., 2024; Jirikowic et al., 2008, 2012) and school (Griffiths, 2022; Jirikowic et al., 2008),

these findings extend understanding by foregrounding adolescents' experiences in UK secondary settings, suggesting sensory processing needs actively shape their educational experiences. Notably, participants demonstrated heightened awareness of sensory needs' comparative to peers, using metaphor to articulate how strategies temporarily supported their experiences to align to perceived norms. This contrasts Hammond's (2021) research where primary-aged students with FASD showed limited awareness or did not experience sensory processing difficulties. This differentiation suggests older students may have greater understanding of their sensory profiles, or that sensory demands may increase in secondary environments. The findings suggest sensory supports are foundational in participating in school, and thus such support should be embedded across secondary settings.

Access to sensory spaces and opportunities for movement were central to managing sensory needs and supporting regulation. Participants highlighted the importance of spaces being familiar and tailored to their needs and interests. This aligns with Eodonable et al. (2024), where adolescents with FASD highlighted the importance of regulatory spaces outside of school, such as their bedrooms, though extends literature by highlighting the importance of regulatory spaces within educational settings. Moreover, participants interpretation of whether physical activity was supportive appeared shaped by environmental factors such as opportunities for shared experiences when support was embedded. Therefore, the current findings contribute the unique experiences of adolescents, extending understanding by highlighting regulatory spaces and opportunities for physical activity as central to regulation. Aligning with Millar et al. (2017) research linking policy, research and practice, together these findings highlight the need to adapt classroom environments to support CYP with FASD by offering movement, sensory resources and creating calming spaces.

Notably, participants rarely referenced their diagnosis and did not reflect frustrations towards diagnoses highlighted in prior research (Knorr & McIntyre, 2016). Instead, difficulties were often attributed to interpersonal, environmental or contextual factors, which shaped their experiences. This is of relevance because it contrasts caregivers' perspectives within research (Griffiths, 2022; Price, 2019), which often foreground the impacts of PAE on children's cognitive and behaviour difficulties, suggesting CYP may conceptualise their experiences differently. It is important to note that participant's diagnosis was not directly explored in interviews, which may have influenced the focus. Caregivers may also have a greater

understanding of the implications of PAE than CYP and therefore place more emphasis on its developmental impact. Despite this, the findings raise considerations about how meaning is constructed and caution against over attributing difficulties to diagnosis, when this may not reflect CYP's perspectives. This is somewhat reflected in international research highlighting how a young man with FASD considered his diagnosis to be one aspect of his identity, and at times a source of strength (Brenna et al., 2017). Therefore, further research is needed in UK contexts to consider how CYP conceptualise their diagnosis and how this may shape their experiences, though the findings highlight the importance of listening to CYP to understand their experiences alongside shifting away from deficit-based narratives commonly noted in FASD research.

3.10.2 Implications for Practice and Future Research

This section highlights implications for practice for Educational Psychologists (EPs) and more broadly, considering participants' conceptualisation of what would be supportive alongside the researcher's interpretation. Areas for future research are also highlighted.

Adults were central in shaping educational experiences, with positive relationships characterised by trust, consistency, and staff who were accessible, experienced and knowledgeable. This leads to implications around relational consistency and key adults. While the importance of student-staff relationships is well established (Allen et al., 2018; Spilt & Koomen, 2022), CYP with SEND are less likely to experience supportive student-teacher relationships (Freire et al., 2019). Moreover, the current findings extend understanding, highlighting relational factors as a foundation to engagement and effective support for CYP with FASD, suggesting relational approaches should be prioritised in education settings. For EPs this highlights a role to consider relational approaches when completing assessments and within provision recommendations, alongside supporting staff to develop relational and attuned practice through training and consultations. While the current findings and literature advocate for relational approaches (Griffiths, 2022; Hammond, 2021), more research is needed about exactly how to engage on a relational level with CYP with FASD, given the complexity and variation of needs (Reedman et al., 2024). However, EPs may draw on areas identified as important in the findings, like consistent communication, listening, being available and avoiding assumptions of ability.

Participants emphasised the importance of staff being knowledgeable and experienced. Therefore, alongside relational approaches, there is a need for classroom-focused training for

educational staff. This is important as literature suggests training often prioritises diagnostic information over practical support (Duquette et al., 2006; Dybdahl & Ryan, 2009; Ryan & Ferguson, 2006a), with teachers relying on informal sources (Blackburn, 2010a) or parental knowledge (Griffiths, 2022; Wilson et al., 2024). EPs could deliver training, although this relies on EPs developing their knowledge of FASD (Griffiths, 2022) through engaging with research and training.

While increased teacher training is commonly proposed, research indicates increasing access to information alone is insufficient to shift practice, as observed in Canada (Reedman et al., 2024). Moreover, limited societal awareness and the ‘hidden’ nature of FASD (Millar et al., 2017), may impact teachers’ awareness of CYP with FASD in their classrooms and thus motivation to engage with training (Bronfenbrenner & Morris, 2006; Mukherjee et al., 2012; Millar et al., 2017; Orsini, 2013). Therefore, future research should critically consider the role of motivation on teacher engagement with training. For EPs, there appears a role in supporting staff to translate knowledge from training into practice within specific contexts, tailoring support to CYP’s unique needs. This may involve consultations and providing reflective spaces for staff to consider attributions of behaviour, shifting from intentional choices to communication of need, to inform support. Notably, participants in specialist settings described positive perceptions of staff’s knowledge and understanding, which meaningfully shaped engagement. This highlights scope for research to explore how such approaches may be translated into mainstream settings. Given that EPs work across settings, they are well placed to share effective practice across contexts and settings.

Findings also highlighted the role of peers in supporting or hindering educational experiences, reinforcing the social vulnerability of CYP with FASD (Knorr & McIntyre, 2016; Mukherjee et al., 2013; Skorka et al., 2020). Participants highlighted how challenges with peer interactions intensified experiences of isolation, but that trusting peer relationships were protective. Peer reliance therefore leads to implications around supportive peer systems and unstructured times in school. At a foundational level, staff should be aware of these CYP’s social vulnerabilities and provide explicit teaching, support and coaching to help them navigate social interactions and develop positive peer relationships. An area identified as supportive by participants was adults facilitating opportunities for peer interactions, which should be considered within educational settings, particularly during unstructured times. EPs can support

this through provision planning and supporting staff to embed approaches through training and modelling (DfE & DoH, 2015).

The findings suggested CYP's experiences are multifaceted and cannot be considered in isolation, as cognitive challenges had potentially adverse implications for perceptions of peers and broader social inclusion. Therefore, EPs and educational professionals should take a holistic perspective within assessments and consultations, considering how needs may be interrelated; what may initially present as cognition and learning needs can adversely impact students' social, emotional and mental health needs, particularly social experiences. This avoids a within-child lens by considering broader influences on experiences, consistent with the social model (Oliver, 2013) and highlights the importance of gathering CYP's voice in practice and research to understand their experiences (BERA, 2024). Given the multifaceted and interacting influences on CYP's experiences, a more comprehensive understanding of their experiences may be achieved through future research triangulating CYP, caregiver, and teacher perspectives, though should critically consider teachers awareness of supporting these CYP, aforementioned as an area needing support, which may need to be explored in isolation before adopting a multi-perspective approach.

Participants' experiences of academic challenges, particularly inattention, highlighted the need for environmental adaptations, (e.g., reducing distractions and opportunities for movement), and in-class support, including clear communication, visual examples, check-ins, adapted resources and additional processing time. Foregrounding strengths and practical learning also enhanced engagement. Academic challenges therefore lead to implications around self-concept and supported advocacy. Such findings may help inform provision recommended by EPs, who can support schools to embed approaches through training and consultations. Provision could draw on self-determination theory (SDT), as motivation was influenced by relatedness to peers and adults, and whether tasks felt attainable (Wehmeyer, 2020). SDT suggests motivation to engage is supported when autonomy, competence and relatedness are met (Ryan & Deci, 2020). This highlights the need to ensure tasks are accessible, offering choice to promote autonomy and fostering relatedness, for example through small group learning with peers with similar needs. Moreover, professionals should understand the broader implications academic challenges can have on CYP's self-concept, confidence and self-advocacy, highlighting the importance of attuned, proactive support.

The findings highlight the importance of flexible and individualised support, though guidance on how to implement such approaches remains limited, contributing to inconsistencies in practice (Carpenter, 2011; Ryan & Ferguson, 2006b). While Blackburn offers frameworks and guidance to support CYP with FASD across early years (Blackburn, 2017; Blackburn & Whitehurst, 2010;) primary (Blackburn, 2010b) and secondary settings (Blackburn, 2010c), these precede reforms in SEND policy, including the SEND CoP (DfE & DoH, 2015) and may not reflect CYP's current educational experiences. This highlights a need for research to explore evidence-informed approaches in supporting learners with FASD, foregrounding strengths and perspectives of CYP (Reedman et al., 2024). Such exploration is timely given changing structures and approaches to supporting SEND nationally, with recent publication of the white paper (DfE, 2026) and emphasis on inclusive practice in mainstream education. While evidence-based approaches are useful, there is a role for EPs to support schools to ensure provision is individualised and grounded in lived experience as well as evidence, reinforced through variations in participants' experiences in the current research.

Participants' experiences of mismatches between others' perception of their abilities and difficulties experienced, highlighted real-life experiences of 'spiky profiles' associated with FASD, where learning needs are frequently overlooked due to co-existing strengths (Davis et al., 2011; Kodituwakka, 2007; Mattson et al., 2011). This has implications for assessment and support, where EPs should draw on and triangulate information, data and evidence from multiple sources, to adopt a holistic approach to understanding needs and guiding support. EPs should remain curious and sensitively explore whether PAE may be impacting CYP's presentation, particularly if 'spiky' profiles are identified through assessments. By modelling this in consultations, EPs can support schools to sensitively explore this aspect of developmental history to inform support, while also helping to reduce stigma around FASD.

Participants highlighted sensory resources and low sensory environments tailored to their needs as foundational in participating in school. This has implications for regulatory spaces and proactive sensory planning. In practice, there is a need to consider environmental adaptations to support CYP with FASD to manage sensory inputs in secondary schools, embedding support rather than viewing it as additional. Moreover, EPs must consider how CYP's sensory needs may be impacting educational experiences within assessments (DfE & DoH, 2015), which is key as research has identified sensory needs can drive these CYP's behaviours (Salmon & Buetow,

2012). As participants' experiences of the usefulness of sensory supports varied, EPs should ensure CYP's views are considered within provision recommendations and could further support schools through sensory audits of the environment.

While there is a need to consider interpersonal factors which shape these CYP's experiences, there is also a need to consider the findings and their implications through a systemic lens. As highlighted in legislation such as the Children and Families Act (DfE, 2014), SEND CoP, (DfE & DoH, 2015) and Equality Act 2010, learning environments should be inclusive for all. Despite this, lack of knowledge of FASD raises questions about whether CYP with FASD are appropriately included, which is crucial given the high prevalence of exclusion and disrupted school experiences for these CYP (Streissguth et al., 1996, 2004). While limited inclusion for CYP with FASD has been highlighted outside of the UK (Duquette et al., 2012; Poth et al., 2014), the current findings alongside prior research (Griffiths', 2022) suggest this challenge is reflected in the UK, specifically in secondary schools. Not only does the issue exist, but the current findings suggest CYP with FASD have heightened awareness of difference, which is intensified when met with inflexibility of adjustments and can adversely impact their sense of belonging and inclusion. This has implications for practice discussed below and highlights a need for research to critically consider the barriers and facilitators to inclusion for CYP with FASD at the individual and systemic level (Flannigan et al., 2021; Poth et al., 2014).

Behaviour policies and approaches shaped participants' experiences, with punitive approaches adversely impacting inclusion, self-concept, wellbeing and engagement. School ethos therefore leads to implications around behaviour policies and inclusion. Due to the lack of physical features associated with FASD, the first indications of FASD may present through behaviour and therefore can be met with strict behaviour policies and exclusions (Blackburn et al., 2012; Carrick & Hamilton., 2023; Henshaw., 2012). Behaviour policies derived from behaviourist theories focusing on reward and punishment, (Wheldall, 2012) likely do not have the intended effect for CYP with FASD, who have difficulties with executive functioning and understanding social consequences of behaviour (Carrick & Hamilton, 2023; Kodituwakku, 2007; Roberts, 2015). Therefore, alongside increased staff and societal understanding of the needs driving behaviour, there is a need for adaptive, restorative behaviour policies which focus on behaviour as communication (Malbin, 2004). EPs have an influential role working at the organisational level to create change within systems, through supporting schools to adapt

behaviour policies and practices which offer appropriate flexibility for these CYP and promote relational, restorative approaches through co-regulation. The findings suggest such approaches would not only support educational experiences but reduce risks of these CYP internalising stigma and heightened awareness of differences. Moreover, Oscar's account offers a lived experience and hopeful example of restorative approaches focused on relationships and co-regulation, which may inform practice. Future research could take a strength-based approach to explore in greater depth how schools supporting CYP like Oscar, implement restorative approaches in practice, considering potential barriers and facilitators.

Viewing the findings through Bronfenbrenner's Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006) reinforces how these young people's educational experiences are shaped by interactions between interconnected systems and the developing individual to shape development. One area which was not deemed pertinent within the literature review was the chronosystem, which reflects the influence of time and historical context on development (Bronfenbrenner, 1986). This was not included as a theme within the review because the individualistic nature of such factors in shaping development was not reflected in multiple participant samples included within available literature. Despite this, the chronosystem offers an important lens for understanding the experiences of CYP with FASD, particularly in relation to the time of key events and the broader socio-historical context in which their development occurs. For example, the age at which CYP receive a diagnosis of FASD may shape how they interpret their difficulties, advocate for support and develop their sense of identity. Later diagnoses may mean prolonged periods of misunderstanding, inconsistent support and internalised feelings of difference, which likely shaped educational experiences. This may reflect participants' accounts of confusion, awareness of difference and sometimes adverse views of themselves. Similarly, the socio-historical context surrounding FASD and how this has changed overtime has implications for these CYP's experiences of education and support. For example, increased awareness of FASD, evolving diagnostic pathways, reduced societal blame and shifting educational policies directly influences the support available to CYP in education at different points in time. While the UK has come some way in understanding FASD and its implications, there is still a need for greater awareness among educators and society in general. For EPs, this highlights the need to consider not only the immediate systems around CYP, but

also how timing of key events, transitions and historical changes in recognition of FASD may shape CYP's experiences, access to support and outcomes.

While EPs have the appropriate skills to further support CYP with FASD through areas highlighted and be involved in multi-agency work, implementation requires support from policy and funding as current practices are limited by capacity and resources. Implementation would perhaps be supported by establishing specialist EPs for FASD, dedicated to enhancing collaboration, understanding and improving outcomes for these CYP, although this would require systemic support.

3.10.3 Limitations

While this study contributes to limited research exploring FASD and education, capturing CYP's perspectives and adopting a strengths-based perspective, limitations are acknowledged.

While IPA aligned with the research aims and epistemological position, this methodology has been criticised for being ambiguous, lacking standardisation, and risks of becoming overly descriptive (Giorgi, 2010; Hefferon & Gil-Rodriguez, 2011). To manage this and enhance rigour, a transparent analytic process was presented, and the researcher kept a reflective diary. However, when considering the double hermeneutic and potential impact on interpretation, the researcher recognises alternative interpretations were possible (Smith & Osborn, 2015; Smith et al., 2022).

Secondly, the small sample size ($n=4$) is a limitation, shaping what can be claimed outside of the study. However, within the aims of IPA and its' idiographic focus, the research sought to gain insight into CYP's experiences and provide contextual depth rather than producing generalisable findings (Chowdhury, 2014; Smith et al., 2022). Moreover, Smith et al. (2022) highlight IPA requires a small sample size, considered on a study-by-study basis. Despite aiming for homogeneity, inclusion criteria were broadened to specialist settings and units, widening recruitment after facing recruitment challenges. Thus, variation in experiences may be considered a limitation, as IPA requires a small, fairly homogenous sample. Though, such variation also reflects the nature of the spectrum of FASD, aligning the research's interpretivist paradigm which highlights multiple, co-existing realities which are shaped by social processes (Bhattacharjee, 2012; Cuthbertson et al., 2019). While recognising this limitation, the researcher followed guidance of being pragmatic and reviewing recruitment as it occurs, adapting inclusion criteria when challenges arose (Smith et al., 2022). Moreover, the researcher recognises the findings cannot be generalised outside the sample, however variation in participants' experiences

highlights how PAE can have vastly different implications, reinforcing the importance of individualised support (BMA, 2016; Cook et al., 2023).

The use of virtual interviews supported recruitment of a hard-to-reach participant sample, though participation required verbal articulation skills and engagement in an online format (Smith et al., 2022). Therefore, the research may have excluded CYP with communication needs or limited access to technology, thus the sample may be biased towards those more able to express their experiences, further limiting generalisability. While participatory approaches were adopted to support accessibility, face-to-face engagement and approaches like photovoice, modelling or involving participants in planning data collection, may have further supported meaningful inclusion and broader representation of CYP with FASD (Aldridge, 2015; Hart, 1992; Poku et al., 2019). While limitations are recognised, IPA's idiographic focus alongside participatory approaches allowed the researcher to ensure all participants with varying needs were included and could meaningfully share their views, which may not have been achieved through approaches focusing on generalisable findings (e.g., thematic analysis).

Due to the potential vulnerability of participants and potential cognitive needs, participants were offered for their caregiver to be present to support them during the interview if this was their preference. While this was offered as a supportive measure, it is recognised that parental presence during the interview may have impacted what the young people felt able to share, particularly regarding more sensitive topics or experiences. Moreover, a set of interview questions were emailed to caregivers prior to the interview as a supportive measure. However, this may have influenced how some of the young people approached the interview and the responses given, particularly if caregivers discussed the questions with them beforehand. While these measures were intended to be supportive and were deemed necessary to support this vulnerable population of learners to access the research process, it is recognised that these adjustments may have impacted the depth and authenticity of the data collected.

The inclusion criteria limited participation to CYP with a confirmed diagnosis. Given ongoing challenges accessing FASD assessment in the UK, many CYP who meet diagnostic criteria may remain undiagnosed and thus could not participate. Therefore, the research could be more accessible by including those awaiting assessment, with careful consideration given to ethics, homogeneity and the focus of exploration, if diagnosis is not confirmed.

While this was not an intention of recruitment, all participants were adopted, therefore the findings may not be representative of CYP who remain with their birth families or experience social care instabilities, making cross-comparisons challenging. The small sample were also limited in relation to cultural perspectives as all participants were White British. Therefore, findings may not be representative of CYP's educational experiences within different cultural contexts. This would be important to explore further given the higher prevalence of FASD in developing countries (May et al., 2018), considering how cultural factors may impact educational experiences at the individual, family, school and societal level (Bronfenbrenner & Morris, 2006).

The findings and literature suggest CYP's educational experiences are multifaceted and shaped by aspects like teacher relationships, knowledge and parental advocacy, thus focusing solely on CYP's perspective may be considered a limitation. Multi-perspective research could offer a more comprehensive understanding of these CYP's educational experiences, but analysis can be complex and risks losing detail at the individual level (Larkin et al., 2019). Aligning with idiographic underpinnings of IPA and the researcher's values of amplifying CYP's voice, the findings offer a unique insight into the lived experiences of these CYP in education. Teacher's views were not included due to concerns that limited awareness of FASD may affect accuracy of accounts of experiences supporting CYP with FASD. This was reflected by Ryan and Ferguson's (2006b), where experienced and inexperienced teachers reported not doing anything different to support CYP with FASD, despite variations in support implemented. A triadic design (child-parent-teacher) may help ensure shared awareness of the child's diagnosis to support meaningful comparison and interpretation.

Despite limitations, the study design was consistent with the epistemological position, research aims and provides valuable insights into the experiences of an underrepresented population. The research also addresses a gap in research eliciting strengths and success stories of CYP with FASD, through some participants' positive experiences (Flannigan et al., 2021).

3.10.4 Conclusion

This study adds to the limited UK evidence base by showing how young people with FASD make sense of school through relationships, trust, peer support, sensory safety, academic self-concept and perceptions of school ethos. Moreover, this was the first study to solely explore the educational experiences of adolescents with FASD in UK secondary education settings,

contributing to limited literature including CYP (Eodanable et al., 2024; Griffiths, 2022; Hammond, 2021), and adding to the collection of IPA studies in educational psychology (Oxley, 2016). As outlined by BERA (2024), “children who are capable of forming their own views should be granted the right to express those views freely and have them taken into consideration in all matters affecting them” (p.18). Adhering to this, the research amplifies the voice of CYP with FASD who are often marginalised in research, demonstrating with appropriate adaptation and support they can meaningfully contribute to research. The research also reinforces the importance of triangulating perspectives in practice, to understand these CYP’s interpretation of their educational experiences (DfE & DoH, 2015).

The findings provide novel contributions from the perspectives of adolescents, highlighting educational experiences as multifaceted, shaped by interactions across multiple systems, which can therefore not be understood in isolation and reduced to individual factors (Bronfenbrenner & Morris, 2006). Notably, few participants commented directly on the impact of their diagnosis in shaping their experiences or frustration towards their diagnosis, which contrasts existing literature from caregiver perspectives foregrounding the impacts of PAE (Griffiths, 2022; Price, 2019). Instead, difficulties were often attributed to environmental or contextual factors, with heightened awareness of how systemic factors shape support. Furthermore, the findings suggest relational factors are foundational to these CYP’s educational experiences and perceived availability of staff and staff knowledge can actively shape perceptions of school. Such findings highlight how CYPs experiences are relational and shaped by interactions within the broader system within which they occur (Bronfenbrenner & Morris, 2006). A further novel finding was participants’ attribution of inattention to external factors (e.g., peers) rather than cognitive needs, highlighting how academic challenges can have broader implications for social inclusion. Some participants generalised difficulties within social interactions to overall perceptions of school and participants demonstrated heightened awareness of difference, highlighting how systemic factors can shape the meaning given to social experiences and inclusion in school. Schools’ approach to managing behaviour was paramount in shaping experiences, though the findings offer hopeful lived experiences of restorative, relational practice, which positively shaped school experiences, wellbeing and self-concept. Participants sometimes attributed academic difficulties to diagnoses, perhaps in an attempt to reduce self-blame, however unlike prior research this did not reflect frustration towards diagnoses, rather a

means of understanding their experiences. In contrast, some academic challenges were internalised and adversely impacted participants' wellbeing and motivation, reinforcing that the impact of cognitive challenges cannot be viewed in isolation. Participants showed awareness of what may support them, though most felt limited autonomy and voice within decisions, with environmental factors like inflexibility of support shaping experiences of challenges in school. Furthermore, the findings contribute unique insights that suggest secondary school places increased demands on sensory processing for these CYP and thus sensory support is foundational to accessing school and should be embedded, alongside opportunities for physical activities positively shaping experiences.

The study aimed to raise awareness of FASD within education and more broadly, with a need for greater understanding across education, healthcare and society (Bronfenbrenner & Morris, 2006). Adopting a positive psychology lens highlighted what supports these CYP in education, with implications for practice, and hopes of reducing stigma to positively impact policy (Bell et al., 2016; Flannigan et al., 2021). As the findings and literature highlight, shifting away from deficit-based practice would enhance not only academic outcomes but also CYP's self-concept, inclusion, self-advocacy, motivation and wellbeing. Thus, the findings underscore the need for a systemic, holistic perspective, recognising how relationships and environmental factors are interrelated and shape the educational experiences of young people with FASD. While not intended to be generalisable due to IPA's philosophical underpinnings, the findings offer valuable insight into how CYP with FASD make sense of their secondary school experiences. As such, the research provides a foundation for future research, which may seek to triangulate perspectives to better understand these CYP's multifaceted experiences in education.

Chapter Four: Reflective Account

4.1 Introduction

Being a reflective practitioner is key as a Trainee Educational Psychologist (TEP) (BPS, 9b), and self-reflection is crucial as a researcher (BPS Code of Human Research Ethics, 2021). This chapter addresses how this was adhered to and offers critical reflection of the research experience, written in first person to reflect my role in the research process. Drawing on the work of Schön (2017), I explore my reflection-on-action (after the event) of the research process, thus this account is retrospective. This chapter was also influenced by my reflections throughout the research (reflection-in-action) recorded through a reflective research diary and discussed through supervision. The chapter considers how my dual researcher-practitioner role and professional values influenced the research, approach to the literature review and empirical chapter.

Reflexivity involves critical awareness of how the researcher's values, beliefs, and biases may shape the research process (Braun & Clarke, 2013) and is essential for rigour and trustworthiness in qualitative research (Teh & Lek, 2018), particularly IPA due to the double hermeneutic. This refers to the researcher interpreting participants' interpretations of their experiences, recognising analysis is inevitably shaped by the researcher's own perspective and experiences (Smith & Osborn, 2015; Tuffour, 2017). Reflexivity was therefore central in considering my positionality. As Tuffour (2017) notes, one may only understand the preconceptions and values they bring to research once they are in the process of interpretation. My reflection-in-action during analysis, captured in a research diary, supported this ongoing reflexive engagement (Schön, 2017; Smith et al., 2022).

4.1.1 Positionality

While there are aspects of shared identity between myself and the participant sample, like being White British and growing up in the UK education system, I considered myself to have mainly outsider status (Braun & Clarke, 2013). This was primarily because I do not share the group identity of navigating secondary school with FASD, which may have subconsciously created power dynamics. While it is important to recognise this, conscious decisions were made to reduce such dynamics, such as semi-structured interviews allowing participants to discuss pertinent areas. Moreover, not sharing participants' experiences helped me remain open and close to participants' accounts, rather than imposing my thoughts and experiences, reducing risks

of bias (Braun & Clarke, 2013). As highlighted by Heidegger, it was also key to consider my prior understanding of the phenomenon of FASD before completing analysis, attempting to bracket pre-conceptions (Smith & Larkin, 2009; Tuffour, 2017). On reflection, any pre-conceptions derived from reviewing literature or placement experiences rather than lived experiences of navigating education with FASD.

4.2 Reflections on my Research Journey

4.2.1 Identifying a Research Topic

My interest in supporting CYP with SEND and neurodivergence began as a Teaching Assistant and Assistant SENCo, primarily working with CYP with autism and ADHD. I became increasingly interested in understanding behaviour as communication (Hibbin & Warren, 2021), which continues to underpin my practice. My values as a practitioner centre around equity, social justice and inclusion, developed through my professional experiences observing the impacts of relational approaches and tailored provision on students' educational experiences (Elfaizi & El Aouri, 2024). These values informed my application for the Educational Psychology doctorate and approach to this research.

My interest in FASD developed during my time as an Assistant Psychologist, following a presentation by a TEP colleague on parental perspectives of FASD in education (Griffiths, 2022), which highlighted the implications associated with FASD in education and more broadly (Ryan & Ferguson, 2006b; Wilson et al., 2024). Alarming, despite prior professional experience in education, I was not aware of FASD. To my surprise, this lack of awareness was echoed by colleagues, something I later understood as a society wide issue. This prompted a desire to develop my understanding and critically consider why I had not encountered FASD in my professional or personal experiences.

Gathering CYP voice is a statutory requirement in EP practice under the SEND CoP, particularly in Education, Health and Care Needs Assessments (DfE & DoH, 2015). However, within research, the views of CYP with SEND are often underrepresented or tokenistic (Faldet & Nes, 2021). My TEP experiences have reinforced the importance of gathering CYP's views, reflecting the United Nations Convention on the Rights of the Child (1989). This is especially relevant in secondary school, where increased autonomy and involvement in decision-making may support motivation, independence, and outcomes. I have also observed that CYP, parents, and teachers often construct different understandings of the 'problem', despite shared intentions

to support the young person. This strengthened my commitment to centre CYP voice, ensuring accessible methods to capture their experiences alongside acting on what CYP share through disseminating the findings.

4.2.2 Reviewing Literature

My developing awareness of FASD led me to engage with literature, websites, and initiate discussions professionally and personally, which highlighted limited understanding, particularly in education. During placement, prenatal alcohol exposure (PAE) often appeared a sensitive topic, likely due to stigma, with teachers sometimes disclosing information privately when parents were not present. Conversations within my professional network also suggested limited EP awareness of FASD, often restricted to associated facial features and executive functioning difficulties, despite facial characteristics being present in only a small proportion of cases (<10%) (Millar et al., 2017).

Initial searches included exploring grey literature (e.g., theses, blogs) and charity sources, which highlighted clear inequalities in support and outcomes for CYP with FASD, resonating with my values of inclusion and social justice. When exploring literature, there were multiple avenues I considered, noticing links between PAE and early trauma. Trauma and PAE can both cause brain damage, thus traumatic childhood experiences can result in similar neurological, behavioural and cognitive implications as those resulting from PAE (Norman et al., 2012; Rutter, 1998), however a combination of PAE and early childhood trauma may exacerbate risks more than PAE alone (Price et al., 2017). Although this intersection could have been interesting to explore, particularly given conversations with a Clinical Psychologist highlighting how EPs often adopt a trauma lens for these CYP which overlooks potential impacts of PAE, unpicking the interplay between these factors would be complex and aligns more with a clinical lens than my focus on educational experiences. I chose to focus on CYP's educational experiences and contribute a strengths-informed perspective to a deficit-focused literature base.

Something which struck me was that prevalence estimates suggest FASD may be higher (1.8–3.6%) (McCarthy et al., 2021) than autism (1.1% in adults, 1–2% in children) (Huang, 2020; NICE, 2025). This prompted reflection about why autism has greater societal and educational awareness and more established diagnostic pathways, whereas FASD remains comparatively under-recognised, potentially linked to stigma and diagnostic complexity. While

initially frustrating given emerging understanding of lifelong implications of FASD, this highlighted a clear gap in awareness and provision, shaping the focus of this research.

Further exploration of the literature highlighted that CYP voices are significantly underrepresented in FASD research, particularly in the UK, as studies largely focus on caregiver perspectives. While Frederickson and Cline (2015) highlight parents are the experts of their children and thus their views are important, my values prioritising centering CYP experiences shaped the focus of this review. Initial broad searches focusing on peer-reviewed, UK research, yielded limited results, with only one study relevant to the educational experiences of CYP with FASD. This scarcity not only supported the research rationale but also justified extending literature searches outside of the UK. Much of the available literature originated from Canada, likely reflecting earlier diagnostic development and support for research (Chudley et al., 2005). This prompted consideration of the interplay between societal understanding, government guidance, research and how this may shape understanding of these CYP's experiences, informing consideration of theoretical frameworks, discussed further below.

Reviewing the literature was emotive, as the difficulties faced by these CYP are significant and lifelong, feeling frustration due to the preventative nature of FASD. Despite feeling sympathy towards children who, by no choice of their own, are born with irreversible implications of PAE, reviewing the literature highlighted complexities of prevention. Thus, I channelled this emotion into raising awareness through my research, as blame towards mothers is unhelpful, if support and understanding are not reflected within research and society.

4.2.3 Theoretical Framework

Throughout the doctorate, there has been consistent emphasis on moving beyond within-child explanations to consider wider systemic influences on development. My practice aligns with the social model of disability (Kattari et al., 2017; Oliver, 2013), recognising while diagnosis can inform understanding, effective support requires consideration of broader contexts in which CYP develop, shifting away from locating difficulties within-child. However, FASD creates tension with this lens, as it has a clear neurological basis linked to PAE and thus can be considered a within-child condition, with majority of literature adopting a clinical, within-child focus. Literature highlighting the importance of diagnosis in accessing support and supporting others' understanding, further challenged my lens. However, further exploration highlighted these CYP's experiences across education, healthcare, home and the community are shaped by

interacting systemic factors, which can be overlooked when adopting a clinical lens, viewing implications and influences in isolation. To capture the complexity of systemic factors shaping experiences, I framed my review through Bronfenbrenner's Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006), which is pertinent to my practice as a TEP, has been identified as relevant to FASD (Flannigan et al., 2021) and applied in international FASD research (Poth et al., 2014). This framework enabled considerations of multiple, interacting influences on educational experiences, avoiding an overly narrow focus on within-child or school-based factors.

4.3 Research Design

4.3.1 Identifying Aims and a Research Question. Reviewing literature and identifying gaps helped formulate the research aims and question. The lack of research exploring these CYP's educational experiences resulted in multiple potential avenues for further exploration, such as belonging as explored in primary settings (Hammond, 2021) or exclusions given the high prevalence among this population. While this supported autonomy, it was overwhelming at times and reiterated how little is known about these CYP's experiences. Following reflection, I chose not to focus on a specific area of school experience to avoid imposing a topic and creating power dynamics. I felt a broader understanding was needed first, considering areas participants consider pertinent through their interpretation. The research aim was to explore the educational experiences of young people with FASD in secondary contexts, with the findings hoped to provide avenues for future research exploring specific areas in depth.

Qualitative research begins with curiosity for a topic, in this case, FASD and education (Janesick, 2000). Qualitative research questions focus on the why and how of interactions, alongside articulating what researchers want to understand about participants' perspectives (Agee, 2009). Engagement with literature in line with my initial curiosity and aims supported consideration of methodology, which shaped research questions aligning with IPA's focus on lived experience. This was a time-consuming process during which supervision was essential. Such discussions highlighted my values of amplifying and centering CYP's voice, aligning with IPA and the interpretivist paradigm adopted (Bhattacharjee, 2012; Cuthbertson et al., 2019; Smith et al., 2022). While alternative positions such as critical realism were considered, literature highlighted the importance of co-constructing meanings, alongside variations in CYP's experiences and therefore co-existing realities (Ashton et al., 2020). This therefore does not align

with the realist ontology of critical realism which suggests a knowable world exists, independent of the human mind, but there are multiple perspectives of this reality shaped by socially located knowledge and experience (Braun, 2013; Sayer, 2000; Willig, 2016).

The focus on eliciting CYP's voice was informed by research gaps, specifically in secondary contexts, with one study exploring adolescents' experiences across home, school and community (Eodanable et al., 2024) and a thesis exploring primary-aged students experiences of school belonging (Hammond, 2021). My research questions at the proposal stage were:

- 1) What are the educational experiences of children and young people with a diagnosis of FASD in UK mainstream secondary education settings?
- 2) What factors do children and young people with a diagnosis of FASD feel contribute to positive educational experiences?

Through feedback, supervision, gatekeeper discussions and ethical approval, I refined my questions, which is common to reflect how understanding of the topic evolves through the research and demonstrating reflexivity (Agee, 2009; Creswell & Poth, 2016). After recruitment attempts, I was faced with suspected complexities recruiting this vulnerable population. Further, my gatekeeper provided caregiver feedback, who expressed they would have been interested though factors limited engagement, which shaped my understanding and subsequent adaptations discussed through supervision. Often CYP with a diagnosis were accessing specialist settings by secondary school, thus did not meet the mainstream school criteria. Therefore, recruitment was extended to specialist settings and units to widen recruitment and reflect this reported pattern of experience, without significantly impacting homogeneity. Parents reported challenges obtaining diagnostic assessment due to limited funding and services, reflecting literature (Carrick & Hamilton, 2023). As my practice aligns with the social model of disability, this created tension, as CYP without a diagnosis, already disadvantaged in accessing services, were also excluded from this research. However, diagnosis remained an inclusion criterion due to ethics and sample homogeneity. Some caregivers expressed interest, but their children were post-education and therefore would report on their retrospective accounts, which did not meet inclusion criteria. Others raised concerns around the 'positive' focus within research questions, which they felt did not reflect CYP's experiences. I acknowledged CYP's experiences vary as informed by my literature review, though remained true to focusing on exploring what may be supportive,

shifting from deficit-focused research while providing space to explore varied experiences. Following ethics amendments and approval, my adapted research questions were:

- 1) What are the educational experiences of young people with FASD in UK secondary education settings?
- 2) What factors do young people with a diagnosis of FASD feel contribute to positive educational experiences?

During analysis, questions were further reviewed and retrospectively reworked, which is common in IPA (Smith et al., 2022). Reflectivity was prompted by difficulties distinguishing which GETs would be specifically relevant to RQ2 rather than the overarching RQ1, as participants' accounts of what supported them were intertwined within their overall accounts. When discussing areas of difficulty (RQ1), participants' suggestions of what would make school more positive, often counteracted difficulties (i.e., more TAs when lacking adult support). Thus, separating what was supportive (RQ2) from their overall experiences within findings was challenging. Moreover, upon reflection, language of 'what factors' does not align with the exploratory and interpretive nature of IPA (Isik, 2026). While in hindsight RQ2 could be considered a sub-question of the overarching RQ1 which focuses more broadly on the phenomenon of school experience, through supervision I decided to remove RQ2 (Creswell & Poth, 2016). However, the research still hoped to explore what would be supportive through a strengths-based approach within SSIs, thus strategies identified as supportive by participants, were captured within implications for practice (see Chapter Three). This reflexive process supported my learning as a novice researcher. If repeated, I would seek feedback from the FASD community to refine research questions, as they may offer insights I do not have due to my outsider status.

4.3.2 Participants

Multiple factors related to the target population, shaped design decisions. Firstly, purposive sampling was necessary to ensure a reasonable degree of homogeneity (Smith et al., 2022), related to having a diagnosis of FASD and currently attending a UK secondary education setting. Inclusion criteria were influenced by diagnostic guidelines, ethics, literature and discussions with professionals. Discussions with my gatekeeper were particularly useful in establishing the participant age range; Year 8-11 students were included because Year 7s would

not have transitioned long enough to reflect on their experiences of secondary school and post-16 students were excluded as they would report on their retrospective experiences, highlighted as a limitation when reviewing literature.

A key point of reflection is the homogeneity of the participant sample, particularly the fact that all participants were adopted. This was incidental, rather than an inclusion criteria, though this mirrors patterns in wider FASD literature, where adopted CYP are frequently overrepresented and CYP living with birth families are underrepresented. This may relate to increased access to diagnostic pathways among adoptive families, especially given the diagnostic challenges associated with FASD, and consequently greater eligibility to take part in research requiring a confirmed diagnosis. As a result, the perspectives captured in this study, like much of the existing evidence base, are shaped through the lens of adoption, which has important implications for how the findings are interpreted. Bronfenbrenner's bioecological systems theory (Bronfenbrenner & Morris, 2006) emphasises that lived experiences are influenced by multiple interacting environmental factors. From this perspective, it is likely that the experiences of young people who remain with their birth families differ from those of adopted young people, as their experiences are shaped by different relational, developmental and environmental factors and contexts. For EPs, this highlights both the value and the limitation of the current findings and existing research. While the perspectives of adopted young people offer crucial insights, they may not fully represent those living with birth families or in other care arrangements. Therefore, when applying these findings to practice, EPs should remain mindful of this contextual bias and consider how adoption-related factors may have shaped the narratives captured in this study and broader research.

4.3.2.1 Recruitment and Associated Ethics. Recruitment of this vulnerable population was challenging and reconsidered multiple times in supervision. A significant point was August 2025 when only one caregiver had contacted me, despite advertising recruitment resources since June 2025, amended in August to include specialist settings and units. A poignant supervision discussion explored plans if recruitment remained challenging, such as extending the research to include perspectives of caregivers and/or teachers through RTA. On reflection, this stage was particularly challenging, marked by uncertainty, self-doubt and whether my aim of amplifying CYP's voice could be realised without compromising my values. These tensions were captured in my research diary (Appendix U). At this time, I instigated a call with Amy Hammond, who

completed her thesis on primary-aged students' with FASD experiences of belonging, who shared her experiences reviewing literature and successfully including CYP with FASD in her research. This reignited my passion for amplifying the voice and experiences of CYP, though this at times felt an isolating experience due to others' concerns of associated stigma and practicality of the research, which may reflect limited understanding of FASD identified through my literature review.

By November 2025, worries were lifted as recruitment became easier after completing the first interview. This perhaps related to the participant's mother, sharing their experiences within her personal networks as she identified wanting to do so, potentially increasing others' confidence to take part. Recruitment highlighted the vital role of trust, as most participants previously engaged with gatekeepers, to whom I owe huge thanks for making the research possible. This prompted reflection about the importance of trust for this community who may often be let down by professionals and shaped my interview approach, prioritising transparency and building rapport.

By the end of November, I had completed two interviews, with further participants in the consent process. The second interview particularly reignited my passion, as the young person offered a very reflective, positive account of their educational experiences, bringing hope and aligning with my aims of moving beyond deficit-focused narratives. Although recruitment pressures eased, supervision highlighted the need to ensure sufficient richness and depth of data for IPA, setting a minimum target of four participants. While I recognise a larger sample size may enhance depth and credibility, my reflections throughout, highlight the complexities recruiting this vulnerable population. Remaining true to my values and epistemology, I prioritised amplifying CYP's voice, particularly given their underrepresentation in research.

4.3.3 Methodology and Design Decisions

Reviewing studies that have successfully included CYP with FASD informed consideration of suitable methods and shaped research aims and questions, aligning with a qualitative approach. IPA was chosen due to its rigorous approach to examining lived experiences, allowing for in-depth insights to explore my research question and aligning with my epistemological position (Isik, 2026; Larkin et al., 2006). Moreover, the IPA's dual analytic of identifying themes in cross-case analysis, alongside an idiographic focus on unique details of participants' accounts, allowed consideration for the variation in experiences reflecting the

spectrum of FASD needs, alongside convergence and divergence (Smith et al., 2022). Furthermore, IPA is commonly used in research which aims to explore subjective experiences such as those related to education (Isik, 2026) and has been successfully used in research exploring the educational experiences of CYP with FASD (Hammond, 2021). IPA's clearly defined steps supported me to navigate this process as a novice researcher and maintain analytical depth (Isik, 2026; Smith et al., 2022).

Prior to determining IPA as the most appropriate methodology, consideration was given to alternative methods like narrative inquiry (NI) and reflective thematic analysis (RTA), informed by lectures and exploring literature. Together, these are some of the most widely used and well-established methods in social research, all focusing on co-constructing meanings (Braun & Clark, 2021; Isik, 2026; Riessman, 2008). NI explores how individuals construct meaning through stories (Isik, 2026), focusing on how events are sequenced, identities are shaped through organising experiences into narratives, and how narratives function within particular cultural and social contexts (Riessman, 2008). NI would have allowed participants to explore pertinent areas due to not imposing structure within interviews, which may have developed more in-depth accounts (Isik, 2026). Moreover, NI has not yet been used to explore these CYP's educational experiences, thus would address a methodology gap. Despite acknowledged strengths, this approach was not adopted as variations in participants' needs and potential language difficulties (reflected through varying scaffolding required within interviews) may have made it difficult for participants to articulate their narrative. Also, narrative inquiry is suited to research questions which focus on identity development, processes of change and life histories (Riessman, 2008), which was not the research aim.

RTA (Braun & Clarke 2013, 2021) involves identifying and interpreting patterns of shared meaning across data through developing themes, rather than exploring individual cases within IPA focusing on meaning given to experiences (Braun & Clarke, 2021, Isik, 2026). RTA has strengths in its theoretical flexibility, aligning with a range of epistemological positions and research contexts (Braun & Clark, 2021), and provides a systemic and flexible approach (Isik, 2026). The possibility of RTA was considered through supervisions, primarily to triangulate multiple perspectives (e.g., CYP, caregivers and educational staff). However, this approach did not align with my values of amplifying CYP's voice, as it risked diluting their perspectives. Instead, I aimed to explore CYP's perspectives in depth, using accessible methods to support

them to share their views in a meaningful, accessible way. As RTA focuses on identifying themes across accounts, it was less suited to capturing individuals' unique experiences, which aligned to IPA's idiographic approach (Braun & Clarke, 2021; Pietkiewicz & Smith, 2014). Moreover, parental accounts have already been explored in the UK (Griffiths, 2022; Mukherjee et al., 2013) and internationally (Duquette et al., 2007; Stade et al., 2011), thus I considered what nuance a multiple-perspective approach would add. Although teacher perspectives are not so well researched, I became aware of a study exploring this and questioned what unique contribution I could offer. Moreover, limited teacher awareness and the 'hidden' nature of FASD, raised concerns about the accuracy of such accounts if teachers were not aware of these students' needs. Moreover, RTA typically requires larger samples than IPA, (Braun & Clarke, 2013), increasing recruitment challenges and risking diluting CYP's views if outweighed by caregiver and teacher accounts. Multi-perspective IPA was also discounted for similar reasons and due to its complexity and potential to shift away from CYP's experiences and meaning making (Smith et al., 2022). While strengths of triangulating perspectives are recognised, I remained true to my values of amplifying CYP's voice through IPA's idiographic focus, aligning with the research aim of exploring lived experiences.

Data Collection. Aligning with my values of amplifying CYP's voice, consideration was given data collection methods to ensure participants' meaningful inclusion. Semi-structured interviews (SSI) were adopted, commonly used in IPA and effective in capturing in-depth accounts of experience (Smith et al., 2022; Smith, 2007). The SSI allowed participants to discuss pertinent areas, minimising power dynamics associated with qualitative interviews, particularly with CYP (Anyan, 2013). SSI were adapted to support potential language and accessibility needs, informed by a university lecture on participatory approaches and exploration of literature including these CYP. Of note was Hammond's (2021) thesis exploring primary-aged CYP's with FASD experiences of school belonging, using a mosaic approach. Hammond sent participants a resource pack of tools (e.g., Lego, Play-Doh and figurines), to model their experiences within SSIs. I drew on Hammond's approach but considered feasibility of sending resources to participants and therefore chose to use visual resources which were shared on screen during interviews, alongside the developmental appropriateness of resources like Play-Doh for secondary-aged students' engagement. Another pertinent study was Eodanable et al. (2024) which adopted photovoice methodology. Further consideration suggested that, although this

method could support inclusion, it was not feasible to provide cameras, and the virtual format raised safeguarding concerns about what CYP might photograph in school without researcher oversight. It was therefore deemed inappropriate. One visual resource I developed, a drawing sheet sent in advance, was not used by participants, prompting reflection. This may reflect participants not feeling they needed alternative methods to share their views or reluctance to commit additional time as this task was optional. In future, I would embed this activity within the interview to encourage engagement, while maintaining autonomy to share their views in ways perceived as most appropriate. Visuals were not formally analysed, instead served as prompts and support to share their views. However, incorporating them into the process for everyone could enrich analysis by offering alternative insights and perspectives which the CYP may not have been able to articulate (Silver, 2013). Though, as a novice researcher it was important to balance autonomy, prioritising participants' preferences. Participants could choose if caregivers were present for interviews. Josh was the only participant who chose this for the duration. While I recognise this supported Josh to access the process, I also acknowledge caregiver presence may have influenced what he felt comfortable to share and therefore shaped the data, recognising the interview context are a part of the meaning-making process.

IPA involves a double hermeneutic, where the researcher interprets participants' sense-making of their experiences (Smith et al., 2022), making it difficult to separate from the participants and analysis. Therefore, I acknowledged and attempted to bracket pre-conceptions I brought to the research (Smith et al., 2022), which I considered to derive from conversations with professionals and exploring literature. On reflection, this became easier across interviews as initial nerves and subconscious pressures to answer the research questions led me to initially rush aspects of the interview. However, my confidence and flexibility developed with each interview, allowing greater comfortability with silence and space for elaboration. Recording reflections after each interview also supported bracketing preconceptions of prior interviews when completing later interviews to remain open-minded.

While skills developed as a TEP supported me to be attuned to participants' presentation during interviews, there were times where I felt conflicted in my dual researcher-practitioner role. Upon reflection, this arose when CYP spoke of challenges or parents added emotive context to experiences. A key part of my TEP role involves problem-solving and exploring alternative narratives, which at times led to instincts to deepen discussions and problem solve. However, I

needed to remain focused on exploring participants' experiences, rather than directing them and problem-solving, highlighting the complexity of the dual researcher-practitioner role.

While I enjoyed data collection and felt privileged to hear participants' stories, the first interview was daunting as a novice experience. It highlighted the importance of allowing time for rapport-building, which informed subsequent interviews. Although piloting the interview could have supported confidence and feasibility of the virtual nature, this was not possible due to recruitment challenges. Instead, I received feedback from ethics and supervision. On reflection, input from the FASD community may have further strengthened rigour. Moreover, ideally interviews would have been completed in person to better support rapport, engagement with visual resources and monitoring engagement (e.g., embedding movement breaks through activities). However, this was not feasible given the recruitment challenges of this hard-to-reach population who lived across the country.

Data Analysis. Adopting seven-stage IPA (Smith et al., 2022) was time-consuming, though allowed me to get close to participants' experiences through my ongoing and in-depth engagement with data (Iski, 2026). At times, my unfamiliarity with this methodology, alongside being conscious of answering my research question, resulted in fears of not getting things 'right' and reluctance to start. However, as I immersed myself in literature, I understood qualitative research is messy and complex (Isik, 2026), bringing comfort to initial uncertainty. Moreover, IPA's clearly defined analytical steps supported me through the process, providing an account of decisions, to ensure transparency and rigour (Braun & Clarke, 2021; Yardley, 2017).

I initially explored each account in-depth, re-reading transcripts and listening to audio recordings, allowing me to immerse myself in the data (Smith et al., 2022). The next step was exploratory noting, which somewhat became embedded with re-reading transcripts, noting thoughts as I went. I found this stage which involved recording initial thoughts and asking questions of the data at an exploratory level, easier than later stages due to reduced pressures on finality. This was done with the understanding that not all exploratory notes would contribute to experiential statements, though it was important to consider all aspects and possible meanings (Smith et al., 2022). This stage was supported by reflective conversations with fellow TEPs and supervision.

A key moment in the analysis was a research supervision drop-in, to discuss constructing experiential statements, reflecting participants words and my interpretation (Smith et al., 2022). I

found myself grappling with the researcher-practitioner role; my instinct was to analyse participants experiences as if it were a psychological formulation, likely reflecting complexities of the dual role alongside shifting between aspects of the doctorate. Supervision therefore centred my interpretation to focus on the deeper meaning of participants words and how they made sense of their experiences, rather than a formulation. This marked a key reflective point which supported rigour, transparency and being explicit about how my perspective shaped the research (Smith et al., 2022; Yardley, 2017). On reflection, my hesitance and limited confidence which prompted organisation of supervision, likely reflected an aspect of the hermeneutic cycle, as this was the first time I fragmented participants accounts, reorganising the data from the whole to the parts. This felt uncomfortable as I did not want to miss implied meanings, with this stage signifying moving further away from participants accounts as I added my interpretation (Smith et al., 2022). Thus, reflexivity and supervision were key to manage uncertainty, which I learnt reduced each time I completed the analysis steps, feeling comfortable that this re-organisation was necessary to later come together.

As recommended by Smith and Nizza (2022), I completed the analysis using paper-based methods to support flexibility, revisiting and reviewing clustering's and themes, supporting reflexivity and trustworthiness (Yardley, 2017). The process of grouping experiential statements into themes and subthemes (PETs), was sometimes overwhelming due to the number of statements, needing to discount statements which were not relevant to the research question. At the PETs stage, for all participants, some experiential statements clearly aligned, though repeated cycles of reviewing groupings for each participant resulted in different configurations, remaining flexible and consider if clusters reflected participants' experiences. The experiential statements were further refined when writing up PETs, such as merging, rewording or removing statements which overlapped to avoid repetition (Smith et al., 2022). This process highlighted IPA's iterative nature, and importance of going back to data before merging statements to ensure meanings within quotes reflected meanings of merged statements.

The iterative nature of IPA was further highlighted once I completed and printed PETs to explore convergence and divergence across accounts, identifying GETs. Before completing this step, I went back to the data for each PET through a top-down process and renamed some PETs to ensure they reflected participants accounts, alongside my interpretation. This top-down process differed from the bottom-up process up to this point in the analysis, whereby

interpretations were drawn from the data, and was an essential step before moving onto GETs reflecting the hermeneutic cycle of moving from the parts to the whole.

Moving from PETs to GETs involved sometimes looking more closely at sub-themes and experiential statements rather than PETs, to consider areas of shared or differing experiences, thus was a time-consuming and creative process (Smith et al., 2022). It was interesting to see how aspects of participants' accounts became more prominent when viewed alongside others' accounts. Two participants were very reflective and offered in-depth insights, however, I was conscious to amplify all voices within GETs. Although variations in accounts initially raised questions about sample homogeneity, variations in participants experiences mirrors the spectrum of FASD. This reinforced the suitability of IPA, as it's idiographic focus allowed for in-depth exploration of individual experiences, while also considering convergence and divergence.

As advised for first IPA studies (Smith et al., 2022), I presented my analysis and discussion separately. Through writing the discussion, the true iterative nature of IPA was reinforced, as I was still making sense of participants' experiences and how this adds to understanding at this stage. When linking findings to literature, I reflected that the findings may be considered novel in their entirety, as the first UK study focusing solely on these CYP's educational experiences. However, it was important to critically consider how the findings offer nuanced insights to existing understanding.

4.4 Research Contributions and Implications

4.4.1 Personal Development

Although completing a thesis initially felt daunting due to its size and my limited experience, the process has been invaluable. However, it has not come without challenges.

Reflecting on my prior research experience during undergraduate, this project offered greater flexibility in choice of topic and methodology. While I always appreciated the complexity of researching this topic and others' reservations regarding stigma and feasibility, I feel the research has taught me the importance of challenging the status quo in an ethical, carefully considered way, to ensure stigmatising topics are brought to people's attention. This process therefore reinforced my values of social justice and inclusion.

Conducting a literature review improved my skills in critically evaluating and summarising research, identifying gaps for further exploration. However, the review was the part

I found most challenging due to initial limited boundaries of exploration, which felt overwhelming. Adopting an IPA methodology undoubtedly developed my skills in interviewing and analysis, installing greater joy of completing research than prior experiences. On reflection, prior experiences related to focus on quantitative data and statistics, which I have realised does not align with my interpretivist positionality.

While this process was challenging, it reinstated my values which I uphold in practice, seeking to amplifying CYP's voice in a meaningful and accessible way. Moreover, the process reinforced the importance of adopting a systemic lens, considering the interacting factors which impact CYP's experiences and thus shape development, aligning with the social model (Oliver, 2013). The part of the process I am most grateful for, is sparking my passion for FASD, which has allowed me to establish connections with professionals, supporting potential work and research in this area upon qualifying.

4.4.2 Dissemination and Implications

A key aim was to produce information which may benefit disadvantaged groups, like CYP with FASD. By adding the unique insights of adolescents with FASD to scarce literature, it is hoped educational professionals, inclusive of teachers and EPs, will better understand and support these CYP. To ensure maximum benefits and address key issues of limited knowledge of FASD evidenced throughout the research, I hope to disseminate the findings to raise awareness and understanding, and act as an example of how these CYP can be meaningfully included in research. Given the research focus and target population, publication would be most appropriate in journals targeting the EP profession like Educational Psychology in Practice (EPIP) and journals relevant to adoption, given the high prevalence of care experiences, such as Adoption and Fostering. I also hope to further disseminate findings to professionals and families through blog posts (e.g., EdPsy). Without the support of professionals, this project would not have been possible, therefore I hope to share a summary of the findings with key organisations and charities. The families will also be sent a summary of the findings and what was learnt from their children sharing their experiences.

Given that my interest in this topic was sparked by a fellow colleague sharing her research journey, it is important to share my findings and knowledge developed from immersing myself in this topic within the EP network. This not only hopes to spark others' interest to complete research in this area, but also, to raise awareness of these CYPs' experiences to support

EPs' confidence when this area arises in their work. This phase of dissemination will involve presentations within my service, alongside hopes to present at the Eastern Region Conference, Division of Educational and Child Psychology, TEP Conference and to fellow TEPs at UEA during research presentation days. As TEPs are in the early stages of their careers, they have the ability to shape the profession, thus sharing knowledge may spark interests and conversations, helping to raise the profile of FASD.

Improved understanding of FASD is of interest to individuals at multiple systems (Bronfenbrenner & Morris, 2006), given risks of later criminality, unemployment, homelessness and substance addiction (Streissguth et al., 2004). Therefore, it would be useful to disseminate findings with interconnected services, like social workers, youth justice and health colleagues, to support understanding, alongside considering opportunities for multi-agency working. This may involve developing bespoke training and CPD sessions, which could also be delivered to teachers, given their lack of knowledge and desire for increased training.

While it is sometimes sensitive to name, this research process and engagement with professionals have reinstated the preventable nature of FASD, thus there appears a gap in supporting preventative work. As aforementioned, knowledge is key in supporting people to make informed decisions. Therefore, knowledge during pregnancy of the detrimental effects of alcohol consumption on the fetus is crucial, with a need to shift towards women as *managers of risk*, who can make informed choices, instead of becoming women *managed as a risk* by healthcare professionals (Lee et al., 2022). While this appears simplistic, it is important to consider the broader systems within which pregnant women are situated, such as cultures associated with drinking alcohol, government guidance, family contexts and aspects such as financial and living situation. Therefore, while presented as a choice, pregnant women's decisions regarding alcohol consumption are significantly socially conditioned (Ruhl, 1999). A blame culture on pregnant mothers is unhelpful, without considering the broader reasons for alcohol consumption, alongside government funding for services and infrastructure needed to reach these families. Moreover, there is a need to shift stigma within healthcare and support professionals to feel confident discussing PAE and providing information to expectant mothers to support decisions (Clarren et al., 2011). Therefore, if possible, I would like to disseminate my findings to raise awareness within healthcare and pregnancy support groups.

Engaging with this research has highlighted the need for professionals to recognise FASD as a brain-based, whole-body condition (Choate & Badry, 2019). Misattributing behaviour to parenting or early life trauma, risks misunderstanding needs and damaging relationships with families (McCarthy et al., 2022; Skorka et al., 2020). While some CYP have experienced early adversity, adopting a solely trauma lens may overlook the neurological impact of PAE. EPs should therefore remain critically reflective of the lenses applied to understanding CYP's needs, maintaining curiosity about other potential contributing factors. Given the high proportion of care experienced CYP with FASD, stronger multi-agency collaboration, particularly between EPs, virtual schools, and social care is needed (DfE & DoH, 2015). Alongside this, improved training for professionals is needed to reduce stigma and promote understanding of the complex, interrelated influences on these CYP's experiences (Bell et al., 2016).

Understanding FASD as lifelong and not something which can be 'fixed', also has implications for the type and duration of provision. While FASD commonly presents through behaviour, short-term targeted interventions commonly used in supporting CYP with SEMH needs, (e.g., time in alternative provision or specialist resource base) are unlikely to have the intended outcomes for CYP with FASD (Bryant et al., 2018; Pillay et al., 2013). Such approaches risk staff viewing provision as ineffective, by not meeting expectations of 'fixing' the young person, leading to repeated cycles of seeking alternative interventions to address difficulties experienced (Pennacchia & Thompson, 2016). Instead, the findings indicated the importance of relational, attuned and consistent practice, suggestive that these CYP benefit from stable placements. Thus, the focus should shift to what schools can offer to support these CYP's experiences, but with an understanding that they cannot 'fix' brain damage caused by alcohol exposure. EPs can support this through offering consultations and reflective spaces to support staff to manage the complexities of supporting CYP with FASD. Moreover, given the risk of placement instability and breakdown due to the complexity of these CYP's needs, support should focus on supporting and listening to the family, fostering collaborative home-school relationships, which EPs can support schools to establish, to reduce risks of exacerbating adverse outcomes.

While this research aligned with the social model of disability, highlighting how societal contexts shape how disabilities are experienced (Oliver, 2013), implications of the findings may also be considered through the rights-based model of disability. This model emphasises that all

people, including those with disabilities, are entitled to inclusion, autonomy, dignity and participation, with societal duties to remove barriers which restrict these rights (Sedova, 2024). The model highlights that disabled and non-disabled individuals should be valued equally, with society adapting to enable, rather than disable, individuals with disabilities (Lawson, 2005).

When considering the current research, adopting a rights-based perspective highlights that CYP with FASD have an inherent right to accessible education, meaningful participation in school and environments which promote their autonomy and wellbeing. Some of the findings suggest that the young people's experiences of inconsistent support, punitive approaches, limited autonomy and inflexibility present not only barriers to education, but also neglect of their rights.

Therefore, framing the implications of the findings through a rights-based model reinforces the need for educational settings and systems to proactively ensure that CYP with FASD are provided with equitable access, agency and support which they are entitled to, rather than optional adjustments. Moreover, this model reinforces the role of EPs in advocating for systemic change, working with schools and educational systems to ensure these CYP have equitable access to education, while also considering how their experiences have been shaped by social contexts as highlighted by the social model of disability (Oliver, 2013).

4.5 Conclusion

Throughout this chapter, I have sought to provide a detailed account of the rationale for this research and decisions made throughout. I have reflected on various challenges and how I managed these, shown awareness of what I brought to the research and offered proposed changes, based on what I learnt. This chapter reflects the complexities of completing research, particularly alongside a professional doctorate, constantly shifting between the researcher-practitioner role.

While the process had its challenges, it has taught me a lot about research and further developed my passion for FASD, which I hope to take forward into practice upon qualifying. It has reinforced my passion for amplifying CYP's views when seeking to understand their experiences, fundamental to my practice as a TEP. This process has also taught me the value of uncertainty in shaping my growth as a practitioner, recognising that reflexivity is an ongoing process of considering what I bring to situations and processes, which will inform my future practice.

As I prepare to submit my thesis, I feel mixed emotions. A sense of relief that I have completed something which did not initially feel was possible, while also feeling immensely grateful for the support of professionals and for the young people who bravely shared their experiences. While the topic remains under researched, under resourced and misunderstood, this process has taught me that education is key and sharing the knowledge I have developed is crucial in creating change. While there have been feelings of isolation and resistance in choosing a unique topic, a poignant email from a parent following the interview mirrored such feelings of isolation and the need for more research: *"I think it's a brilliant study you're doing and so appreciated. We need more of you!...we can only keep shouting"*. This research was always more than completing part of the doctorate. It was driven by raising awareness for these families and CYP who live with the daily implications of FASD. Therefore, I will continue to shout about FASD professionally and personally, as I embark on my journey as an EP!

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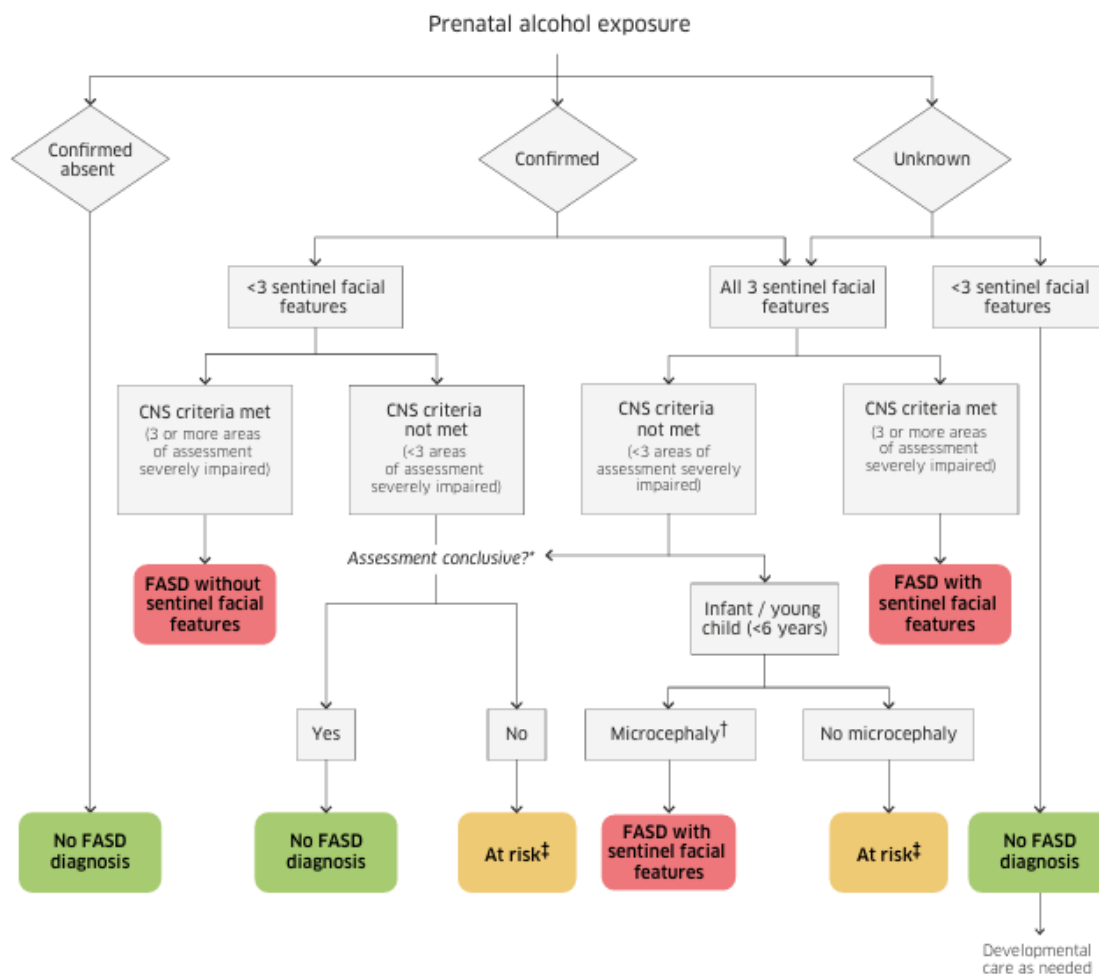
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Appendices

Appendix A

Diagnostic Algorithm for FASD Produced by SIGN (2019)



Appendix B

Flow Diagram of the Eligible and Final Sample for the Primary FASD Prevalence Estimates by Missing Data Strategy (McQuire et al., 2019)

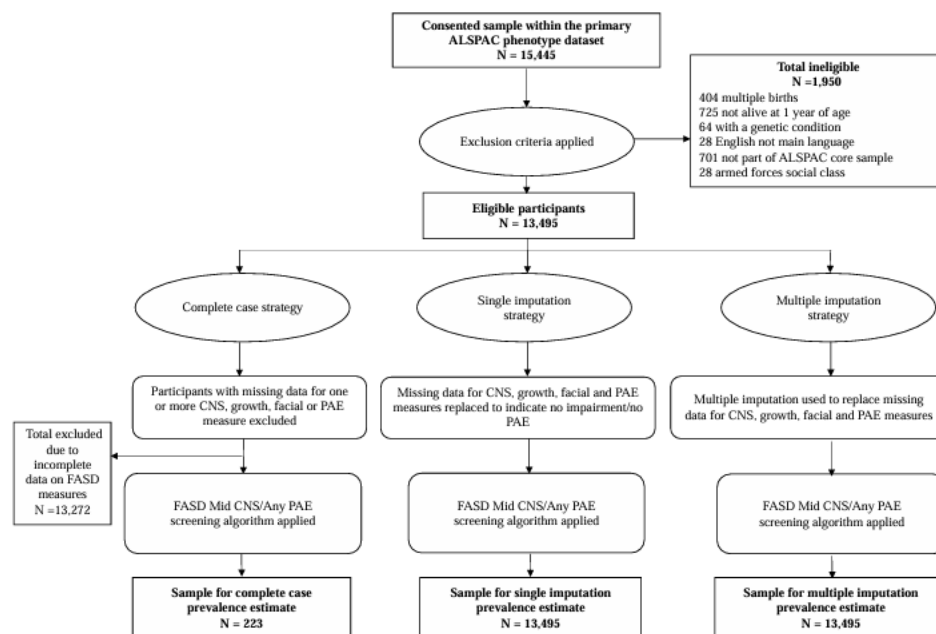


Fig. 2. Flow diagram of the eligible and final sample for the primary FASD prevalence estimates, by missing data strategy.

Appendix C

Initial Search Terms Applied in Scoping Literature Review Searches, Before Extending Outside of the UK due to the Scarcity of Research

"Foetal alcohol spectrum disorder" OR "fetal alcohol spectrum disorder" OR
"foetal alcohol syndrome" OR "fetal alcohol syndrome" OR "partial foetal
alcohol syndrome" OR "partial fetal alcohol syndrome" OR "alcohol related
neurodevelopmental disorder" OR "alcohol related birth defects" OR
"prenatal alcohol" OR "pre-natal alcohol"

AND

"education" OR "school" OR "teaching" OR "classroom"

AND

"views" OR "experiences" OR "opinions" OR "perspective" OR "voice"

AND

"child" OR "children" OR "young people" OR "student" OR "pupil"

AND

United Kingdom" OR "England" OR "Great Britain"

Limiters Applied	English Language
Results	14
Articles Selected as meeting inclusion criteria	2 1. Hammond, A. (2021). <i>Children with Foetal Alcohol Spectrum Disorder and their experiences of school belonging : an interpretative phenomenological analysis</i> . Hammond, A. University of East London. (not published)

	2. Eodanable, M., Rhodes, S., & Cebula, K. (2024). 'It's a learning curve throughout your entire life': Experiences and impact of FASD in adolescence explored in online photovoice research. <i>Research in Developmental Disabilities</i>, 146, 1–12. https://doi.org/10.1016/j.ridd.2024.104676
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Appendix D

Recruitment Poster

TRAINEE EDUCATIONAL PSYCHOLOGIST: DOCTORAL THESIS



Lauren Whiting



Exploring: The educational experiences of children with a diagnosis of FASD in secondary education settings (UK)

The study:

- This research will explore the **educational experiences** of young people with a diagnosis of **FASD** in UK secondary schools (**inclusive of mainstream, specialist, specialist units**)
- To do this, I will be speaking to young people with a diagnosis of FASD about their experiences through a **semi-structured interview**, with me on Microsoft Teams.
- Participants **can have an adult they trust with them** to support the process if they would prefer, and we may use **visual activities** to support the young people to share their views.
- The questions will be about **young people's experiences in school**, considering what they may find supportive in school; participants can choose which questions they want to answer.
- It will take roughly **1 hour**.

To be part of my study participants need to...

- Have a diagnosis of FASD (includes FASD with or without sentinel facial features, and previously used diagnostic terms, pFAS, ARBD, ARND or NDPAE).
- Be attending a UK secondary education setting (inclusive of mainstream, specialist, specialist units)
- Be in Year 8–11 at the time of data collection (this includes young people transitioning into Year 8 in September 2025 as interviews can be conducted following this transition).
- Be aware of their diagnosis.

Want to take part?

Parents/carers need to email me to show interest in their child/child they care for taking part (see below)

I will email parents/carers a video explaining the process, information sheets and consent forms to read (young person and parent/carer)

If the young person wants to take part, they and their parent/carer need to sign the consent forms and email them to me (via parent/carer email address)

I will contact parent/carers to arrange an interview, where we will discuss the young person's educational experiences



Parents/carers, please email me to express interest in your child/child you care for taking part in this research: lauren.whiting@uea.ac.uk

Thank you!

Appendix E

Semi-Structured Interview Schedule

Semi-Structured Interview Schedule

Prior to the interview, parents/carers will be emailed the short Microsoft forms questionnaire to collect demographic information about their child/child they care for. They will also be emailed the consent form for the interview.

Document was last saved: Just now
<https://forms.cloud.microsoft/Pages/ResponsePage.aspx?id=YdFxi26UUOKBwhl5djiwkiQ1vAiZSyhHgHmUihnpL39UMUQOVpOMFpLMFc0N1EwT0EYtEiOVk4zUy4u>

Part 1: Introduction and Ethical reminders

- Introduce myself and my role as a TEP. Share one-page profile on screen.
- Thank you for agreeing to take part in my research.
- The purpose of this research is to explore the educational experiences of children and young people in secondary school, who have a diagnosis of FASD (inclusive of different labels as outlined in the information sheet).
- There are no right or wrong answers to any of the questions, and you do not have to answer any questions or take part in any activities if you don't want to. Outline the activities which we may use.
- Go over the participant information sheet again and offer time for the young person and parent/carer to ask any questions.
- Explain that the content of this interview is confidential unless you share something which is a safety concern, putting you or others at risk, then this information may need to be passed on.
- The interview will be recorded and transcribed using Microsoft Teams - check consent again to record audio and video.
- Reaffirm child's informed consent and parental/carer consent (who will be present unless requested and deemed not needed at pre-interview stage) by asking
 - 1) Do you want to be part of this study?
 - 2) Can you tell me a bit about the study and what might you have to do?
 - 3) Do you understand the risks and benefits of the study? Can you explain them to me?
 - 4) Did you make the choice to be part of the study, or did someone tell you to?
 - 5) Are you happy to continue?

- Reminder that breaks will be provided but they can ask for a break at any point if needed.
- Are you happy for me to begin the recording? If yes begin recording.

The following questions will be asked at the interview. However, this is a semi-structured interview therefore, questions may be adapted and questions may be modified in the light of participants' responses, and so that areas relevant to the research questions which arise can be explored further. The order of questions may change alongside this, the time spent on each topic may differ. The questions may also be reworded by the researcher to make the

- Can you tell me about a time at school that felt really positive for you? What made it feel that way?
- Can you tell me what does a good day at school look like for you? What happens on those days?
- Can you tell me what helps you in school to have a positive experience/ makes things easier within school?
 - Within the classroom?
 - During social times?
 - During transitions between home and school?
- What are the main difference between a good and bad day at school?
- Is there anybody at school who helps you? How do they make you feel?
- If you could change something about school to make it better, what would it be and why?
 - how would that change make you feel?
- What makes school more challenging for you?
- Has there ever been a time when school was more difficult? What made it harder? How did it make you feel?
- Was there anything important to you about your experiences at school that we didn't talk about?
- How did you find talking about your experiences today?

Prompts may be used to extend conversations such as "can you tell me more about that?" or "can you tell me why that was helpful?". "What did that feel like at the time?" "What did that mean to you?"

Alternative, visual tools will be used if participants struggle to verbally answer questions or this is a support method needed which is established prior to the interview with parents/carers. This may include virtual card sorting activities using the principles of talking mats to highlight likes and dislikes within school/ factors which help make school positive which will be shared and organised on screen, the blob classroom activity shown on screen and/or drawing of the things which support positive educational experiences (see below).

End of interview:

- Thank child and parent/carer for their involvement
- Remind child of their right to withdraw and reaffirm their consent for use of their data. Remind child that no personal information will be kept about them, and data cannot be removed following fully anonymising transcripts.
- Explain how data will be stored on password protected laptop and destroyed 10 years after last use.
- Discuss next steps in process (e.g. analysis)
- Ask if there are any questions
- Close involvement with young person.

information accessible in line with the participants language and cognitive needs. At times, the answer may be reworded by the participant's parent/carer present during the interview, so the researcher can better understand their response. In line with Smith et al (2009), the researcher will endeavour to support participants to express their experiences on their own terms (p.42) and will use language used by participants within interview questions to support participants to tell their story in their own words (p.57)

Rapport building activity

- Can you tell me a little bit about yourself and your school? (e.g. how long have you been there, what year you're in, subjects enjoy?)
- What does a typical school day look like for you? (can you walk me through this?)
- How was your last week at school?

Questions

RQ1- What are the educational experiences of CYP with a diagnosis of FASD in UK secondary education settings?

- Can you tell me what is it like for you being a pupil at your school?
- How do you feel about different parts of the school day (e.g. breaktimes, lessons, assemblies) explore why they may feel that way.
- On a scale of 1-10, 1 being you really don't enjoy school 10 being you really enjoy school, how much do you enjoy secondary school? (Provide visual slide showing scale. 'enjoy' may be adapted to 'like' etc. to suit language needs. This question is provided as a support to extend conversation and deeper exploration)

Potential prompts:

- What made you choose that number?
- What would you need to change or to be different for you to say X number higher?
- How would it feel to be at a number X?
- Solution focused approach- why did you choose 6 not 5, what helped you get to a 6?

RQ2 What do CYP with a diagnosis of FASD feel contribute to positive educational experiences?

- What does the word positive mean for you? Explore their interpretation and understanding (scaffold their understanding if required and discuss this term but allow time to explore their understanding)
- What does having a good experience at school mean to you?
- What do you enjoy about school/ and why?
- What is going well at school at the moment?
 - Were there things before that were going well?

Card Sorting

See appendices of PowerPoint- 'Views gathering tools for interview. Please note these cards may be adapted through discussions with my supervisor and as research emerges.

For each picture identified as supportive in positive experience:

- Can you explain how that helps you/why is it positive?

Blob Classroom shared on screen (Long and Wilson 2017) (paper copy emailed to parent/carer prior to interview)

Show Blob Classroom Picture



- What do you notice about the picture?

Prompt:

 - Can you see if they are boys or girls, or if they are children or adults? (Encourage them to consider that the artist has drawn them so you can't identify anything about the characters such as gender or age.)
 - Draw attention to feelings of blob characters- how can you tell how the blobs may be feeling? How is X blob feeling? (Encourage noticing body position and facial expression. Make it clear that there are no right or wrong answers, it is his/her responses that I am interested in).
 - Is there anything which is the same or different to your school?
- Which Blob best represents you most of the time during lessons at school? (place circle around this on screen)

Prompt:

 - Why did you choose that blob?

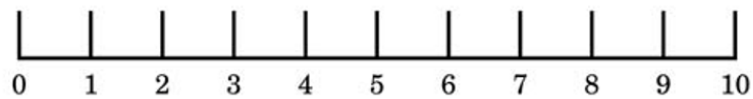
- *What are they doing?*
- *How are they feeling?*
- Which Blob best represents you during a lesson you like?
Prompt:
 - *Why did you choose that blob?*
 - *What are they doing?*
 - *How are they feeling?*
 - *What makes X a good lesson for you?*
- Which blob best represents you during a lesson you don't like?
Prompt:
 - *Why did you choose that blob?*
 - *What are they doing?*
 - *How are they feeling?*
 - *What makes X a lesson you don't like?*

Appendix F

Scaling Activity

Scaling (commonly used tool in gathering children's views in educational psychology)

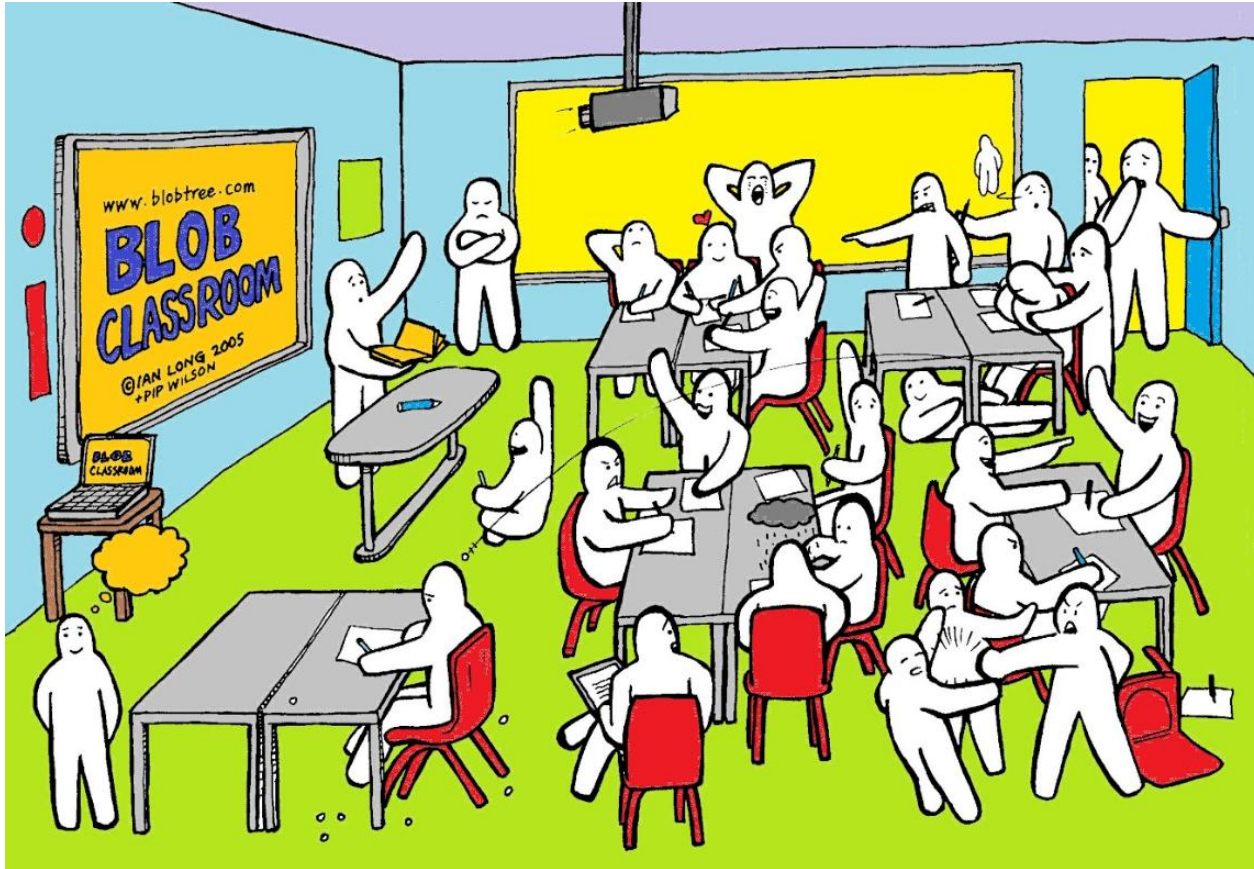
- Scaling questions will be used to quantify where the young person feels in relation to a particular area on a scale of 1-10, 1 being not positive at all, 10 being very positive.



Appendix G

Blob Classroom Resource

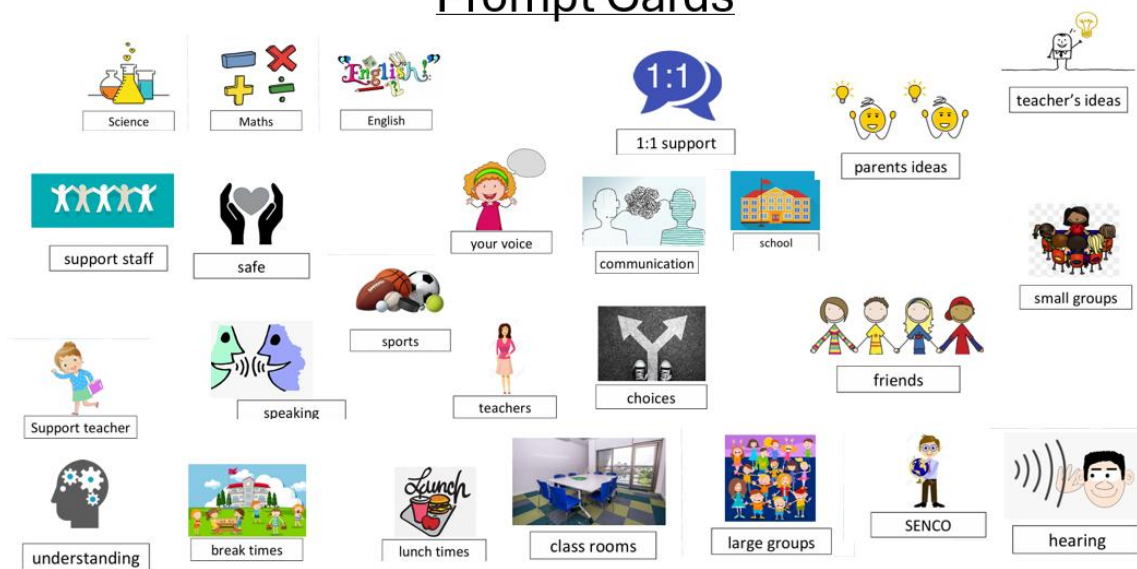
Participants were asked which blob best represented them in different scenarios in school.



Appendix H

Card Sorting Activity (blank)

Prompt Cards



Help to make school positive	Not sure	Don't make school positive

Appendix I

Drawing Sheet

Participants would be asked to share their drawings on screen if completed to prompt conversation. They will also be asked if they are happy for these to be shared with the researcher via email following completion of the interview.

Things I like doing at school

People who help me at school

My experiences at secondary school
(write or draw in the boxes- you can draw more boxes if you want to)

Things which are going well at school

Things that would make school better

Appendix J

Sample of Transcript

Transcript 2: 21 November 2025, 01:03pm

I= interviewer

P= participant

M= mother

Italics are non-verbal elements of conversation

(brackets are additional context)

I: Mm-hmm.

P: But yeah, I find cooking really fun and it's ~~it's~~ quite funny and I find cooking something and then cooking something you can eat just really like satisfying that you. You made something you can eat.

I: Hmm, amazing. So, is there anything...do you do any writing at school, anything like that?

P: Yeah...But I really like writing personally because it's I'm... yeah I just really like writing.

I: OK. Yeah. Oh, you're back. So I got to you said you really liked writing. Is there anything that would be helpful when you're writing or when you're reading or anything like that?

P: I personally just, I just like... I have to have a good pen. I do have to have a good pen like I just like the. I've got actually one right here (shows pen on screen). I like the inky ones so.

I: None. Mm-hmm.

P: The liquid ink. That's it. Liquid. I don't like Birs or anything because the ink takes a while to come out. I like an inky like found fountain pen or something like that. I am a bit picky with my pens but.

I: Oh, OK. You're allowed to be picky with your pens. (both laugh) I just want to check only because we've been doing it for about half an hour. Are you happy to carry on or do you want to break?

P: None. Yeah. No, that's all. Yeah, I'm fine.

I: OK. You let me know if you need one though. OK, OK. So is there anything about school that you would change to make it better?

P: Erm... I don't, I don't think so actually.

I: OK. And if I asked you the question about your old school, what would you have changed about that?

P: A lot (laughs). I'd change...I'd personally change. What's it called... PE? Because I personally really, really, really, really didn't like running and you didn't have a choice unless you had a little like note saying he can't run. You had to run and I didn't. And I ended up bunking in the toilets and trying to hide from it.

I: OK.

P: It wasn't good and it didn't make me want to do it. And again, it didn't want to make me get to school so. But with (current independent school since Y9), let's say you can, you can skip it. You don't have to do it, but you just you have to do something like colouring or word search you.

I: Mm-hmm.

P: And as well as (previous secondary school for Y7-8), you could never sit and do nothing. But with the with (current independent school since Y9) you can sit and do nothing, but you just can't really sit through the whole day and do nothing, basically.

I: Mm-hmm.

P: You've got to do at least something like a word search? At least something.

I: OK. And when you were at your other school, what, like what would have helped you about sitting and doing nothing? Did you feel like you needed that?

P: Yeah, I (feel like if I had to do the lessons I had to do, I couldn't. I couldn't focus on them. It was just too much, as though I had quite a few like.

I: Mm-hmm.

P: Rude classmates and they were just always trying to drag my attention away from the class and trying to get me in trouble, and it didn't help. And it wasn't a good like atmosphere to try and learn. And what learn. And then of course, they didn't have enough staff to really take you in another room and say, do you want to do this in a quieter room?

I: Mm-hmm. Mm-hmm.

P: They didn't have enough staff to monitor that so, but with (current independent school since Y9) they have a lot of staff to take you to another room and do it in a quiet room so they have a sensory room in (current independent school since Y9) and they could have sensory corners of the rooms in (current independent school since Y9).

I: Hmm. Mm-hmm.

P: each hub has a corner for sensory, but there's a whole other hub just a whole sensory: Sofas, boxing bags, fidgets, loads of fidgets, carpets, bean bag, blankets. All of that stuff is all in hub. And then you can just, like, do your work in there, you can lay on the sofa. I find it really cosy in there, they got all the lights on the ceiling on and then they ~~they~~ can turn all the lights off and put the there's stars on the ceilings. It's really cool but yeah.

I: Mm-hmm. Oh, OK. So that helps you does it?

P: Yeah. And when you first start (current independent school since Y9), there's a thing called outreach. So they'll come out with you, and you won't go straight into (current independent school since Y9). They'll first start

So they'll take the person, let's say, then let's go for a walk, let's go get some food and take it away from the other person. So nothing ever happens.

I: Mm-hmm. Ok.

P: I've never seen anything happened to a student. I've never seen anything happen to a student. I've seen a couple of things happen to staff when kids have got angry, but it's never been that bad and I think because the staff know how to handle it.

I: OK. Really. Yeah. Mm-hmm.

P: It's us never got to that point.

I: And how does that make you feel when you're at school in terms of adults being able to handle it?

P: I I feel much more safe and I feel like because in (previous secondary school for Y7-8) there's so many kids and so less staff.

I: Mm-hmm.

P: They're they're just. I just feel like anything can happen and no one will know. Like I go into this hall and it wasn't really a fight, but it was a little play and no one knew. And then I jumped over the fence. No one knew, until I got home and my mum had to text them. No one knew, and it was just.

I: OK.

P: Like I think it's bad that they don't know if anything happened because if it was a serious thing, what happened, dangerous and no one would know.

I: Hmm. Mm-hmm. And it sounds like the relationships that (current independent school since Y9) are important to you?

P: Yeah, yeah, I find... Yeah.

I: What is it about those relationships that helps you do you think?

P: So I think I have always someone to talk to if I like, ever feel sad or angry, I can always go up to a friend or a teacher and just say I'm. I'm feeling quite angry, can we go walk or can we talk and then it just when you get it out. It feels so much better.

I: OK. Mm-hmm. What you mean when you talk about what you're feeling?

P: Yeah. Yes.

I: OK. And is there anything else that you find really helpful at school or things that you really enjoy about school?

P: I find that when so, I personally really like the gym, so it's like my happy place. I like getting all the anger out in the boxing bags and everything, so we do to the gym. You do trips to the gym erm...

I: Mm-hmm. Mm-hmm.

P: We go to the gym, we go for trips out, we went pretty recently, we went to an animal place. We went to the animals and that was really fun. We've got to see foxes and lizards, snakes, tarantulas and everything like that. Today we, we did a couple of things about snakeskin and stuff.

I: Mm-hmm. Yeah wow.

P: it is pretty cool, but that's what I really like as well. You got the freedom of just saying, can we go out and we're out. In the other school, you'd never be allowed to go out. The whole day sitting on your bum, on the chair, listening to.

I: Mm-hmm.

P: To the watching of whiteboard like I just couldn't handle that, and especially because I got ADHD. I'm always moving.

I: Yeah. So tell me a little bit more about that. So when you were in your other school about sitting still, what was difficult about that?

P: I found it just, because like, there... I was allowed a fidget to it, but there's rules about it and like, I don't think the rules about fidgeting like, what's wrong with fidgeting. Like I couldn't sit here like this. I'd have to like and like.

I: Mm-hmm. That's maybe why you like your swingy chair.

P: And I just find it a bit mean that you can't fidget. And I find sitting still on a chair watching someone, say, do this, do that, do that. I find that really hard. And then when, like, I normally zone out on something and then when they ask, OK, (young person's name) are you going to do it? I have. I find saying yes, like a lot easier to say no when they get through to the whole conversation about it. So I just say yes, it sorts it. And I never get my work done. And then I can never get to the next lesson because I'm always trying to finish the work off before the end of the lesson and I found it a lot stressful.

introducing you into it, and then they'll take you out to to, like, meet all the staff.

I: Mm-hmm. Mm-hmm.

P: So your outreach teacher will be personal, like to you, and it'll kind of be like mine was a lady called X. And then then.

I: Mm-hmm. Mm-hmm. Yeah.

P: It will be a different person because they have to be an outreach teacher they can't just be a normal teacher, so they'll go out with you and get like tea, if you like tea or a coke, yeah you can even go to McDonalds and just get stuff and again they'll buy it for you, you never pay for it yourself. It will always be out of their money and they always get it back. So yeah.

I: Is there anything else about your other school that you would change?

P: erm....

I: Don't worry if there's not.

P: Wait, wait. (current independent school since Y9)?

I: No, because you said there was nothing you'd change about (current independent school since Y9). But what about your school before? If that could have been better, what would you change.

P: Yeah, yeah. Yeah, I don't. Well, there's just so much, everything would be changed. Like the classrooms, probably a lot of, I didn't like the big classrooms with all the kids. I'd rather be in a classroom with like three to four kids, like I am at the moment which I find

I: OK. Mm-hmm. Mm-hmm.

P: Much more better because it's not as big distractions. It's not as loud, although we do have a kid what's very loud so (laughs) But...

I: How is that?

P: it's so funny. He's a funny guy. He's this. He be be does, he's a chatterbox. He's a big chatterbox, he's funny, but of course it does sometimes get quite annoying, so you just go out into another hub because... and there's a little thing we do with him who can keep quiet for the longest and we just all do our work but he never listens and he goes 'Well I'm not doing that'. (both laugh)

I: Mm-hmm.

P: Yeah.

I: When you say the hub, is that like a different classroom?

P: Yeah. So you've all got hubs. So they're like, you know, containers like the big containers and ships what go, it's like that, but big one big, big, big ones and.

I: Yeah. Oh wow.

P: Yeah, they're all dotted around the field, so you just can learn into each one and they and it's not like in you go from year two to year three in a different class from different class, from different classroom. It's ...

I: Part. OK. Mm-hmm.

P: Normally in the same hub, but there's a couple that you might change... if you and it's well, if you didn't like that hub, you can change into other hubs like I was when I first started in a hub and I didn't not like it, but it didn't suit me. It was too easy. So, we go into a different hub.

I: Mm-hmm. OK. Mm-hmm.

P: So yeah.

I: So your hub, you stay in your hub the whole time you're at (current independent school since Y9).

If you like it, yeah?

P: Yeah. Yeah, I'm pretty sure.

I: And does that have the same so you have the same teachers every day, do you or?

P: Unless they're. I'll. It's the same teachers.

I: OK. And I guess that's a difference, isn't it from your other school because you would have had lots of different teachers. So is that helpful for you having one teacher?

P: Yeah. Yeah, exactly. Personally, I like having the same teachers because as well if you can get to know them and then get to know them more. And you know like you get you get more time with them and you don't just switch every teacher and have to get to know them, then get to know them, you get to know one teacher and that's the teacher that teaches you.

Appendix K

Step Two and Three of IPA, Exploratory Noting and Constructing Experiential Statements

Experiential statements	Transcript	Exploratory noting
At his current setting he feels a sense of relatedness to his peers, who have similar needs such as FASD and ADHD Independent setting has a focus of supporting transitions into post-16 education Direct comparison of sport as therapy for young people, supporting their mental health and wellbeing which is a central part of his current school experience. Setting is attuned to individual preferences and likes and will adjust to meet these. Sport is a central part of the setting and his preferences changed to align with this, attributed to the supportive environment. Young people are provided autonomy about when they do their work, completing it when they feel ready-reduced pressures and rules. Setting creates a sense of belonging, feels a valued member of the school community, relating to feeling at home.	I= interviewer P= participant M= mother <i>Italics are non-verbal elements of conversation</i> (brackets are additional context) I: OK, so first of all, can you tell me a little bit about yourself and the school that you go to? P: Yeah, of course. My name is (young person's name) and I go to a school in X called (names independent setting), and it's a great school because it helps kids like me with FASD and ADHD, and they support you with your journey to getting into college and the transition into college so you can go there and you can start your lesson and then you can play football and it just really helps me because for a lot of kids, football is therapy for them and. I: Mm-hmm. OK. Mm-hmm. P: For me, I never really like football, but when I joined there because football is quite a big thing there, I started to like football and they're very supportive of what you like and they can stretch into things what you like and what you don't like. <u>So</u> you've got a lesson. I: OK. Uh-huh. P: <u>So</u> you've got math and you don't want to do it, so you can stop the math and then do it a bit later or do it <u>tomorrow</u> or do it another day. <u>So</u> I think it's a really good and I really fit in and I feel at home. I: Mm-hmm. (technical difficulties) Oh, I lost you again. <u>So</u>. M: Yes, it's lagging out. Every time it glitches there's a little message. I'm sorry, my glasses, every time there's a little message that pops up. I: OK. What does it say? OK. M: It's to do with the Chromebook. Just so I think it's just about update and stuff. <u>So</u> I think that's all that is. <u>So</u> whenever that pops up, that's what seems to then make you freeze. And that's so I'll just keep on that. Leave it. I: OK, I don't know. It's not a Wi-Fi thing, do you think? M: No, well, the Wi-Fi is not brilliant here typically, but see. Oh, you've disappeared. Hang on, we've lost your window. Some other screen. Bear with. There we go. We have a lot of stuff open as well, which doesn't help. I: I know that feeling. I've got many tabs open.	<u>Descriptive – what not is saying</u> <u>Linguistic – language or specific words</u> <u>Conceptual – overall concept</u> His current setting <u>support</u> his FASD and ADHD needs and students with similar needs Consideration of post-16 provision and preparing young people for the next steps in their education journey. Relating sport to therapy- power this has over their experiences and mental health? Support is adapted to individual <u>needs</u> and the approach is supportive of students interests and preferences. Football is central to the provision Sense of community and feeling a sense of belonging, relating to feeling like home. Autonomy to do the work when suits them and their needs.
High staff: child ratios are supportive Staff are flexible and adapt support to individual needs, responding to students being aware of support needed and asking for this from staff Importance of outdoor space and being able to regulate away from the classroom or access an alternative space. Independent setting place certain rules and routines before young people enter the setting such as placing phones in toolbox and being security checked, accepted as the norm in the setting-higher level of security? Nurturing approach of providing <u>meal times</u> with wide variety of food choices, part of daily routine.	I: OK, so really small classes. P: Yes, M: a lot of staff there isn't there. P: Yeah, there's more staff than children, so you'll never, like, go into a hub and you'll have more children than staff. <u>So</u> there will be like three staff with two kids or something like that. I: I'm OK. Mm-hmm. OK. P: And if they're like short of staff, you'll be put in a different hub. I: OK, OK. Is there anything that the staff do that is that is really helpful? P: Yeah. Yeah. So they're pretty, free like as in, if you ever wanted to, if you ever needed space from the classroom, you can go up to one of them and ask can we go for a walk or can we go for a drive or can we go to Tesco's and then we'll go shop or walk on the field and as well they have a massive field. I: Mm-hmm. OK. P: they have a big field to play football and yeah, it's a football ground. <u>So</u> the whole school is a football ground, but we're allowed to play around the football ground. I: Mm-hmm. I see. I see. OK. <u>So</u> could you if you can tell me a little bit about what a normal day at school might look like? Just so I can understand. P: Yeah, so you'd get a taxi from your house to X, and then you'll wait until the taxi until they come out. They come out of a toolbox and then you've got your phone in the toolbox, and then you go get <u>your</u>. <u>So</u> they have a security wand. You get <u>wanded</u> down, you get a pat down and then you go into the school, and so you go into a hall and they do breakfast. They do the best breakfast- you get, pain au <u>chocolats</u>, croissants, croissants, cheese toasties, everything like that. I: Mm-hmm. Yeah. Wow. M: I get ever so jealous. I: I know! I don't get that for breakfast, that's for sure. (all laugh) P: And then you go through to your hub, so and then you'll go through to the hub and either do your, so there's a <u>warm up</u> worksheet which usually is word searches and colouring and then you go into. I: Mm-hmm. P: <u>So</u> what you do is you get math out of the way, you get it out of the way and it's really a small maths sheet. It's just one <u>one</u> math sheet and then that's all for the day. And then on that you can play football, you can have a break and then you go back in	More staff than children present at all times-higher staff: child ratios. Staff ratios are maintained at all times and if staff absence occurs then the children are moved to different hubs Free- suggesting autonomy, choice, Students can ask if they need space and time away from the classroom and staff will allow this and take them off school site if needed. Large school grounds and outside space School is a football <u>ground</u> and they can access this space throughout the day Taxi to get to school First thing which happens is they put <u>everyone's</u> phones in the toolbox Security <u>want</u> to check what you have on you- strict rules before entering, need for this in context of students? Breakfast is provided- wide variety of foods which he enjoys Warm up activities provided when entering hub Out of the way- suggests dislike of doing this so better to do it quickly? That's it for the day- limited demands on work each day though some expectations?

Work is seen as a task students want to complete quickly in order to complete more desirable activities. Work is delivered in short bursts each day, interspersed with breaks. There are clear expectations of the amount of work needed to be completed each day. The setting dedicates lots of time to sporting activities within lessons and breaktimes. Learning is made to be fun and is broken down into small manageable chunk therefore feels achievable. Staff support students when they are stuck by providing the answers and asking them to retain the information, rather than them struggling to work things out independently. High number of learning support staff who are viewed as easily accessible for support and have time to provide this.	and it's normally English. And then once you have that you go play football, have a break and then I think it's normally PSH ggg (pause). I: OK. Mm-hmm. Mm-hmm. P: it's either physical, so physical is football and you go like football. It could be up to football, it could be tennis, it could be <u>ping</u> pong, it could be any sport. And then after that's normally lunch. <u>So</u>... I: OK. Mm-hmm. M: I'm just going to pop downstairs. I'm around (mum leaves meeting as agreed by participant and requested in consent form) P: erm, and then at lunch you have curry erm, <u>You</u> have quite erm...It's really good food. And then you finish lunch. And I think you go back to hub and then you do other stuff. I can't exactly remember I: That's alright, don't worry. P: but yeah, that's all I can remember at the moment. I: <u>So</u> when you said there about getting maths done, how do you feel about maths? P: I don't actually mind it because they put it in a way that it's fun. I: How do they do that then? P: <u>So</u> they all give you a set of tasks, so it'll be like a worksheet and then it'll be like 6 x 7, let's say and then (pause) you have to. I: Mm-hmm. P: Work it out in a way. What's fun for you, and they can break it down to really small bits. Like let's do 1 x 1, 1+1, and then they'll it up and if <u>if</u> you don't know it, they'll just give you the answer and try... what I like about it is if you don't know it, they will just give you all the answers and try and get you to. I: Mm-hmm. P: Remember the answers for the next day I: Oh, OK. So, you're not sat there, stuck. P: Yeah. exactly. And there's so many LSAs, like always free for you to, like, have a chat with or, you know, you needed ever help. You could always. I: Mm-hmm. How many, how many adults are in the class when you're doing like your maths work? P: So normally we have one teacher, teacher. We have two LSAs, and sometimes there's someone who just comes in and watches or stands around, normally four or four to three I'd say.	Structure of work in short bursts followed by physical activity Sports vary- can be football, tennis or any other sport- focus on emotional and physical regulation? Food at school is good Focused time is spent in the hubs Difficulty remembering things Learning is made to be fun so then he doesn't mind it. - increased motivation if its engaging? What's fun is dependent on individual- approach tailored to needs Staff will provide answer if student is struggling and get them to recall the next day - avoid frustration? Lots of staff available to support with learning or other areas such as regulation- if you need <u>help</u> they are there. Roughly four members of staff in each hub- combination of teaching and support staff- almost 1:1 ratios and support
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High ratio of 3-4 members of staff per class. The importance of breaks in supporting engagement and regulation, viewing this as sometimes out of his control rather than a conscious choice which the setting <u>understand</u>. Football is regulatory in providing a break to support re-engagement in the learning. Feels a strong sense of belonging within his setting, enjoying social times and easily making friends with peers. Staff create supportive scenarios for students to interact and experience success within this, while also providing autonomy about the level of interaction students engage with. Staff are viewed as nice and supportive. Students have individual workstations and chairs, providing a sense of ownership and belonging within community alongside giving them responsibility to have equipment and use it safely.	I: OK. OK. And how many say is about four children as well. Is there? P: Yeah, yeah, 3-4, yeah. I: OK, that's really useful. Thank you. So how do you feel about different parts of your school day? So, you know, we could think about lessons or break times or how are different bits of the day for you? P: <u>Yeah</u> so breaktime for me <u>is</u>. I really like break because there's two breaks in the day and I really feel like you can get away from the lesson if you don't like <u>want</u> to really engage or you can't engage I: Mm-hmm. Mm-hmm. OK. Yeah. P: I find that really useful, so it's like a getaway basically, if you can't do <u>if</u> you can just go out and play that football and then come back to it. I: Mm-hmm. P: For, lunch is. I really like it because I get to sit with my friends and it's really easy to make friends, everyone's really nice in there I: Amazing! P: and all the staff is really nice and as well, they just do <u>if</u> so you do make friends, they put everyone together and try and socialise everyone. I: OK P: <u>So</u> like in math, they'll try and get you to sit next to someone. If you don't, you don't and you'll just go back to your table so you can sit next to people. And I feel like that's really nice that you get to bond with people and have time to chat with your friends. I: OK. Mm-hmm. Mm-hmm. Amazing. And do you normally in class do you sit in your own table? P: Yeah. <u>So</u> you all get a <u>table</u> and you get you, well I don't have one yet because I've just joined, but you get, you get a proper <u>spiny</u> office chair. So that's quite fun, you get to just spin around. (both laugh) I: <u>So</u> if you were thinking, you said something, that it's really easy to make friends in your school, now was it easy when you're at your mainstream school? P: No, everyone was a lot, so I'm mixed with the wrong group in my other school, everyone was a bit immature, and it didn't go great. So, but everyone in the (current independent school since Y9) is much more mature and everyone understands everyone else, I: OK.	Good they get multiple breaks Get away- suggestive of escaping lessons- is learning particularly challenging? Contrast of don't want to vs can't engage- suggestive of choice vs lack of control related to need - autonomy and supporting students to identify and manage their needs and when they need a break Making friends is easy because everyone is nice- lunch is a sociable time Staff are nice and support you to socialise and make friends - importance of shared experience and social environments to support wellbeing- scaffolding interactions to enhance success. Have access to own <u>work station</u> Each child has own resources- sense of belonging once you get the <u>spiny</u> chair? Direct comparison of two settings and his experiences of peer relationship- mainstream peers considered negative influence and immature whereas current peers are understanding of <u>each others</u> needs and are more mature
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Appendix L

Step Four of IPA, Searching for Connections Across Experiential Statements

sense of community = ↑ motivation

understanding & relatedness

At his current setting he feels a sense of relatedness to his peers, who have similar needs such as FASD and ADHD. (p.1)

Students within the setting can relate to one another and understand each others needs, creating a sense of mutual understanding and shared goals. (p.4)

Places importance on others' understanding his needs and being responsive to this in supporting his co-regulation, both students and staff though placing greater value on peers understanding. (p.4)

Within mainstream setting, the young person did not feel he could relate to his peers and they didn't understand what needs which made it harder to establish a sense of belonging. (p.4)

There is a mutual understanding within his current setting that everyone has their own unique needs, which can make it complex in meeting everyone's needs.

Places value on feeling related to his peers who have similar needs. (p.8)

Awareness that his difficulties interacting with others within mainstream may have been unique to him and therefore feeling a sense of difference to his peers and awareness of the challenges he experienced. (p.4)

Felt staff within his previous didn't understand FASD and his needs whereas current setting have staff who understand and can relate to his difficulties as they are also neurodivergent. (p.10)

autonomy

Students have individual workstations and chairs, providing a sense of ownership and belonging within community alongside giving them responsibility to have equipment and use it safely. (p.4)

Students are provided autonomy and choice if they need to go out of school grounds, comparative to mainstream settings where rules and restrictions in place did not allow for autonomy. (p.6)

Young people are provided autonomy about when they do their work, completing it when they feel ready- reduced pressures and rules. (p.1)

home

Setting creates a sense of belonging, feels a valued member of the school community, relating to feeling at home.

Comparing his current setting to another home, reflecting his sense of belonging and supportive relationships in this setting, creating a safe and welcoming atmosphere, something he didn't feel at his prior mainstream setting. (p.10)

community kindness

The supportive and less punitive approach at the independent setting creates an environment where he is motivated to attend, with a sense of belonging and community. (p.4)

Small gestures such as welcoming from staff and students creates a positive atmosphere and sense of community. (p.5)

School is a friendly and motivating place to be attributed to the kindness of students and staff, creating a sense of community and belonging. (p.5)

friendship

Feels a strong sense of belonging within his setting, enjoying social times and easily making friends with peers. (p.3)

Forming friendships within mainstream was challenging, limiting his sense of belonging. (p.10)

Navigating unstructured times and interacting with peers, particularly those who are older and more intimidating, was challenging in mainstream school resulting in him being alone most of the time (p.10)

Staff create supportive scenarios for students to interact and experience success within this, while also providing autonomy about the level of interaction students engage with. (p.3)

There are numerous opportunities to socialise within his setting, which are encouraged though sometimes he doesn't want to interact (p.7)

tailored support and adaptation.

staff availability impacting feasibility

Awareness that limited staff meant that making reasonable adjustments was challenging, even when he had some awareness of what might be supportive there was an understanding that staff numbers didn't allow for this support. (p.8)

Current setting are more flexible and adaptable to students needs on the day in terms of their engagement in learning, rather than forcing them to engage the whole day. (p.7)

individualised

Setting is attuned to individual preferences and likes and will adjust to meet these. (p.1)

School will order resources tailored to students interests such as books. (p.6)

Hub are carefully considered in terms of whether they are appropriate for each student and their needs, making adaptations when needed. (p.9)

flexibility

Flexibility around clothing is supportive particularly due to sensory needs, providing autonomy though awareness there are limits to this such as appropriate clothing. (p.1)

Staff are flexible and adapt support to individual needs, responding to students being aware of support needed and asking for this from staff (p.2)

Current setting provides higher adult ratios which supports individual adjustments when needed. (p.8)

(mainstream is independent) behaviour management approach.

hierarchies?

Safety -- adults

Staff are well trained and equipped to manage all presenting behaviour. (p.5) merge

Young person feels a sense of safety and trust in staff to manage any challenging situations which arise. (p.5) meg

High staff ratios support students to feel safe and know situations will be dealt with appropriately. (p.5)

Toilets at times could feel unsafe and a place for bullying in mainstream setting, with limited support or oversight from teachers. (p.9)

At mainstream setting, limited staff resulted in staff not being aware of issues and therefore students feeling unsafe and lacking confidence in staff members' ability to support them when challenges arose, feeling situations which were challenging and putting themselves in danger. (p.5)

Punitive.

Contrasting approaches of mainstream and specialist setting: support tailored to his needs and strengths makes him feel much more comfortable than a strict and rigid approach. (p.1)

Punitive approaches in previous school were scary, awkward and uncomfortable and such approaches made it less motivating and supportive to come into school, resulting in behaviour to avoid school. (p.4)

Educational consequences provide a restorative and supportive approach to challenging which arise, supported by co-regulation from attuned adults. (p.4)

Not having the threat of detention supports students to be their unique self, with an awareness that there are consequences but these are in place to support their understanding and resolving challenging which arise. (p.4)

There is an understanding that some days will be less positive and there are supportive measures in place to navigate these days, with reduced blame cultures and punitive consequences. (p.5)

Views mainstream settings as 'real schools'; societal expectations on what education looks like and mainstream being seen as the norm and route which holds educational value. (p.4)

Detentions or being told off in mainstream high school impacted his self-esteem and self-concept. (p.4)

rules / restrictions

Restrictions around toilet use in independent setting are supportive in keeping everyone safe. (p.9)

Some adjustments at mainstream such as allowing fidgeting, though rules around this were confusing and considered mean, presenting with limited control over this behaviour. (p.6)

Strict rules around PE and requirements to take part when he disliked running, resulted in him avoiding the lesson entirely and getting into trouble. (p.7)

Staff are playful and fun within cooking lessons, reducing power hierarchies and allowing students to make jokes with them which supports his engagement even more in an area he already enjoys. (p.7)

Strict rules and lack of flexibility impacted his motivation to engage in certain lessons and attend school at all. (p.7)

Independent setting have certain rules and routines before students enter the setting such as placing phones in toolbox and being security checked, and this higher level of security is accepted as the norm in the setting (p.2)

diff between approaches

Nothing about his current setting he would change, though expression of laughter when referring to mainstream setting highlights how much would need to change. (p.7)

His previous mainstream setting appears so far from what he finds supportive in school that he considers everything would need to change to make it a positive learning experience for him. (p.8)

Adult relationships
key in supporting
success

familiarity & consistency

Students access one hub consistently for their time in the setting, providing consistency and reducing transitions between year groups. (p.9)

Having the same teacher all of the time is supportive in terms of building a trusting relationship overtime with one adult rather than trying to get to know lots of members of staff. (p.9)

skilled & supportive

Perception that staff are skilled and passionate about their jobs and want to support young people like him (p.9)

Staff are attuned to students needs and support their co-regulation by offering supports before situations escalate. (p.5)

Staff are viewed as nice and supportive. (p.3)

All staff members are viewed as approachable, safe and trustworthy, therefore while the teacher relationship is crucial, all adults are viewed as supportive which feels comforting to him. (p.9)

available

Important that staff are always available to discuss thoughts and feelings with and support his co-regulation and ability to access regulatory tools/spaces. (p.5)

High number of learning support staff who are viewed as easily accessible for support and have time to provide this. (p.3)

Lesson challenges & support strategies

Short bursts

Learning is made to be fun and is broken down into small manageable chunk therefore feels achievable. (p.3)

Work is delivered in short bursts each day, interspersed with breaks. (p.3)

Work is seen as a task delivered in short bursts, which students want to complete quickly in order to complete more desirable activities. (p.3)

pace of lessons are challenging

Found it easier to say he understands and attempt a task, than having to listen to a whole conversation again, which resulted in him feeling behind and stressed to keep up with the pace of lessons in school. (p.6)

Lack of engagement within mainstream was not considered a conscious choice but rather an area he found extremely difficult, especially with the pace of lessons and expectations to engage all day. (p.8)

attention diff

Sustaining his attention and retaining multiple step instructions was challenging. (p.6)

Elements of his current setting can be distracting though supports and adaptations are in place to support his attention and engagement with learning. (p.8)

Difficulties sustaining his attention for long periods of time described as not being able to handle long periods of sitting, attributing this to his ADHD rather than a conscious behaviour. (p.6)

enjoys practicals

Cooking lessons provide practical skills and a sense of achievement, creating an end product he is satisfied with. (p.7)

Enjoys practical lessons such as learning how to cook (p.7)

Enjoys writing, with preferences about writing equipment to support his engagement and limit frustrations. (p.7)

-ve peers influence

Negative influence of peers within mainstream school made him frequently get into trouble. (p.4)

His peers were distracting and made it increasingly challenging to focus on the learning, creating an unsupportive learning environment. (p.8)

overall school approach & the physical environment

high staff: student ratios.

The size of his mainstream classrooms and the number of children present was difficult to manage. (p.8)

Places value on smaller classes with less children as this is easier to manage noise and distractions. (p.8)

High ratio of 3-4 members of staff per class. (p.3)

Small classes and high staff: student ratios in independent setting are supportive (p.2)

post-16 / life skills.

Independent setting has a focus of supporting transitions into post-16 education. (p.1)

There are some accepted boundaries about how the allowance is spent, though some sense of ownerships that items bought are solely for the student not school. (p.6)

Students are given a weekly allowance and autonomy to spend this how they want to, teaching budgeting, life skills and encouraging students to take responsibility about how they spend the allowance. (p.6)

transition

Each student is nominated a person outreach teacher, supporting them to form a trusting relationship through activities the young people enjoy. (p.8)

Outreach team supports a gradual transition into specialist setting to support familiarisation before starting the setting. (p.8)

A slow and staged transition supported his success in moving to a new setting (mum) (p.2)

spot / movement

The importance of breaks in supporting engagement and regulation, viewing difficulties engaging as sometimes out of his control rather than a conscious choice which the setting understand. (p.3)

The setting dedicates a variety of sporting activities within lessons and breaktimes. (p.3)

Setting has lots of open space and is based at a football ground which they are allowed to access. (p.2)

Direct comparison of sport as therapy for young people, supporting their mental health and wellbeing which is a central part of his current school experience. (p.1)

Sport is a central part of this setting and his preferences changed to align with this, attributed to the supportive environment. (p.1)

Enjoys the team aspect of football, feeling part of this and a sense of belonging. (p.7)

Football is regulatory in providing a break to support re-engagement in the learning. (p.3) - repeat of breaks

The gym within school is considered his happy place and an activity which supports him to externalise his feelings and manage his emotions. (p.5)

reg spaces / sensory

Each learning space is separate and referred to as a hub, providing space between each hub. (p.8)

Learning spaces each have relaxing spaces students can access if they feel need to, creating a sense of comfort (p.7)

Importance of outdoor space and being able to regulate away from the classroom or access an alternative space such as activities in the community. (p.2)

Current setting provides regulatory spaces to access such as a dedicated sensory room and sensory spaces within each classroom with sensory resources (p.8)

Appendix M

Step Four of IPA, Naming Personal Experiential Themes (PETs), Consolidating and Organising into a Table

Key:

- **PETs**
- **subthemes**
- under each subtheme is set of experiential statements brought together to develop each subtheme (given page number related to transcript) followed by key words/phrases in the transcript which resulted in the experiential statement.

Participant 2- Personal Experiential Statements

Oscar is a young boy in year 9 attending an independent specialist setting. Throughout his account he makes interested and articulate comparisons between his experiences in mainstream secondary school up until Year 8, and his current experiences of an independent specialist setting.

THE IMPORTANCE OF TRUSTING ADULT RELATIONSHIPS

TRUSTING ADULT RELATIONSHIPS SHAPING ATTUNED AND CONSISTENT SUPPORT

Staff are available and accessible to provide co-regulation and access to support

High number of learning support staff who are viewed as easily accessible for support and have time to provide this. (p.3)

And there's so many LSAs, like always free for you to, like, have a chat with or, you know, you needed ever help.

Important that staff are always available to discuss thoughts and feelings with and support his co-regulation and ability to access regulatory tools/spaces. (p.5)

I have always someone to talk to if I like, ever feel sad or angry. I can always go up to a friend or a teacher and just say I'm. I'm feeling quite angry, can we go walk or can we talk and then it just when you get it out. It feels so much better.

Staff in the independent setting are perceived as passionate, skilled and attuned in their approach

Staff are viewed as nice and supportive. (p.3)

all the staff is really nice and as well, they just do it so you do make friends

Staff are attuned to students needs and support their co-regulation by offering supports before situations escalate. (p.5)

but the staff are so good before that happens, they know. So they'll take the person, let's say, then let's go for a walk, let's go get some food and take it away from the other person. So nothing ever happens

but it's never been that bad and I think because the staff know how to handle it

All staff members are viewed as approachable, safe and trustworthy, therefore while the teacher relationship is crucial, all adults are viewed as supportive which feels comforting to him. (p.9)

I must say there, there's no teachers that I don't like. All of them. I like all of them and I can go to because I feel safe around every single one..... I find it really comforting.

Perception that staff are skilled and passionate about their jobs and want to support young people like him (p.9)

I just feel like they're really trustworthy and they got their job because they understand kids, just like me.

Building trusting relationships with staff overtime supports consistency.

Having the same teacher all of the time is supportive in terms of building a trusting relationship overtime with one adult rather than trying to get to know lots of members of staff. (p.9)

Unless they're. I'll. It's the same teachers

Personally, I like having the same teachers because as well it you can get to know them and then get to know them more. And you know like you get you get more time with them and you don't just switch every teacher and have to get to know them, then get to know them, you get to know one teacher and that's the teacher that teaches you.

Students access one hub consistently for their time in the setting, providing consistency and reducing transitions between year groups. (p.9)

it's not like in you go from year two to year three in a different class from different class, from different classroom....It's normally in the same hub

SUPPORT TAILORED AND ADAPTED TO STUDENTS' INDIVIDUAL NEEDS

Staff availability shaping if adjustments feel possible ~~impacting feasibility of adjustments~~

Awareness that limited staff in mainstream setting meant that making reasonable adjustments was challenging, even when he had some awareness of what might be supportive there was an understanding that staff numbers didn't allow for this support. (p.8)

And then of course, they didn't have enough staff to really take you in another room and say, do you want to do this in a quieter room? They didn't have enough staff to monitor that

Current setting provides higher adult ratios which supports individual adjustments when needed. (p.8)

with (current independent school since Y9) they have a lot of staff to take you to another room and do it in a quiet room so they have a sensory room in (current independent school since Y9) and they could have sensory corners of the rooms in

Need for an individualised approach to ~~meet each students' unique needs~~

Setting is attuned to individual preferences and likes and will adjust to meet these. (p.1)

So I personally feel like it's like I like that it's based around me and that I just feel a lot more comfortable there than what my other school.

School will order resources tailored to students interests such as books. (p.6)

we do like 20 minutes of reading and you can choose whatever book you want to read. You can order books like so if you want to order a book that you really like, they would order it for you.

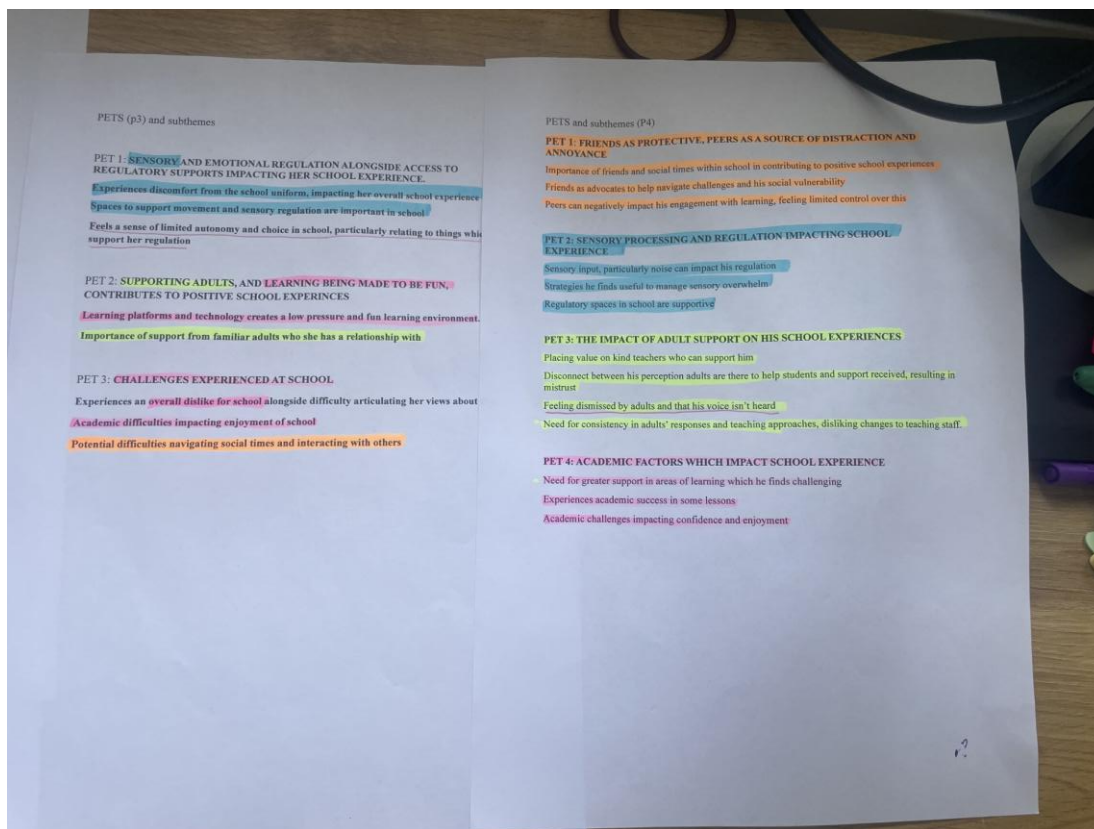
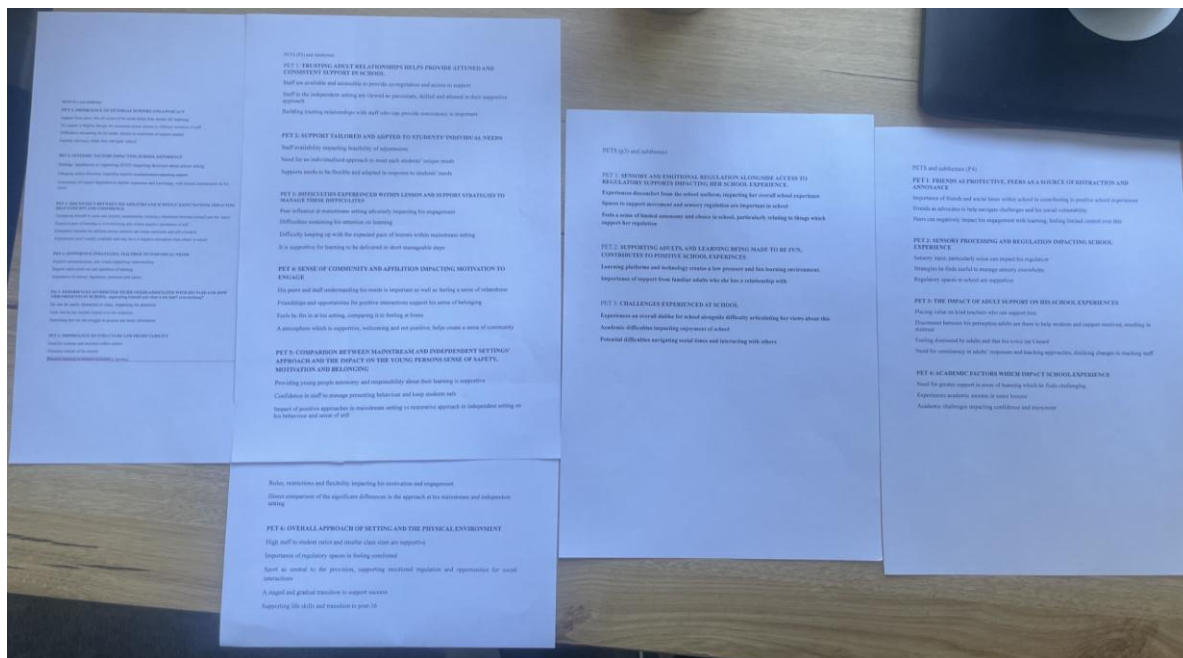
Hub are carefully considered in terms of whether they are appropriate for each student and their needs, making adaptations when needed. (p.9)

if you didn't like that hub, you can change into other hubs like I was when I first started in a hub and I didn't not like it, but it didn't suit me. It was too easy. So, we go into a different hub.

~~Flexibility of support, adapted in response to students needs~~ Support needs to be flexible and adapted in response to students' needs

Appendix N

Step Seven of IPA, Working with PETS to develop Group Experiential Themes (GETs) Across Cases



PET 1: (P1) and subthemes

PET 1: IMPORTANCE OF EXTERNAL SUPPORT AND ADVOCACY

Support from peers who are aware of his needs helps him access his learning
On support is helpful, though not consistent across lessons or different members of staff
 Difficulties advocating for his needs, despite an awareness of support needed
 Possible advocacy helps him navigate school

PET 2: SYSTEMIC FACTORS IMPACTING SCHOOL EXPERIENCE

Settings' reputations in supporting SEND impacting decisions about school setting
Changing school structure impacting support *Academicisation impacting support*
Continuity of support dependent on teacher experience and knowledge, with limited consideration for his views

PET 3: DISCONNECT BETWEEN HIS ABILITIES AND SCHOOLS' EXPECTATIONS, IMPACTING SELF-CONCEPT AND CONFIDENCE

Comparing himself to peers and schools' expectations, creating a disconnect between himself and the 'norm'
Expected pace of learning is overwhelming and creates negative perception of self
Disconnect between his abilities across sessions can cause confusion and self-doubt
Adjustments aren't readily available and may have a negative perception from others in school

PET 4: SUPPORTIVE STRATEGIES TAILORED TO INDIVIDUAL NEEDS

Explicit communication, and visuals supporting understanding
Regular adult check-in and repetition of learning
Importance of sensory regulation, resources and space

PET 5: EXPERIENCES ATTRIBUTED TO HIS NEEDS ASSOCIATED WITH HIS PAST AND HOW THIS PRESENTS IN SCHOOL: 'regulating himself and what is his best' 'externalising'

He can be easily distracted in class, impacting his attention
Views that he has limited control over his responses
Describing how he can struggle to process and recall information

PET 6: IMPORTANCE OF STRUCTURE AND PREDICTABILITY

Need for routines and structure within school
Elements outside of his control
Practical learning vs abstract concepts in learning

PETS (P2) and subthemes

PET 1: TRUSTING ADULT RELATIONSHIPS HELPS PROVIDE ATTUNED AND CONSISTENT SUPPORT IN SCHOOL

Staff are available and accessible to provide co-regulation and access to support
Staff in the independent setting are viewed as passionate, skilled and attuned in their supportive approach
Building trusting relationships with staff who can provide consistency is important

PET 2: SUPPORT TAILORED AND ADAPTED TO STUDENTS' INDIVIDUAL NEEDS

Staff availability impacting feasibility of adjustments
Need for an individualised approach to meet each students' unique needs
Supports needs to be flexible and adapted in response to students' needs

PET 3: DIFFICULTIES EXPERIENCED WITHIN LESSON AND SUPPORT STRATEGIES TO MANAGE THESE DIFFICULTIES

Peer influence at mainstream setting adversely impacting his engagement
Difficulties sustaining his attention on learning
Difficulty keeping up with the expected pace of lessons within mainstream setting
It is supportive for learning to be delivered in short manageable steps

PET 4: SENSE OF COMMUNITY AND AFFILIATION IMPACTING MOTIVATION TO ENGAGE

His peers and staff understanding his needs is important as well as feeling a sense of relatedness
Friendships and opportunities for positive interactions support his sense of belonging
Feels he fits in at his setting, comparing it to feeling at home
A atmosphere which is supportive, welcoming and not punitive, helps create a sense of community

PET 5: COMPARISON BETWEEN MAINSTREAM AND INDEPENDENT SETTINGS' APPROACH AND THE IMPACT ON THE YOUNG PERSONS SENSE OF SAFETY, MOTIVATION AND BELONGING

Providing young people autonomy and responsibility about their learning is supportive
Confidence in staff to manage presenting behaviour and keep students safe
Impact of punitive approaches in mainstream setting vs restorative approach in independent setting on his behaviour and sense of self

Rules, restrictions and flexibility impacting his motivation and engagement

Direct comparison of the significant differences in the approach at his mainstream and independent setting

PET 6: OVERALL APPROACH OF SETTING AND THE PHYSICAL ENVIRONMENT

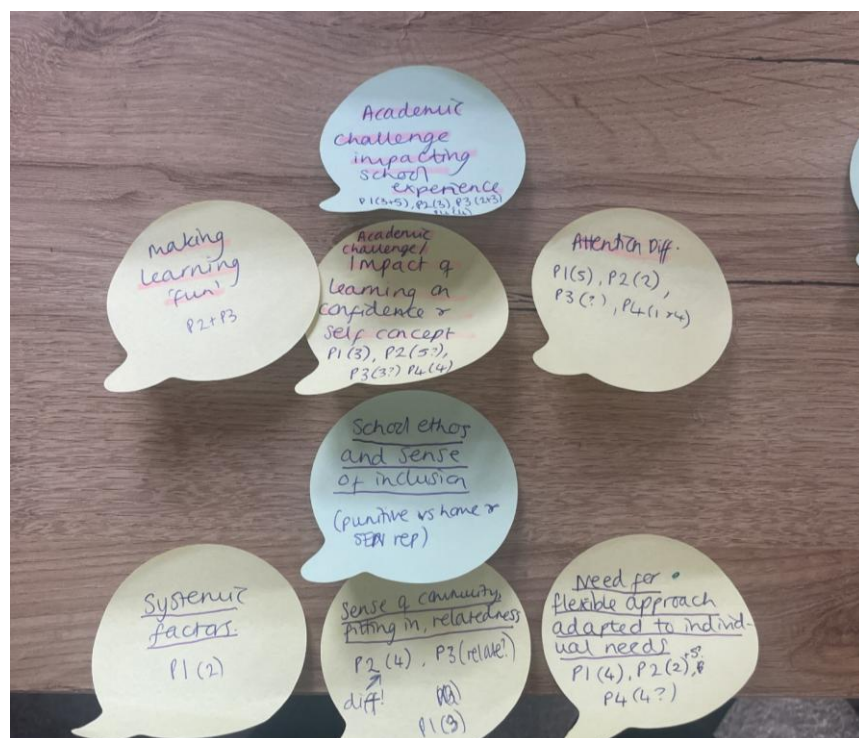
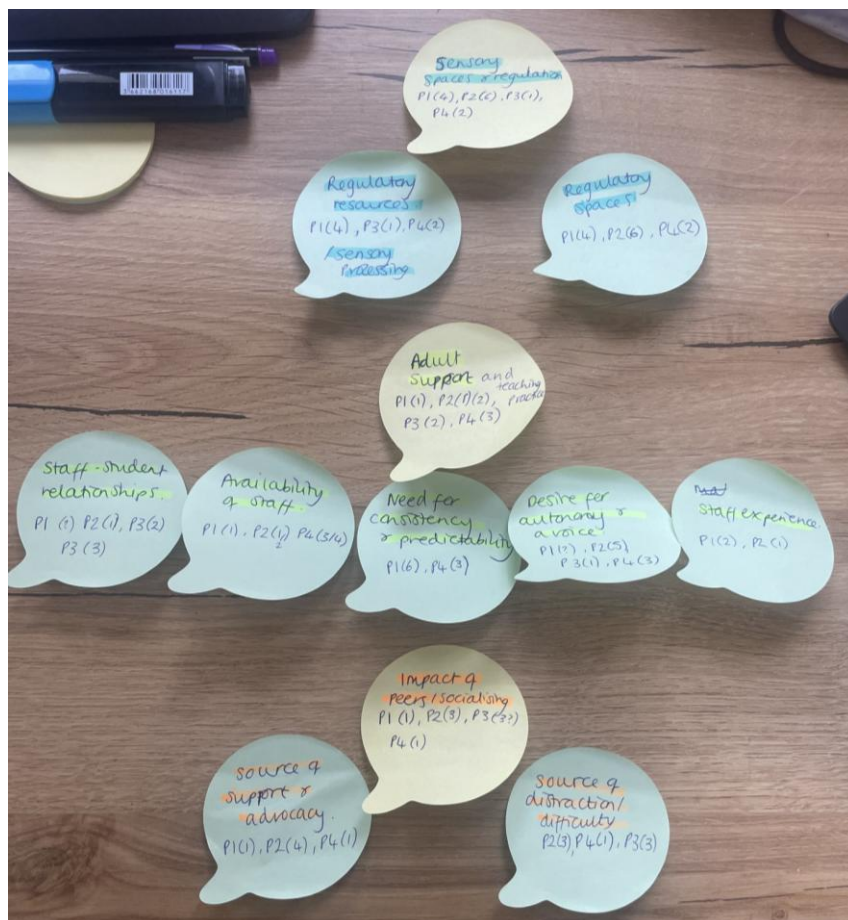
High staff to student ratios and smaller class sizes are supportive

Importance of regulatory spaces in feeling comforted

Sport as central to the provision, supporting emotional regulation and opportunities for social interactions

A staged and gradual transition to support success

Supporting life skills and transition to post-16



Appendix O

Table of Group Experiential Themes GETs (sample)

Table of GETs

Key:

GET

Subthemes

Experiential statement

Quote (name and p.no)

1: ADULTS AS SHAPING SAFETY, TRUST AND ACCESS TO LEARNING

Adult presence providing sense of safety and consistent access to support and adaptation

TA support is provided based on attainment and therefore despite being viewed as the most helpful provision for him in supporting his understanding and focus, this isn't provided consistently across lessons (p.4)

'The SENCo has put where you know I've not done. I've not done so well on my end of year test. That's what we put the TA's. But that means I've only got it. The TA's for English and Science'

'If I had like maybe if I had like 1 TA for me lessons, just so you know I understand a bit better and then I can you know focus more'

'When I say I've got a TA for like science and English, that's only for half an hour'

'for that I'd need a lot more TAs in a lot more lessons' (Josh, p.4)

High number of learning support staff who are viewed as easily accessible for support and have time to provide this.

And there's so many LSAs, like always free for you to, like, have a chat with or, you know, you needed ever help (Oscar, p.3)

Important that staff are always available to discuss thoughts and feelings with and support his co-regulation and ability to access regulatory tools/spaces.

I have always someone to talk to if I like, ever feel sad or angry, I can always go up to a friend or a teacher and just say I'm. I'm feeling quite angry, can we go walk or can we talk and then it just when you get it out. It feels so much better. (Oscar, p.5)

Awareness that limited staff in mainstream setting meant that making reasonable adjustments was challenging, even when he had some awareness of what might be supportive there was an understanding that staff numbers didn't allow for this support.

And then of course, they didn't have enough staff to really take you in another room and say, do you want to do this in a quieter room? They didn't have enough staff to monitor that (Oscar, p.8)

High staff ratios support students to feel safe and know situations will be dealt with appropriately.

I feel much more safe and I feel like because in (previous secondary school for Y7-8) there's so many kids and so less staff. (Oscar, p.5)

At mainstream setting, limited staff resulted in staff not being aware of issues and therefore students feeling unsafe and lacking confidence in staff members' ability to support them when challenges arose, fleeing situations which were challenging and putting themselves in danger.

I just feel like anything can happen and no one will know. Like I got into this fight and it wasn't really a fight, but it was a little plan and no one knew. And then I jumped over the fence. No one knew, until I got home and my mum had to text them. No one knew, and it was just.

I: OK

Like I think it's bad that they don't know if anything happened because if it was a serious thing, what happened, dangerous and no one would know. (Oscar, p.5).

Small classes and high staff: student ratios in independent setting are supportive

there's more staff than children, so you'll never, like, go into a hub and you'll have more children than staff (Oscar, p.2)

High ratio of 3-4 members of staff per class.

So normally we have one teacher, teacher. We have two LSAs, and sometimes there's someone who just comes in and watches or stands around, normally four or four to three I'd say.

I: OK. OK. And how many say is about four children as well. Is there?

P: Yeah, yeah, 3-4, yeah. (Oscar, p.3)

Support is available from both teachers and teaching assistants in school.

I: Is there anything else that the teacher... Is it the teachers or do you have teaching assistants?

P: I have both. (Thomas, p.1)

Trusting adults as a foundation for safety, support and being understood

All staff members are viewed as approachable, safe and trustworthy, therefore while the teacher relationship is crucial, all adults are viewed as supportive which feels comforting to him.

I must say there, there's no teachers that I don't like. All of them. I like all of them and I can go to because I feel safe around every single one..... I find it really comforting. (Oscar, p.9)

Having the same teacher all of the time is supportive in building a trusting relationship overtime with one adult rather than trying to get to know lots of members of staff.

Unless they're. I'll. It's the same teachers

Personally, I like having the same teachers because as well it you can get to know them and then get to know them more. And you know like you get you get more time with them and you don't just switch every teacher and have to get to know them, then get to know them, you get to know one teacher and that's the teacher that teaches you. (Oscar, p.9)

His experiences of school and enjoyment are significantly impacted by who is teaching him. (p.12)

I: Do you not like science?

P: ~~hmm~~ I... it depends who's teaching me (Thomas, p.12)

Places value on members of staff being kind and helping him when he needs it, viewing these teachers as good teachers.

I: OK. When is it good then?

P: On a Wednesday.

I: Why is that?

P: Because I've got a good science teacher.

I: But what makes them good?

P: Erm. They're very kind and they help me if I need help. (Thomas, p.12)

His experiences have led to him identifying certain members of staff he can speak to in school such as his head of year, attributed to them being more trustworthy.

P: Oh pause The teachers that like my head of year

I: You're heads of year, OK. What is it about them? Do you think that makes it easier?

P: I just trust them more than my teachers. (Thomas, p.4)

Important for him to feel that teachers are going to act on their word and sort out issues that he reports and his experiences have developed a view that those in leadership roles are more likely to sort issues than teachers.

what does that mean, trust in the adults?

P: I know they they'll sort it the head of years will sort it, but the teachers don't sort it so if I tell them that they'll sort it.

I: Mm-hmm. OK. OK. So it's important for you, It sounds like to tell them something and then they do something about it. Is that right?

P: Yeah. (young person nods) (Thomas, p.4)

Comparing his experiences in his primary school and secondary school, preferring secondary school because teachers are nicer and more supportive which didn't happen in primary school

P: It's better than my primary school.

I: Oh, OK. What makes it better?

P: Just the teachers and what we do.

I: What do you mean by that?

P: The teachers are much nicer and... They help me.

I: Did your other teachers not do that before?

P: No. (Thomas, p.14)

Staff are viewed as nice and supportive.

all the staff is really nice and as well, they just do it so you do make friends (Oscar, p.3)

Has a desire for agency and a voice in decisions which impact her experiences, such as who is employed by school, placing importance on student-staff relationship and teachers' approach.

And what would make it a 10? What would have to happen?

P: Maybe let the children when people are hiring, let the children look because we're not... because we're the ones being taught by them.

I: I see. So you mean so when they get interviewed that you can be involved?

P: Yes. (Lily, p.9)

Staff's perceived knowledge and understanding shaping support provided

Limited teacher knowledge of how FASD presents in the classroom and support adaptations needed, rather than choosing to not engage with learning.

M: yeah, because apparently he wasn't aware that (young person's name) needed processing time or that it was part of his FASD and not just (young person's name), you know, procrastinated. P: Oh, right, yeah. (Josh, p. 14)

Perception that staff are skilled and passionate about their jobs and want to support young people like him.

I just feel like they're really trustworthy and they got their job because they understand kids| just like me. (Oscar, p.9)

Staff are attuned to students needs and support their co-regulation by offering supports before situations escalate.

but the staff are so good before that happens they know. So they'll take the person, let's say, then let's go for a walk, let's go get some food and take it away from the other person. So nothing ever happens but it's never been that bad and I think because the staff know how to handle it (Oscar, p.5)

Young person feels a sense of safety and trust in staff who are well equipped to manage any challenging situations which arise.

[There's been things what has happened when someone's got annoyed of someone, but the staff are so good before that happens they know. So they'll take the person, let's say, then let's go for a walk, let's go get some food and take it away from the other person. So nothing ever happens.]

I've never seen anything happen to a student. I've never seen anything happen to a student. I've seen a couple of things happen to staff when kids have got angry, but it's never been that bad and I think because the staff know how to handle it. (Oscar, p.5)

He experiences a mismatch between expecting teachers to sort things out in the lessons which doesn't match his experiences, which can result in him feeling unhappy and an area he would like to change.

If there's anything you could change about school to make it better, what would it be?

P: the teachers sorting things out that happen in the lesson.

I: Mm-hmm. Yeah. Is there anything else?

P: No.

I: OK. How would that make you feel if they did that? The teachers?

P: It would make me feel much happier. (Thomas, p.7)

Predictability and familiarity in adult relationships as key in navigating learning and school

Need for predictability and consistency in adults supporting and their language used/responses otherwise it can be confusing to know what they mean.

'all the TA say things in different ways. So when I get used to one TA saying something one way I've got another one' 'And I've got trying to figure out what they mean' (Josh, p. 4)

Appendix P

Ethical Approval from UEA Ethics Committee (following amendments to extend to specialist settings and units)

Ethics ETH2425-1353 : Miss Lauren Whiting

Date Created	23 Jan 2025
Date Submitted	04 Mar 2025
Date of last resubmission	27 May 2025
Date forwarded to committee	29 May 2025
Researcher	Miss Lauren Whiting
Category	PGR
Supervisor	Dr Christopher Clarke
Faculty	Faculty of Social Sciences
Current status	Approved after amendments made

Ethics application

Applicant and research team

Principal Applicant

Name of Principal Applicant

Miss Lauren Whiting

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School/Department

School of Education and Lifelong Learning

Category

PGR

Primary Supervisor

Name of Primary Supervisor

[Dr Christopher Clarke](#)

Primary Supervisor's school/department

School of Education and Lifelong Learning

Project details

Project title

What are the Educational Experiences of Children and Young People (CYP) with a Diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in UK **Mainstream** Secondary Education Settings: an Interpretive Phenomenological Analysis (IPA).

Project start date

02 Jun 2025

Project end date
01 Sept 2026

Describe the scope and aims of the project in language understandable by a non-technical audience. Include any other relevant background which will allow the reviewers to contextualise the research.

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong, neurodevelopmental disorder which can result in physical, emotional and cognitive disabilities. As outlined in diagnostic guidelines (SIGN, 2019), if difficulties are not anticipated and understood, children with FASD are at risk of experiencing poor educational attainment, mental health difficulties and later addiction. Moreover, the UK has the 4th highest rate of alcohol consumption during pregnancy globally, thus prenatal alcohol exposure (PAE) is considered a public health concern, with a need to enhance knowledge within education, healthcare and society.

When alcohol is consumed during pregnancy, it can pass directly into the placenta and disrupt cell growth. The effects of alcohol consumption on the developing foetus are not homogenous, however studies highlight commonalities in the implications of PAE on brain development (BMA, 2016), commonly impacting regions supporting memory, attention, language development, processing speed and visual-spatial abilities. These differences can result in difficulties accessing and managing education environments.

UK literature exploring educational experiences of CYP with FASD is sparse, particularly that which focuses on experiences rather than deficits. Through their systematic review of 39 studies exploring school experiences of CYP with FASD and their teachers, Reedman et al., (2024), highlight a significant lack of research which includes CYP perspectives, despite school being consistently reported as a primary stressor. While awareness is developing, there is need for greater understanding, recognition and support for FASD. Therefore, the primary aim of this research is to explore the educational experiences of CYP with FASD in **mainstream** secondary schools and to identify the factors which contribute to positive educational experiences. This research addresses a knowledge gap as the first UK study to focus solely on the educational experiences of CYP with FASD in secondary education, seeking to learn from CYP's experiences, rather than indirectly exploring their views' through others' accounts.

Provide a brief explanation of the research design (e.g. interview, experimental, observational, survey), questions, methodology, and data gathered/analysis. If relevant, include what the participants will be expected to do/experience.

1) What are the educational experiences of CYP with a diagnosis of FASD in UK **mainstream** secondary education settings?

2) What do CYP with a diagnosis of FASD feel contribute to positive educational experiences?

Data will be collected through semi-structured interviews, analysed through IPA to generate superordinate and subordinate themes, effective in capturing rich personal and collective accounts. Interview will be conducted and transcribed using Microsoft Teams widening recruitment, lasting roughly 1-hour. Framed within positive psychology and solution-oriented lens, questions will explore CYPs' educational experiences and what supports them. Open-ended questions will allow flexibility to discuss pertinent areas and follow-up questions to deepen discussions.

Prior to interviews, parents/carers will be emailed a Microsoft Form collecting demographic information.

To accommodate FASD's diverse cognitive needs, a mosaic approach will use creative, person-centered methods to enhance accessibility. Visual resources e.g. drawing, scaling, blob classroom, and card sorting will reduce language demands and support participants to share their views. Use of participatory resources will depend on participants' needs', assessed through parent/carer discussions pre-interview about their child's language and cognitive needs. Participants may require parents/carers present during the interview to scaffold language or activities or because they feel more comfortable. If after pre-interview parent/carer discussions (recorded via email) it's deemed support wouldn't be needed and the CYP expresses preference to not have their parent/carer present (recorded on consent form), this will be adjusted. I will gauge support needed and adapt activities, informed by TEP experiences.

The drawing sheet will be emailed to parents/carers for printing before the interview and shared on camera with consent, aiding discussions. Resources e.g. card sorting and blob classroom will be interactive, shared on-screen. With consent, screenshots of responses will be stored with transcripts. Visual resources won't be formally analysed, they will support discussions and referred to within analysis, to enhance understanding of participants' experiences.

Detail how any adverse events arising in the course of the project will be reported in a timely manner.

Any adverse events arising will be reported in the first instance to my research supervisor as soon as possible after they occur. If required after this discussion and deemed appropriate by my supervisor, concerns about any adverse events will be reported to the EDU Ethics Committee via Ethics Monitor.

If disclosures are made in relation to safeguarding, it will be important for myself as the researcher to be transparent with the participants. I will make participants aware at the beginning of the interview that "I won't tell anyone else what you say to me, except if you talk about someone hurting you or about you hurting yourself or someone else. Then I might need to tell someone outside of the study to keep you and other people safe." If a disclosure is made, I will discuss my concerns with my supervisor, to see if further action is needed and decide on the best course of action to raise safeguarding concerns if required. If agreed that further action is needed, I will report to the appropriate safeguarding authority as required, in relation to where the child lives. This will be done as soon as the interview finishes, or if needed the interview will be stopped if the disclosure is deemed to make it unsafe for participants to continue and procedures above will then be followed. If my supervisor is unavailable, I will contact the course directors, Dr Imogen Gorman and Dr Andrea Honess.

Will you also be applying for Health Research Authority approval (HRA)?

No

Indicate if you are applying for approval for an experiment to be conducted in the School of Economics' Laboratory for Economic and Decision Research (LEDRE).

No

Is the project?:

none of the options listed

Does the project have external funding administered through the University's Research and Innovation Services (RIN)?

No

Will the research take place outside of the UK?

No

Will any part of the project be carried out under the auspices of an external organisation, or involve collaboration between institutions?

No

Do you require or have you already gained approval from an ethics review body external to UEA?

No

Does this new project relate to a project which already has ethics approval from UEA?

No

Research categories

Will the project include primary data collection involving human participants?

Yes

Will the project use secondary data involving human participants?

No

Will the project involve the use of live animals?

No

Will the project have the potential to affect the environment?

No

Will the project have the potential to affect culturally valuable, significant or sensitive objects or practices?

No

Will the project involve security sensitive research?

No

Will the project involve a generative Artificial Intelligence (AI) tool?

No

Human participants - selection and recruitment

How many Participant Groups are there who will receive tailored participant information?:

One

Name of Participant Group 1.

Children and young people with a diagnosis of FASD, attending mainstream secondary education settings

How will the participants be selected/recruited?

A purposive sampling strategy will be used to gather information-rich cases within a limited sample (Patton, 2002; Palinkas et al., 2015). There is no 'right' sample size (Smith & Osborn., 2003), however IPA requires a small number of participants who can provide detailed reflections. Therefore, as advised within my research proposal feedback, I aim to recruit 4-6 participants who are able to provide enough reflections on their experiences. I have considered the diverse cognitive needs of participant sample therefore, if participants are not able to give rich enough information for analysis, recruitment will be extended until I have enough participants who are able to provide rich enough data for analysis and saturation point is reached. This is not likely to exceed 10-15 participants.

To address challenges recruiting vulnerable populations (Dow et al., 2020), I will use pre-established connections with professionals working in FASD (e.g. Clinical Psychologist supporting children with FASD and the Director for Education and Wellbeing at the National Organisation for FASD). During scoping discussions, these individuals have agreed to act as gatekeepers. On the basis of ethical approval, they have provisionally agreed to share recruitment resources via websites, social media and within their professional networks. Following approval, I will contact them to thank them for their initial agreement and confirm whether they are still happy to be gatekeepers. I will also share resources on open platforms commonly used by EPs which do not require a gatekeeper (e.g., LinkedIn, EPNET, Bluesky etc.). Colleagues within my placement provider, may also share recruitment resources in their professional networks- colleagues emails are publicly available.

To ensure information is accessible and can be understood by participants with varied cognitive needs, information will include visuals and a short video describing the research to ensure participants can access materials and provide informed consent if they wish to take part.

If appropriate, upload a copy of the proposed advertisement, including proposed recruitment emails, flyers, posters or invitation letter.

How and when will participants receive this recruitment material?

Recruitment materials will be advertised following ethical approval through gatekeepers, EP colleagues (email addresses publicly available) and shared on commonly used EP platforms (e.g., LinkedIn, EPNET,

Bluesky etc.). The recruitment poster asks parents/cares to email me to express their interest in their child/child they care for taking part.

Following this parents will be sent an email to explain the criteria that CYP must be aware of their diagnosis, asking parents/carers to confirm this before sending other materials. If confirmed, parents/carers will be emailed the recruitment video, participant(parent and CYP) information sheets providing more information about the research and includes consent forms (parent and child). This ensures participants make an informed decision of whether to participate. Information will clearly outline what parent/carers' role is in supporting their child/child they care for during the research process- explained further later in this application. Participation in the project is entirely voluntary.

and this is made explicit within information sheets, with no obligation to take part because parents/carers express interest via email for more information.

The time which participants receive recruitment information will vary depending on their interactions with above listed platforms and dissemination of recruitment materials through gatekeepers.

Social media draft: I am recruiting for my thesis research project as part of the Educational Psychology Doctorate.

I am exploring the educational experiences of children and young people with a diagnosis of FASD in **mainstream** secondary schools, hoping to provide these young people a voice in matters affecting them. Please see the recruitment poster below- parents and carers can email me at lauren.whiting@uea.ac.uk if you are interested in your child/child you care for taking part in the research and I will send some additional information before your young person decides whether they want to take part.

Thank you,

Lauren Whiting (UEA Post-graduate researcher and Trainee Educational Psychologist).

In terms of UEA participants only, will you be advertising the opportunity to take part in this project to?:

None of the above (i.e. UEA's Student Insight Review Group (SIRG) does not need to be informed)

What are the characteristics of the participants?

•Participants must have a confirmed, clinical FASD Diagnosis.

In line with diagnostic SIGN guidelines(2019), this includes:

- FASD with sentinel facial features
- FASD without sentinel facial features.

The third SIGN diagnostic category in this guidance, 'at risk of for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure' describes individuals who have confirmed prenatal alcohol exposure and some indication of neurodevelopmental concerns, but who do not meet the whole criteria for either of the above FASD categories. Therefore, FASD may not be the diagnosis, and further clinical judgement is recommended; children meeting this criteria will not be eligible to take part given the uncertainty around a diagnosis.

The SIGN guidelines are in preliminary stages, particularly when considering the age of my participant sample and when they may have received their diagnosis, therefore, in line with prior diagnostic terms, participants who have a clinical diagnosis of the following will also be eligible to take part:

- Foetal Alcohol Syndrome (now reflected within FASD with sentinel facial features)
- Partial Foetal Alcohol Syndrome (pFAS), Alcohol Related Birth Defects (ARBD), Alcohol Related Neurological Disorder (ARND) or Neurobehavioural Disorder Associated with Prenatal Alcohol Exposure (NDPAE) (now reflected within FASD without sentinel facial features).

Participants must also be:

- Attending UK **mainstream** education setting at the time of data collection, in Years 8-11. Based on FASD professionals' guidance, Year 7 students are excluded due to transitional adjustments which would not reflect secondary educational experiences. Post-16 (Year 12 onwards) students are

EDIT: Recruitment has been extended to specialist settings following gatekeeper feedback and to broaden recruitment as many CYP by secondary school have received a diagnosis and often also received an EHCP and specialist placement. Discussed in supervision on 08/14/25

excluded to avoid reliance on retrospective accounts, given FASD-related memory difficulties reported across research. **Recruitment focuses on mainstream settings because resources, training and support within specialist settings can vary significantly, thus comparisons across accounts would be challenging.**

•Participants must be aware of their diagnosis. Parents/carers will be emailed after expressing interest to confirm this before recruitment resources are shared.

Will the project require the cooperation of a gatekeeper for initial access to the individuals/groups to be recruited?

Yes

Who will be your gatekeeper for accessing participants?

D. **Cassie Jackson** (Consultant Clinical Psychologist) who specialises in FASD and works at the Psychology Clinic of East Anglia. **Cassie** previously ran the Suffolk FASD centre before its recent closure due to funding.

Brian Roberts is the **Director of Education and Wellbeing** at the National Organisation for FASD, a charity who support individuals with FASD and their families.

Both **Cassie** and **Brian** have provisionally agreed to act as gatekeepers to participants for this project and have informed some decisions around appropriate inclusion criteria such as participants must be aware of their diagnosis for ethical reasons before taking part in the research.

How and when will a gatekeeper permission be obtained?

Already obtained via email (attached below) following brief discussions about the feasibility of my initial research ideas, on the basis of ethical approval.

Provide any relevant gatekeeper documentation (letters of invite, emails etc).

How will you record a gatekeeper's permission?

Audit trail of email which will be saved in UEA OneDrive account.

Is there any sense in which participants might be 'obliged' to participate?

Yes

If yes, provide details.

There is no obligation for participants to take part. Following distribution of the recruitment material, participants parents/carers will be invited to contact me if they wish to take part. I will then email the participant's parent/carer the information sheets (one child friendly, one parent/carer version) to provide more information about the research. This will ensure that participants and their parents/carers make an informed decision about whether to participate in the research or not, making voluntary participant explicit within this information provided. While no feelings of obligation are intended, it is important to consider that participants may have previously worked with the gatekeepers as they are specialised in their roles in the FASD community or with other educational psychologists in their providing authorities. Therefore, they may feel some obligation to take part due to potentially establishing relationships with these support services and wanting to maintain these. However, I will aim to reduce feelings of obligation by stressing the importance that this is voluntary

research, and that gatekeepers are not involved in data collection or analysis, their primary role is to share recruitment materials. Therefore, whether participants choose to take part or not, will not impact any existing relationships with these professionals.

What will you do to ensure participation is voluntary?

Participants will be sent the information sheets, with a link to the video explaining the project included alongside all relevant information about the research, prior to consenting to take part. They will therefore have the opportunity to voluntarily take part in the absence of external pressure. Their right to withdraw will be emphasised and no follow up emails will be sent encouraging participation if the individual decides not to take part. No financial incentives will be offered as part of this research.

Will the project involve vulnerable groups?

Yes

If yes, explain the necessity of involving these individuals as research participants and what will be done to facilitate their participation, or the participation of people with physical disabilities.

As stated within the United Nations Convention on the Rights of the Child (UNCRC, 1989), all CYP have the right to express their views freely in relation to matters affecting them. The proposed research therefore aims to give CYP with FASD a voice to share their experiences within education, rather than indirectly exploring this through others' accounts.

The research will adopt use of participatory methods such as drawing and visual prompts, tailored to each individuals' in relation to cognitive needs but also social and emotional needs such as nerves meeting a new person for this process. This will ensure participants are supported to share their views in alternative formats, with reduced language demands where necessary. Using participatory tools and a mosaic approach is intended to ensure these CYP are meaningfully included within the research (UNCRC, 1989) in line with Hart's (1992) Ladder of Participation, rather than tokenistic inclusion, commonly observed in previous research which indirectly explores these CYP views through the perspectives of supporting adults (e.g. teachers and parents).

Despite ethical considerations which are outlined in the application, the researcher is committed to including this vulnerable population, as their perspectives can inform strategies to improve educational experiences of CYP with FASD moving forwards (Dow et al., 2020) and raise awareness of the difficulties these young people can face within education. It is hoped that greater knowledge of their experiences, will later result in improved support to ultimately reduce the commonly reported adverse outcome in later life. Additionally, research suggests opportunities to share one's voice can be therapeutic and foster feeling valued (Elmir et al., 2011; Nordentoft & Kappel 2011) therefore, participants will hopefully find this a positive experience to reflect on their educational journeys.

Will payment or any other incentive be made to any participant?

No

Include any other ethical considerations regarding participation.

Prior to participation, I will outline the parent/carer role and contributions to this research. It is intended parents/carers will be present for the interview, to ensure they can support their child to access the process and mediate language; it's not intended parental views will be gathered within

the research. CYP can request parents/carers not to be present if it is deemed that the CYP will manage the interview process independently. It will therefore be paramount to outline in the parental information sheet and consent form that parents/carers are consenting to their child's/child they care for involvement in the research and to being present during the interview to scaffold, given the vulnerability of the target population. This will be reiterated at the start of the interview. There will be a separate CYP information sheet and consent form.

I recognise there may be challenges recruiting this vulnerable population and extensive thought has been given to using methods which promote accessibility. With this in mind, I will agree a cut off to recruitment with my supervisor and if not enough participants have been recruited by this date, I would submit a new ethics application with adaptations (e.g. participant group). This would likely focus on teacher perspectives in supporting CYP with FASD, analysed through thematic analysis. I have discussed with my supervisor and tutors on the course how including teacher perspectives would align with current literature. However, I feel passionately about giving CYP the opportunity to share their voice and I'm dedicated to ensuring this process is ethical and positive for participants. Communications with gatekeepers suggests this research is important for the FASD community and they will be able to support successful recruitment outlined within this application. While recognising challenges, I am passionate about providing these CYP a voice, with an alternative plan if required.

Human participants - consent options

By which method(s) will consent to participate in the research be obtained?:

Participant Information Sheet and Consent Form

Human participants - information and consent

Participant Information and Consent

Will opt out consent for participation in the research be used?

No

You can generate a Participant Information Text and Consent Form for this application by completing information in the Participant Information Text and Consent Form Generator tab. Alternatively you can upload your Participant Information Text and Participant Consent Form which you have already prepared. Confirm below:

Generate automated Participant Information Text and Consent Form.

When will participants receive the participant information and consent request?

After ethical approval, the recruitment poster will be distributed as outlined in this application. Parents/carers will email me to express their interest in their child/child they care for taking part. Following this the following email will be sent to confirm whether the CYP is aware of their diagnosis before sending materials.

'Dear XXXX,

Thank you for expressing an interest in your child/child you care for taking part in my research exploring the educational experiences of children and young people with a diagnosis of Foetal Alcohol Spectrum Disorder. Part of the criteria for taking part in the research is that the CYP are aware of their diagnosis. Therefore, before I send over the recruitment video explaining the research

in more depth, information sheets and consent forms, please can you confirm whether or not the young person you are expressing an interest in participating, is aware of their diagnosis or not.

Many thanks,

Lauren Whiting

Post-Graduate Researcher and Trainee Educational Psychologist*

If confirmed, parents/carers will be emailed the recruitment video, participant (parent and child) information sheets, which will provide more information about the research and includes the consent forms (parent and child). This will ensure participants make an informed decision of whether to participate in the research or not. It will include information to clearly outline what the parent/carers' role is in supporting their child/child they care for during the research process- this is explained further later in this application. Participation in the project is entirely voluntary, and this is made explicit within the information sheets.

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 sheets (one parent copy, one CYP copy). Participants and their parent/carer will keep a second copy for their own records.

How will you record a participant's decision to take part in the research?

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 (one parent copy, one young person copy). They will keep

a second copy for their own records. The copy I have will then be stored on a password protected laptop on UEA OneDrive during the project and destroyed in line with data management guidelines, 10 years following last use. Their consent and the date this was provided will be recorded on the master spreadsheet which will also be kept on a password protected laptop on UEA OneDrive during the project and destroyed in line with data management guidelines.

Parental/Guardian Information and Consent

Are you asking for parental/guardian (or other responsible person) consent?

Yes

You can generate a Parental/Guardian Information Text and Consent Form for this application by completing information in the Parental/Guardian Information Text and Consent Form Generator tab. Alternatively you can upload your Parental/Guardian (or Other Responsible Person) Information Text and Consent Form which you have already prepared. Confirm below:

Generate automated Parental/Guardian Information Text and Consent Form.

When will parents/guardians (or other responsible person) receive the parental/guardian (or other responsible person) information and consent request?

Following ethical approval, recruitment resources will be shared. If parents/carers express interest via email, I will respond to clarify whether their CYP is aware of their diagnosis before sending further

material. Once confirmed, the parent/carer will be emailed the recruitment video, information sheets (CYP and parent/carer) inclusive of the consent forms.

How will you record a parent's/guardian's (or other responsible person's) decision regarding consent for their child (or other vulnerable person) to participate in the research?

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. They will keep

a second copy for their own records. The copy I have will then be stored on a password protected laptop on UEA OneDrive during the project and destroyed in line with data management guidelines. Their parental/carer consent and the date this was provided will be recorded on the master spreadsheet which will also be kept on a password protected laptop on UEA OneDrive during the project and destroyed in line with data management guidelines.

Human participants - method

Which data collection methods will be used in the research?:

Interview

If your research involves any of the methods (including Other) listed above, upload supporting materials.

How have your characteristics, or those of the participants influenced the design of the study or how the research is experienced by participants?

Given the cognitive challenges and differences in language and communication for many children and young people with FASD, careful consideration has been given to the approaches used within the research. I have considered that the needs for these young people is likely to vary from being able to access the language demands of a typical spoken semi-structured interview, to needing lots of visual supports to share their views. I have therefore developed non-verbal tools to scaffold individuals to share their views where needed, to create a positive experience which enhances accessibility of the research regardless of cognitive and language needs.

My role as a trainee educational psychologist has influenced the design of this study as a key area of our work is being person centred and child led alongside supporting children to share their views using a variety of methods in our everyday work. Therefore, my values in ensuring children are supported to share their perspectives and have their voice heard has influenced the participatory elements of this research and passion to ensure their voices are heard. The visual resources have been informed by views gathering tools used as a trainee educational psychologist and are informed by research within the field.

Will the project involve transcripts?

Yes

Select ONE option below:

Transcription software

If yes provide details.

Microsoft Teams has an inbuilt transcription function, therefore the use of this will be outlined in the consent form before being used during the interview process.

Due to some inaccuracies with this software, I will review the transcript following the interview and email a copy to the parent/carer once complete, asking them to review it with their child/the child they care for to ensure it is reflective of their views shared within the meeting. Given participants potential cognitive challenges, parents/carers will be encouraged to support this process if the young people want to complete this step. This will be voluntary, and I will outline within the email sharing the transcript that there is a return time of 5 working days for parents/carers to share any comments with me if they choose to review it, to ensure there is a cut off point to this process to not delay analysis.

Will you be capturing photographs or video footage (digital assets) of individuals taken for University business?

No

Is this research using visual/vocal methods where respondents may be identified?

Yes

If yes, confirm what safeguards are in place for participants who are vulnerable or underage.

Visual and vocal information shared via Microsoft Teams will be needed to inform transcriptions of the interviews. Information about the recording of visual and vocal information will be included within the participant information sheets, so parents/carers and the young people are informed about this before agreeing to take part. I will also outline that having the video function on is required during the interview, because participatory tools such as drawings completed by the participants will be shared on screen to support discussions. It will also be important for me to ensure that a parent/carer is present throughout, which I will be aware of during the interview and can ensure, through using the video function. As part of the information sheet and consent form, the researcher will ask the parent/carer to share photos of any material developed as part of the interview process, such as drawings. These will not be formally analysed but will provide greater context to the discussions and write up. Consent to include these within the final write up will also be sought from the young person prior to taking part and reaffirmed at the end of the interview once completed. Video and vocal data will be stored on a password protected laptop on UEA OneDrive during the project and destroyed once data is transcribed for the purpose of analysis, to ensure no identifiable data is kept by the researcher. Only I and my research supervisor will have access to this data during the project.

Will it be necessary for participants to take part in the study without their knowledge and consent at the time?

No

Will deception or incomplete disclosure be used?

No

Will the participants be debriefed after data collection?

Yes

If yes, how will they be debriefed and what information will be provided?

At the end of the interview, participants will be thanked for their participation, offered time to ask any questions they may have and I will explain the next steps in the process (such as data will assigned a pseudonym, transcribed and stored on a password protected laptop). Participants will then be emailed a debrief form. This will include contact details of both myself as the researcher and my research supervisor should parents/carers or participants feel they have questions or need to arrange a debrief time to talk about the interview. Participants will also be provided with contact details of organisations which are available for additional support such as: <https://nationalfasd.org.uk/helpline-contact/>

<https://www.fasdawareness.org.uk/services>

If yes, upload a copy of the debrief information.

Will substances be administered to the participants?

No

Will involvement in the project result in, or the risk of, discomfort, physical harm, psychological harm or intrusive procedures?

Yes

If yes, provide details.

Asking participants to reflect on their educational experiences may result in discussion of areas they find challenging and distressing. While my research is framed within a positive psychology lens, I am aware that participants may discuss difficulties they may have had at school which may be upsetting and cause them discomfort. Please see earlier responses in this application regarding management of adverse events arising.

Will the project involve prolonged or repetitive testing?

No

Will the project involve potentially sensitive topics?

Yes

If yes, provide details.

Sensitivity of FASD and pre-natal alcohol assumption has been carefully considered, considering potential psychological harm discussing such topics (e.g., distress, anxiety, upset) and associated stigma. While the research poses no intended harm, I recognise vulnerable groups are at increased risk of experiencing harm from research and some experiences raised within interviews may be difficult, complex and sensitive. I will take extra steps to reduce risk (HCPC SoCPE 6.1,6.2) carefully considering participants experiences during interviews and ensuring participants are psychologically contained before leaving.

The interview schedule will be framed within positive psychology lens, structured around what is supportive with an appreciation that negative experiences may also arise in discussion. While children must have an FASD diagnosis to take part, no questions will directly ask about early life experiences, or their diagnosis. Participants do not have to answer questions if they don't want to and will be reminded they can withdraw themselves by terminating the interview at any point.

Participants will be made aware that following interview completion, they can withdraw their data at

any time up until data has transcribed and anonymised. A master spreadsheet (stored on password protected laptop on UEA OneDrive) will be kept during data collection to record participants name and school in case I need to report safeguarding concerns to the school's designated safeguarding lead and data before it's anonymised to ensure participants can withdraw data before anonymisation. Please see later in this application for details regarding master spreadsheet.

Participants will be offered movement breaks and wellbeing check-ins and I will monitor withdrawal signs, consistently reaffirming assent (BPS CoHRE 4.7). If present, parents/carers can monitor CYP's emotional state and withdraw if required. Before ending the interview, I will ensure participants are safe and not distressed. Debrief information will provide my and my supervisors' contact details and information about support resources (e.g. charities).

Will the project involve elite interviews?

No

Will the project involve any incitement to, encouragement of, or participation, in an illegal act (by participant or researcher)?

No

Will the research involve an investigation of people engaged in or supporting activities that compromise computer security or other activities that may normally be considered harmful or unlawful?

No

Does the research involve members of the public in participatory research where they are actively involved in undertaking research tasks?

No

Does the research offer advice or guidance to people?

No

Is the research intended to benefit the participants, third parties or the local community?

Yes

Provide an explanation.

The research aims to give children and young people with FASD a voice to share their experiences, using participatory methods to ensure their meaningful inclusion (UNCRC, 1989) in line with Hart's (1992) Ladder of Participation. Research questions aim to identify factors that support positive experiences of education, therefore it is hoped that by these individuals sharing their experiences, knowledge about what may be supportive for these children and young people in education will be developed. This knowledge can then be used to inform recommendations for possible future interventions/support strategies which will likely be a benefit to both the participant, the FASD community and wider society. In future, this may inform support for other children and young people with FASD, as well as potentially benefitting participants if they are still in education at the time developments in support occur.

Additionally, research suggests opportunities to share one's voice can be therapeutic and foster feeling valued (Elmir et al., 2011; Nordentoft & Kappel 2011) therefore this process may provide a unique opportunity to share their experiences and reflect on these. By discussing positive educational experiences, participants may benefit from the opportunity to reflect and remind themselves of positive times which may support participant wellbeing.

What procedures are in place for monitoring the research with respect to ethical compliance?

This research will be conducted in line with ethical approval from the UEA EDU ethics committee and relevant guidelines will be adhered to, including British Educational Research Association (BERA, 2014), BPS Code of Human Research Ethics (2021), HCPC Standards of Conduct, Performance and Ethics (2024). Respect for participants' privacy and dignity is a priority (HCPC SoCPE, 1.1). I will ensure I have regular supervision with my researcher supervisor to ensure ethical compliance throughout the research process and any ethical breaches will be immediately reported to my supervisor and the ethics committee via ethics monitor.

Does the study involve the use of a clinical or non-clinical scale, questionnaire or inventory which has specific copyright permissions, reproduction or distribution restrictions or training requirements?

No

Health and safety - participants

Is there a possibility that the health and safety of any of the participants in this project including a support person (e.g. a care giver, school teaching assistant) may be in question?

Yes

If yes, describe the nature of any health and safety concerns to the participants and the steps you will take to minimise these.

The researcher recognises that exploration of participant lived experience may evoke strong feelings and emotions for participants and their parents/carers therefore any health and safety concerns arising, will most likely relate to distress. In order to minimise risk of harm and health and safety concerns participants will have a parent/carer present throughout the process. The interview will take place in a familiar environment (their home) and the researchers will work to build a good rapport with participants prior to completing the interview. The interview schedule will be framed within a positive psychology lens, structured around what is supportive within education with adjustments made to resources used to support a positive and inclusive experience.

It is important to note that research thus far involving the topic of children with FASD has most commonly received interest from adoptive or foster families. Therefore, if I observe the same patterns within my research, the potential impact of distress about discussing often stigmatised prenatal alcohol consumption is reduced, as it is likely participants parents/carers will be their adoptive or foster carers. Despite this, I recognise biological parents may come forwards to express their interests and to reduce harm, all efforts will be made to ensure both parents/carers and participants leave the interview process psychologically contained and the contributing factors to the participants diagnosis will not be discussed.

What procedures have been established for the care and protection of participants?

Participants will be fully debriefed and contact details for the researcher and research supervisor will be made available in the debrief letter. As well as this parents/carers and participants will be signposted to relevant support agencies supporting those affected by prenatal alcohol exposure. During data collection, the master spreadsheet will keep a record of the child's name and school so that if needed, I can contact the school's designated safeguarding lead- whether this is required will be discussed with my research supervisor first. I will obtain the school's name through the Microsoft form. This information will be deleted following anonymisation as safeguarding concerns will have been reported and therefore there is no reason to keep this data.

Describe your safeguarding protocol. What procedures are in place for the appropriate referral of a participant who discloses an emotional, psychological, health, education or other issue during the course of the research or is identified by the researcher to have such a need?

I have a full DBS and I am on the update service, this will be shared with parents/carers prior to the interview. As part of my role as a TEP, I have also had extensive safeguarding training and will embed my understanding and procedures throughout the interviews and research process as a whole. If disclosures are made in relation to safeguarding, it will be important for myself as the researcher to be transparent with the participants. I will make participants aware at the beginning of the interview that "I won't tell anyone else what you say to me, except if you talk about someone hurting you or about you hurting yourself or someone else. Then I might need to tell someone outside of the study to keep you and other people safe.". I will speak with the participants and their parents/carers about my concerns and take appropriate action. I will report to the appropriate safeguarding authority as required, in relation to where the child lives (see interview schedule). This will be done as soon as the interview finishes, or if needed the interview will be stopped if the disclosure is deemed to make it unsafe for participants to continue.

What is the possible harm to the wider community from their participation or from the project as a whole?

There is no intended harm to the wider community from the project. Despite this, the researcher acknowledges that discussing participants educational experiences may result in discussion of their frustrations about particular educational settings or support services related to education. Discussions referring to named settings or support services will be avoided where possible and at the beginning of the interview I will outline that we should avoid naming settings and services where possible. If settings and services are named within discussion, I will remind participants to speak anonymously, and these will be anonymised in transcription if they do arise. If there are safeguarding concerns regarding the practice of named professionals or services, I will follow safeguarding procedures in reporting this.

What precautions will you take to minimise any possible harm to the wider community?

To minimise the risk of their discussions impacting relationships with such settings outside of the research, at the start of the interview, I will outline that identifiable information such as the names of schools should be kept anonymous and I will not collect data about the names of the school the participant is attending, only their year group and confirmation that it is a **mainstream** setting. I will also reiterate that the interview transcripts will be anonymised and no identifiable information will be

within the transcript, therefore if participants do mention particular professionals or educational settings, this will also be anonymised within transcripts.

Health and safety - researcher(s)

Is there a possibility that the health and safety of any of the researcher(s) and that of any other people (as distinct from any participants) impacted by this project including research assistants/translators may be in question?

Yes

If yes, how have you addressed the health and safety concerns? Describe any safeguards included and relevant protocols.

The researcher will conduct interviews within their home, therefore I will ensure that when using Microsoft teams, an appropriate background will be applied to ensure no identifiable or personal information is visible during the interview.

The researcher is on the DBS update service which ensures I am safe to work with children and young people up to the age of 25 in my role as a Trainee Educational Psychologist. This will be shared with parents/carers prior to the interview.

The researcher has access to research supervision sessions throughout the research process and should I require it, I will seek clinical supervision through my placement provider or university course to discuss emotional responses to the stories I may encounter.

All data collection will be done online so no extra precautions re travel plans are necessary for the researcher.

Risk assessment

Are there hazards associated with undertaking this project where a formal risk assessment will be required?

No

Data management

Will the project involve any personal data (including pseudonymised data) not in the public domain?

Yes

If yes, will any of the personal data be?:

Anonymised and pseudonymised

If using anonymised and/or pseudonymised data, describe the measures that will be implemented to prevent de-anonymisation.

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, password protected laptop on UEA OneDrive account during the project.

Participants data will be anonymised once transcribed and participants have been given the opportunity to review their transcription. At this point any raw data will be destroyed. Within transcripts, any identifiable information will be anonymised. For example, if the child mentioned their schools name, this will be replaced with just 'school'. 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.

A master spreadsheet will be kept during data collection to keep a record of the young person's name and school attended to support safeguarding referrals if required alongside the young person's FASD diagnosis, gender, whether they are LAC and year group. Participant transcripts will also be kept here before anonymised so that participants can review the transcripts and remove their data if they choose to before anonymisation. This master spreadsheet will be stored on a password protected laptop on UEA OneDrive. Once transcribed and anonymised, names and schools will be deleted from the spreadsheet, replaced with participant (number). The spreadsheet will be deleted following successful viva completion.

If not using anonymised or pseudonymised data, how will you maintain participant confidentiality and comply with data protection requirements?

Will any personal data be processed by another organisation(s)?
No

Will the project involve access to records of sensitive/confidential information?
No

Will the project involve access to confidential business data?
No

Will the project involve secure data that requires permission from the appropriate authorities before use?
No

Will you be using publicly available data from the internet for your study?
No

Will the research data in this study be deposited in a repository to allow it to be made available for scholarly and educational purposes?
No

Provide details.
UEA do not have an appropriate repository for data to be held. Therefore data will be held on a password protected laptop on UEA OneDrive during the project.

Who will have access to the data during and after the project?
All data will be anonymised using pseudonyms. Only myself and my research supervisor will have access to the raw data during the project for the purpose of transcription. Once transcribed and all

identifiable information is removed/anonymised, raw data including video recording will be destroyed in line with UEA policy.

Anonymised participant data will not be shared and will only be accessed by the researcher and research supervisor during the research. Transcribed data will be destroyed 10 years after the date of last use.

After the project, the findings and conclusion following completion will be shared more broadly (for example with FASD charities and Educational Psychology services) to raise awareness of the experiences of these young people in education. The research findings may also be disseminated through publication of my thesis research.

Where/how do you intend to store the data during and after the project?
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. Raw data used during the project will be stored on a password protected laptop, saved in secure UEA OneDrive account. Once anonymised using pseudonyms, some transcripts may be printed for the purpose of analysis. No identifiable information will be included on printed transcripts and these will be stored in a locked filing cabinet when not in use, at my place of residence. Following completion of the project, raw data will be destroyed on the password protected laptop and printed data will be shredded by a private company (service provided by my current placement host).

How will you ensure the secure storage of the data during and after the project?
Following transcription review by participants, data will be anonymised and kept on a password protected laptop saved in secure UEA OneDrive account, or if printed, it will be kept in a locked filing cabinet when not in use, at my place of residence. Following completion of the project, raw data will be destroyed on the password protected laptop and printed data will be shredded by a private company (service provided by my current placement host).

How long will research data be stored after the study has ended?
10 years from the date of last use

How long will research data be accessible after the study has ended?
10 years from the date of last use

How are you intending to destroy the project data when it is no longer required?
Printed data will be shredded by a private company (service provided by my current placement host) as soon as I successfully complete my viva. All files will be stored on the password protected laptop, saved in an secure UEA OneDrive account and will be destroyed 10 years from the date of last use, in line with UEA policy.

Generate and upload files
PARTICIPANT INFORMATION TEXT AND CONSENT FORM

Upload the Participant Information Sheet and Consent Form.
Enter Participant Group number and name.

Children and young people with a diagnosis of FASD, attending mainstream secondary school

PARENTAL/GUARDIAN INFORMATION TEXT AND CONSENT FORM

Upload the Parental/Guardian Information Sheet and Consent Form.
Enter Participant Group number and name.
Parent/carer

Attached files

- Recruitment Video.mp4
- Lauren Recruitment Poster final.pdf
- CJ email gatekeeper.png
- BR gatekeeper email.png
- Views gathering tools for interview.pptx
- Interview schedule - with edits .docx
- Debrief forms- parent-carer and young person.docx
- Child Friendly Information Sheet and Consent Form final.docx
- Parental_Guardian Information Sheet and Consent Form - ethics edits.docx

Appendix Q

Information Sheet and Consent Form

Miss Lauren Whiting
Post Graduate Researcher/Trainee Educational Psychologist
14th August 2025

Faculty of Social Sciences
School of Education and Lifelong Learning
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom
Email: lauren.whiting@uea.ac.uk
Tel: N/A
Web: www.uea.ac.uk

What are the Educational Experiences of Children and Young People (CYP) with a Diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in Secondary Education Settings in England/UK

PARENTAL/GUARDIAN INFORMATION SHEET

There is a sheet at the end of this document which parent/carers must sign in order for the young person to take part.

(1) What is this study about?

Your child/the child you care for is invited to take part in a research study about the experiences of children with a diagnosis of Fetal Alcohol Spectrum Disorder in secondary schools and what these young people find positive or supportive about school. Your child/the child you care for has been invited to participate in this study because they are currently in Year 8, 9, 10 or 11 at a UK secondary school and have a diagnosis of Fetal Alcohol Spectrum Disorder.

They must be able to willingly consent to take part in this research themselves, in order to take part. To do this, they must understand what the study will entail and why they have been asked to participate. They also must understand the benefits and the risks involved with being in the study.

This Participant Information Sheet tells you about the research study. Knowing what is involved will help you decide if you want to let your child/the child you care for take part in the study. It is also important that your young person is able to willingly consent to take part in this research themselves as well as providing parental/carer consent.

In line with the Mental Capacity Act, in order for your young person's consent to be valid, you must believe that they:

- show some understanding of the information given to them
- are able to retain the information for long enough
- can weigh up information and use it to make the decision
- can communicate the decision

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 for your child/the child you care for to take part in this study you are telling us that you:

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

ETH2425-1353

(2) Who is running the study?

The study is being carried out by the following researcher(s): Miss Lauren Whiting.
This will take place under the supervision of Dr Christopher Clarke, UEA Academic Tutor (christopher.d.clarke@uea.ac.uk).

(3) What will the study involve for my child?

In order to give consent for your child/the child you care for to participate in the research, you must have parental responsibility. Furthermore the child you care for must meet the following criteria:

- Have a clinical FASD Diagnosis (this includes Fetal Alcohol Syndrome with or without sentinel facial features, Foetal Alcohol Syndrome, Partial Foetal Alcohol Syndrome (pFAS), Alcohol Related Birth Defects (ARBD), Alcohol Related Neurological Disorder (ARND) or Neurobehavioural Disorder Associated with Prenatal Alcohol Exposure (NDPAE).
- Be attending a UK secondary education setting.
- Be in Year 8-11 at the time of data collection.
- Your child/the child you care for is aware of their diagnosis.

This study involves completing a semi-structured interview. The interview will take place virtually via Microsoft Teams, therefore it will be conducted at a location familiar and comfortable for your child/the child you care. In the interview, your child/the child you care for will be asked questions about their experiences of school and the factors they feel contribute towards positive educational experiences. The researcher will take notes about what they say. If your child/the child you care for struggles to answer verbally, they can use pictures, prompts, card sorting activities or drawing to help them. Prompt cards and images will be provided, but they can also bring along anything they want to help them. Your child/the child you care for can also be accompanied by an adult who knows them well, such as yourself to support them through the interview process. It is intended parent/carer will be present unless within pre-interview discussions you deem that your child/the child you care for will access the interview and language of questions independently and the young person has requested that parents/carers are not present. The adult would be present to help your child/the child you care for to express or explain their views but cannot add their own personal views.

An audio/video recording will be taken for the purpose of transcription.

You and your child/the child you care for will have the opportunity to review information generated about your child/the child you care for together, prior to publication.

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

The interview will take roughly an hour to complete, depending on how much information your child/the child you care for wants to share with me. This can be shorter if they have a preference for this. They are welcome to have a break whenever they need one. Following the interview, I will share a copy of the transcript with you, which you can review with your child/the child you care for to check it is an accurate representation of our conversation. Any comments on this can be shared via email with me up to 5 working days following receipt of the email. Reviewing the transcript is entirely voluntary and if I do not receive a response within 5 working days of sending it to you, I will assume you do not wish to review the transcript and don't have any comments.

(5) Does my child have to be in the study? Can my child withdraw from the study once they have started?

Being in this study is completely voluntary and your child/the child you care for does not have to take part.

ETH2425-1353

Their decision whether to participate will not affect yours or their current or future relationship with the researchers or anyone else at the University of East Anglia now or in the future.

If you choose to let your child/the child you care for, takes part in the study and then changes their mind later (or they no longer wish to take part), they are free to withdraw from the study at any time and they can withdraw their consent up to the point their data is fully anonymised. You can do this by emailing me. Due to anonymity, data cannot be removed once anonymised as it will not be possible to identify child/the child you care for answers and remove them.

(6) What are the consequences if my child withdraws from the study?

Your child/the child you care for is free to stop the interview at any time. Unless you say that you want us to keep them, any recordings will be erased and the information your child/the child you care for has provided will not be included in the study results. Your child/the child you care for may also refuse to answer any questions that they do not wish to answer during the interview. If you decide at a later time to withdraw your child/the child you care for from the study their information will be removed from our records and will not be included in any results, up to the point data has been fully anonymised.

(7) Are there any risks or costs associated with my child being in the study?

I understand that answering questions about school and trying to remember back in time may be stressful for some people. While the questions are not designed to be sensitive, school could potentially be a difficult subject for some participants. Your young person will be encouraged to stop the interview if at any time they feel uncomfortable. Moreover, the interview style will be flexible and adapted to your young person's needs, with the aim of making this a positive and comfortable experience for them.

If you or your young person feels affected by or worried about anything discussed in the interview after it is completed, you can access support through the following organisations:

<https://nationalfasd.org.uk/help/line-contact/>
<https://www.fasdawareness.org.uk/services>

(8) Are there any benefits associated with my child being in the study?

- It is hoped that this research will raise awareness of the educational experiences of children and young people with a diagnosis of FASD.
- With raised awareness and knowledge, it is hoped that schools and education settings will be better informed of how to support these young people in education, to enhance their positive experiences in school settings.
- Moreover, it is hoped that your young person will feel that their voice has been listened to and heard as this research provides a unique experience to reflect on and share their experiences within education.
- The methods used to gather views will hopefully provide other researchers in Educational Psychology with confidence that it is possible to capture the views and experiences of those with FASD or other learning or communication difficulties, providing methods for further research gathering the voices of these young people.

(9) What will happen to information provided by my child and data collected during the study?

By agreeing to your young person taking part, you agree to their responses being collected and used for the purpose of this study. Personal data will be removed and data collected during the study will be analysed in order to find key themes within the data and then reported in the findings of the study. Any data collected will only be used for the purpose of this study. All data will be stored on the UEA

ETH2425-1353

If you (or your child/the child you care for) 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 School of Education and Lifelong Learning: Yann Lebeau (yann.lebeau@uea.ac.uk).

(13) How do we know that this study has been approved to take place?

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the EDU 5-REC (School of Education and Lifelong Learning Research Ethics Subcommittee).

(14) What is the general data protection information my child needs to be informed about?

According to data protection legislation, we are required to inform you that the legal basis for processing your data as listed in Article 6(1) of the UK GDPR is because this allows us to process personal data when it is necessary to perform our public tasks as a [University](https://www.uea.ac.uk).

In addition to the specific information provided above about why your child/the child you care for's personal data is required and how it will be used, there is also some general information which needs to be provided for you:

- The data controller is the University of East Anglia.
- For further information, you can contact the University's Data Protection Officer at dataprotection@uea.ac.uk
- You can also find out more about your child/the child you care for's data protection rights at the [Information Commissioner's Office \(ICO\)](https://www.uea.ac.uk/information-commissioners-office).
- If you are unhappy with how your child/the child you care for's personal data has been used, please contact the University's Data Protection Officer at dataprotection@uea.ac.uk in the first instance.

(15) OK, I am happy for my child to take part – what do I do next?

You need to fill in one copy of the consent form and sign it electronically (using Microsoft Word) and return via email to lauren.whiting@uea.ac.uk. Please keep the letter, information sheet and the second copy of the consent form for your information.

(16) Further information

This information was last updated on 23rd March 2025.

If there are changes to the information provided, you will be notified by email

This information sheet is for you to keep

ETH2425-1353

One Drive on a password protected laptop. Only Lauren Whiting and Dr Christopher Clarke will have access to the data. The overall results of the study will be written up into a thesis and submitted as part of the Educational Psychology Doctorate that the researcher is undertaking at UEA. Your young person's data and information will only be used as outlined in this Participant Information Sheet. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy. The information you provide will be stored securely and your child/the child you care for's identity will be kept strictly confidential, except as required by law. Study findings may be published and may also be used for other scholarly and educational purposes such as in teaching, but you will not be identified if you decide to participate in this study. The data will be kept for at least 10 years beyond the last date the data was used. The study findings may be deposited in a repository to allow it to facilitate its reuse. The deposited data will not include your name or any identifiable information about you.

Your child/the child you care for's personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Data management will follow the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's [Research Data Management Policy](https://www.uea.ac.uk/research-data-management-policy).

Your child/the child you care for's information will be stored securely and their identity will be kept strictly confidential, except as required by law. Study findings may be published and may also be used for other scholarly and educational purposes such as in teaching, but your child/the child you care for will not be identified if you and your child/the child you care for decide to participate in this study. The data will be kept for at least 10 years beyond the last date the data were used. The study findings may be deposited in a repository to allow it to facilitate its reuse. The deposited data will not include your child/the child you care for's name or any identifiable information about your child/the child you care for.

(10) What if we would like further information about the study?

When you have read this information, Miss Lauren Whiting (lauren.whiting@uea.ac.uk) will be available to discuss it with you further and answer any questions you may have about the study.

(11) Will my child be told the results of the study?

You and your child/the child you care for have a right to receive feedback about the overall results of this study.

You can tell us that you wish to receive feedback by email. This feedback will be in the form of a one-page lay summary in July 2025, once the research is complete, if your young person wants this. You will also be able to read the full thesis, should you want to, once it becomes available. The researcher will email you to notify you when this is possible.

(12) What if I have a complaint or any concerns about the study?

If there is a problem, please let me know. You can contact me via the University of East Anglia at the following address:

Miss Lauren Whiting
 School of Education and Lifelong Learning
 University of East Anglia
 NORWICH NR4 7TJ
lauren.whiting@uea.ac.uk

Or my supervisor, Dr Christopher Clarke, UEA Academic Tutor (christopher.d.clarke@uea.ac.uk).

ETH2425-1353

PARENTAL/GUARDIAN CONSENT FORM (First Copy to Researcher)

I, _____, [PRINT PARENTS/GUARDIAN'S NAME], consent to my child/the child I care for _____, [PRINT CHILD'S NAME] participating in this research study.

In giving my consent, I state that:

- I understand the purpose of the study, what my child/the child I care for will be asked to do, and any risks/benefits involved.
- I have read the Parental/Guardian Information Sheet and have been able to discuss my child/the child I care for's 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 my child/the child I care for does not have to take part. My decision whether to let them take part in the study will not affect our relationship with the researchers or anyone else at the University of East Anglia now or in the future.
- I understand that my child/the child I care for can withdraw from the study at any time.
- I understand that my child/the child I care for may stop the interview at any time if they 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 results. I also understand that my child/the child I care for may refuse to answer any questions they don't wish to answer.
- I understand that the results of this study will be used in the way described in the information sheet.
- I understand that personal information about my child/the child I care for 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 my child/the child I care for will only be told to others with my permission, except as required by law.

I consent to (please tick yes or no):

Audio-recording of my child/the child I care for	YES	☐	NO	☐
Video-recording of my child/the child I care for	YES	☐	NO	☐
My child/the child I care for reviewing transcripts following the interview	YES	☐	NO	☐
I confirm that my child/the child I care for meets all elements of the inclusion criteria, inclusive that my child/the child I care for is aware of their FASD diagnosis.	YES	☐	NO	☐
I consent to being present during this interview if my child/the child I care for consents to this, to support with mediating language and supporting my child/the child I care for to access the activities and interview if required.	YES	☐	NO	☐
I understand that my parental/carer views will not be gathered as part of this research as the focus is on the voice of the child.	YES	☐	NO	☐
Would you like to receive feedback about the overall results of this study?	YES	☐	NO	☐

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.....
Signature

.....
PRINT name

.....
Date

ETH2425-1353

PARENTAL/GUARDIAN CONSENT FORM (Second Copy to Keep)

I, [PRINT PARENT'S/GUARDIAN'S NAME], consent to my child/the child I care for [PRINT CHILD'S NAME] participating in this research study.

In giving my consent, I state that:

- I understand the purpose of the study, what my child/the child I care for will be asked to do, and any risks/benefits involved.
- I have read the Parental/Guardian Information Sheet and have been able to discuss my child/the child I care for's 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 my child/the child I care for does not have to take part. My decision whether to let them take part in the study will not affect our relationship with the researchers or anyone else at the University of East Anglia now or in the future.
- I understand that my child/the child I care for can withdraw from the study at any time.
- I understand that my child/the child I care for may stop the interview at any time if they 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 results. I also understand that my child/the child I care for may refuse to answer any questions they don't wish to answer.
- I understand that the results of this study will be used in the way described in the information sheet.
- I understand that personal information about my child/the child I care for 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 my child/the child I care for will only be told to others with my permission, except as required by law.

I consent to (please tick yes or no):

Audio-recording of my child/the child I care for YES ☐ NO ☐

Video-recording of my child/the child I care for YES ☐ NO ☐

My child/the child I care for reviewing transcripts following the interview YES ☐ NO ☐

I confirm that my child/the child I care for meets all elements of the inclusion criteria, inclusive that my child/the child I care for is aware of their FASD diagnosis. YES ☐ NO ☐

I consent to being present during this interview if my child/the child I care for consents to this, to support with mediating language and supporting my child/the child I care for to access the activities and interview if required. YES ☐ NO ☐

I understand that my parental/carer views will not be gathered as part of this research as the focus is on the voice of the child. YES ☐ NO ☐

Would you like to receive feedback about the overall results of this study? YES ☐ NO ☐

ETH2425-1353

.....
Signature

.....
PRINT name

.....
Date

Appendix R

Adapted Child Friendly Information Sheet and Consent Forms



University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
Email: lauren.whiting@uea.ac.uk

[14th August 2025]

What are the Educational Experiences of Children and Young People (CYP) with a Diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in Secondary Education Settings in the UK

Study Information Sheet



Hello. My name is Lauren Whiting, and I am a Trainee Educational Psychologist/Post Graduate Researcher at the University of East Anglia.

I am doing a study to find out more about the experiences of children with a diagnosis of **Fetal Alcohol Spectrum Disorder (FASD)** in secondary school and what they like about school.

I am asking you to be in my study because you are in Year 8, 9, 10 or 11 at a secondary school and have a diagnosis of FASD. I need your help because I am hoping to better understand how children and young people with FASD experience education and the things which help you in school. Therefore, you have been invited to take part in this research to share your experiences about school.

You can decide if you want to take part in the study or not, it's up to you.

This sheet tells you what I will ask you to do if you decide to take part in this study. Please read it carefully or ask an adult you trust to help you. Your parent or carer has received an information sheet too, so they can help you understand. I've also made a video about the study

(https://drive.google.com/file/d/1Pscub7WkxHfuz0VoxlujzyvKxaTheWn3/view?usp=share_link)

If you decide you want to be in the study and then you change your mind later, that's ok. All you need to do is tell me that you don't want to be in the study anymore. You can do this anytime during the interview and if after the interview you decide you don't want your data to be used, you can remove it up until the point it has been anonymised (your name and all information about you taken out). Due to the anonymised data, it will not be possible to identify your answers and remove them after this point. Your parent/carer can email me at lauren.whiting@uea.ac.uk if you want to remove your data after the interview.

If you have any questions you can speak to me during the study or your family/carer.

What will happen if I say that I want to be in the study?

- I will invite you to come to an interview.
- The interview will happen online on Microsoft Teams. I will be at home on my laptop and you will be in a place that you know and feel comfortable in (likely your home) on a device you can use such as a laptop.
- An adult you know well and trust will be with you during the interview to help you if you need it.
- I will ask you some questions about school.

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Are there any good things about being in the study?



- This study will help the voice of people like you be heard!
- This study will help people to understand the experiences of young people with FASD in secondary schools and the things which can be supportive in school.
- You might find it useful to think about the positive times you have had in school.
- You won't get anything for being in the study, but you will be helping me do my research.

Are there any bad things about being in the study?



- This study will take up some of your time.
- Sometimes, you might find it tricky to explain your answers- that is why I will offer you different ways of sharing your views such as card sorting or drawing.
- If you don't enjoy school, some questions about your experiences might be tricky to answer.

Will you tell me what you learned in the study at the end?

Yes, I will if you want me to. There is a question on the next page that asks you if you want me to tell you what I learned in the study. If you circle Yes, when I finish the study, I will tell you what I learned.

What if I am not happy with the study or the people doing the study?



If you are not happy with how I am doing the study or how I treat you, then you can tell me during the study or someone who looks after you can:

- Email me lauren.whiting@uea.ac.uk
- Contact my supervisor Christopher.D.Clarke@uea.ac.uk
- Email my Head of School Y.Lebanu@uea.ac.uk

How do I know that this study is ok to take part in?



All research I undertake is checked and approved by an Ethics Committee at the University of East Anglia before I can start it.

What if I want to know more about the information collected on me in the study?



When we talk in the study, I will collect some information which is unique to you. I can only collect this information if I have a reason to do so. My reason to do so for this study is because the study is in the public interest.

This information is stored by me within the University of East Anglia. They help me protect your information and look after it.

If you want to know more about the information collected about you, your parent/carer can email me lauren.whiting@uea.ac.uk or they can email the University's Data Protection Officer (dataprotection@uea.ac.uk) who helps to protect your information. The Information Commissioner's Office

ETH2425-1353

- If these are tricky to answer, I will give you some activities to choose from which may help you to tell me about school. This might be sorting some cards with pictures on them about school or doing some drawings about school. You can decide which activities you want to take part in and can stop at any time.
- Some questions and activities will be about your positive experiences in school, this means things you like or enjoy or that helped you to learn. We will also consider the things which are more challenging if you want to talk about them.
- When I ask you questions, you can choose which ones you want to answer. If you don't want to talk about something, that's ok. You can stop talking to me at any time if you don't want to talk to me anymore.
- You will be with me for about an hour and can stop the interview whenever you want to and can have as many breaks as you need to.

If you say it's ok, I will record what you say with an audio recorder.

If you say it's ok, I will make a video of our interview with a video recorder.

Will anyone else know what I say in the study?



I won't tell anyone else what you say to me, except if you talk about someone hurting you or about you hurting yourself or someone else. Then I might need to tell someone outside of the study to keep you and other people safe.

All the information that I have about you from the study will be stored in a safe place and I will look after it very carefully. I will write a report about the study and show it to other people, but I won't put your name in the report, and no one will know that you're in the study. I may also share your information with other researchers and use it for teaching and outreach purposes, but I will take out your name.

You may choose to do some drawings in the interview, if it is ok with you, I may ask you to show me these on the laptop screen so I can understand them a bit better. Once we have finished, if it is ok with you, I will ask your parent/carer to share any drawings with me using a link I send them so I don't forget what you shared with me during our conversation. If you say it's ok, I will include pictures of the other activities we did when I write up the interview.

How long will the study take?



- The interview will take roughly an hour to complete, depending on how much information you want to share with me.
- You are welcome to have a break whenever you need one.
- At the end of the interview, your parent/carer will be sent a copy of the transcription (our conversation recorded in words) and offered to check that it is what you thought it would be, this is up to you if you want to do this. You can do this in your own time, and you will have 5 days to complete it and send me any feedback if you choose to.

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(ICO) helps to protect everyone's information. If you are unhappy with mine or the University Data Protection Officer's responses about your information, you can speak to the [ICO](https://ico.org.uk).

Further information



This sheet was last updated on 23rd May 2025. I will update you if I make any changes to this sheet.

This information sheet is for you to keep.

ETH2425-1353

Participant Consent Form (First Copy to Researcher-send via parent/carer)

If you are happy to be in the study, please:

- write your name in the space below.
- sign your name at the bottom of the next page.
- put the date at the bottom of the next page.

You should only say 'yes' to being in the study if you know what it is about, and you want to be in it. If you don't want to be in the study, don't sign the form.

I, [PRINT NAME], am happy to be in this research study.

In saying yes to being in the study, I am saying that:

- ✓ I know what the study is about.
- ✓ I know what I will be asked to do.
- ✓ Someone has talked to me about the study.
- ✓ My questions have been answered.
- ✓ I know that I don't have to be in the study if I don't want to.
- ✓ I know that I can pull out of the study at any time if I don't want to do it anymore and it will be possible to remove any information I have already provided up until the information is anonymised.
- ✓ I know that I don't have to answer any questions that I don't want to answer.
- ✓ I know that the researchers won't tell anyone what I say when I talk to them unless I talk about being hurt by someone or hurting myself or someone else.
- ✓ I know that an adult I trust will need to be with me during the interview.

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Now I am going to ask you circle 'Yes' or 'No' to tell me what you are happy to do or not do in the study.

Are you happy to speak to me ?	Yes	No
Are you happy for me to take a video of our interview on Teams?	Yes	No
Are you happy for me to audio record your voice?	Yes	No
Are you happy to have your parent/carer present during the interview to support you if you need it?	Yes	No
Are you happy to share the activities you complete on the screen during the interview and for your parent/carer to share these with me after the interview?	Yes	No
Are you happy for me to use images of the activities we did on the screen when I write up our conversation ?	Yes	No
Are you happy to look at a copy of our conversation to make sure it captures your views accurately? I will send this to your parent/carer after the meeting.	Yes	No
Do you want me to tell you what I learned in the study?	Yes	No

Signature

Date

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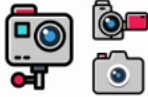
Information Sheet containing more visuals if required

Research Project Title: What are the Educational Experiences of Children and Young People (CYP) with a Diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in Secondary Education Settings in England/UK

Name of researcher: Lauren Whiting

	My name is Lauren, and I am training to become an Educational Psychologist. This means that I work with lots of young people just like you and help them with <u>their</u> learning in school.
	I want to find out about how children like you feel about school.
	If you would like to take part, this is what will happen.
	I will meet with you and the person who cares for you on the computer and will ask you some questions about school.
	I will be at my house, and you will be in your house (or somewhere you feel comfortable) with an adult you trust there to help you if needed
	If the questions are hard to answer, we may complete some activities like drawing or sorting cards to help you share your views.

ETH2425-1353

	If there are any questions you are unsure of or don't want to answer, you don't have to answer them.
	If it is ok, I will record a video of what we talk about so that I can use it to remember what we spoke about.
	After the meeting, you can check the written copy of our conversation if you would like to, to see if it says what you were expecting. You don't have to do this if you don't want to
	What you say will be kept safe until I have written it up for my <u>University</u> project and then it will be deleted.
	I won't tell anyone else what you say to me, except if you talk about someone hurting you or about you hurting yourself or someone else. Then I might need to tell someone outside of the study to keep you and other people safe.
	I might use some of what you say for my university project. But I will not use your name. I will use a made-up name instead.

ETH2425-1353

Participant Consent Form with reduced language

Please read the following and circle YES or NO....



I have read the participant information or have had it read to me	YES	NO
I know what the study is about.	YES	NO
My questions have been answered.	YES	NO
I know what I will be asked to do.	YES	NO
I agree to what I say being videoed and recorded	YES	NO
I know that at the end of the interview I can check what has been recorded through a copy sent to my parent/carer	YES	NO
I know that I don't have to be in the study if I don't want to.	YES	NO
I know that I can stop the interview at <u>anytime</u> and the information will be deleted	YES	NO
I know that I can choose not to answer questions if I do not want to, I can ask to skip to the next question	YES	NO
I know that I can decide not to take part at all	YES	NO
I know that I can ask to have a break at any time	YES	NO
I understand that what I say will be kept in a safe place and will be deleted when it has been written up	YES	NO
I know that the researchers won't tell anyone what I say when I talk to them unless I talk about being hurt by someone or hurting myself or someone else.	YES	NO
I know that I can have an adult I trust with me to help if I want to.	YES	NO
I would like to take part in this study	YES	NO
I am happy to have the activities I do shared on the screen and shared with the researcher after the meeting.	YES	NO
I am happy for pictures of my activities to be in the write up.	YES	NO
Do you want me to tell you what I learned in the study?	YES	NO

Name.....

Date.....

Appendix S

Debrief Forms

Parent/Carer Debrief Form



University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email:
lauren.whiting@uea.ac.uk

Thank you for consenting for your child/child you care for to participate in my research exploring the educational experiences of children with FASD in secondary schools in the UK. Hopefully, this research will inform professionals and others' knowledge of the educational experiences of children and young people affected by prenatal alcohol exposure. Greater knowledge will therefore hopefully result in more informed support and potentially benefit other children having similar experiences.

Your child's/child you care for responses within the semi-structured interview will now be transcribed and any form of identifying information will be omitted or pseudonymised for the purpose of publication. Once the recordings have been transcribed, they will be destroyed. Once the data has been analysed, I will endeavour to send you a summary of the research and the main findings if this would be of interest to you?

If you have any questions, please do not hesitate to contact myself (lauren.whiting@uea.ac.uk) or my research supervisor (Christopher.D.Clark@uea.ac.uk).

For further support and advice, the following websites have some useful resources and support services

National Organisation for FASD (NO-FAS) <https://nationalfasd.org.uk/helpline-contact/>

FASD Awareness <https://www.fasdawareness.org.uk/services>

Lauren Whiting

Trainee Educational Psychologist, University of East Anglia

Dr Christopher Clarke

Academic Tutor, University of East Anglia



University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ

Email:
lauren.whiting@uea.ac.uk

Participant Debrief Letter



Thank you so much!

Thank you for sharing lots of information about your experiences at school and for being involved in my research. Hopefully sharing your experiences will help others learn more about how to make school better for children with FASD.

You helped me:



- Understand about your experiences at school.
- Understand what helps make school a positive experience and what supports you in school.



We spoke about this in the session together but just to remind you that I recorded what you told me and will keep this information safe. I will use what you have said to help me with my University project and then it will be deleted. No one will know who said the information because I won't use your name or your school's name.



If you are feeling worried about anything you said, or are upset by any of the questions asked, please let me or a grown up that looks after you know. You can also contact me, and I will help you to find a service that can help you with these feelings or worries. My email address is lauren.whiting@uea.ac.uk. If you need to contact my supervisor, their email address is Christopher.D.Clark@uea.ac.uk.

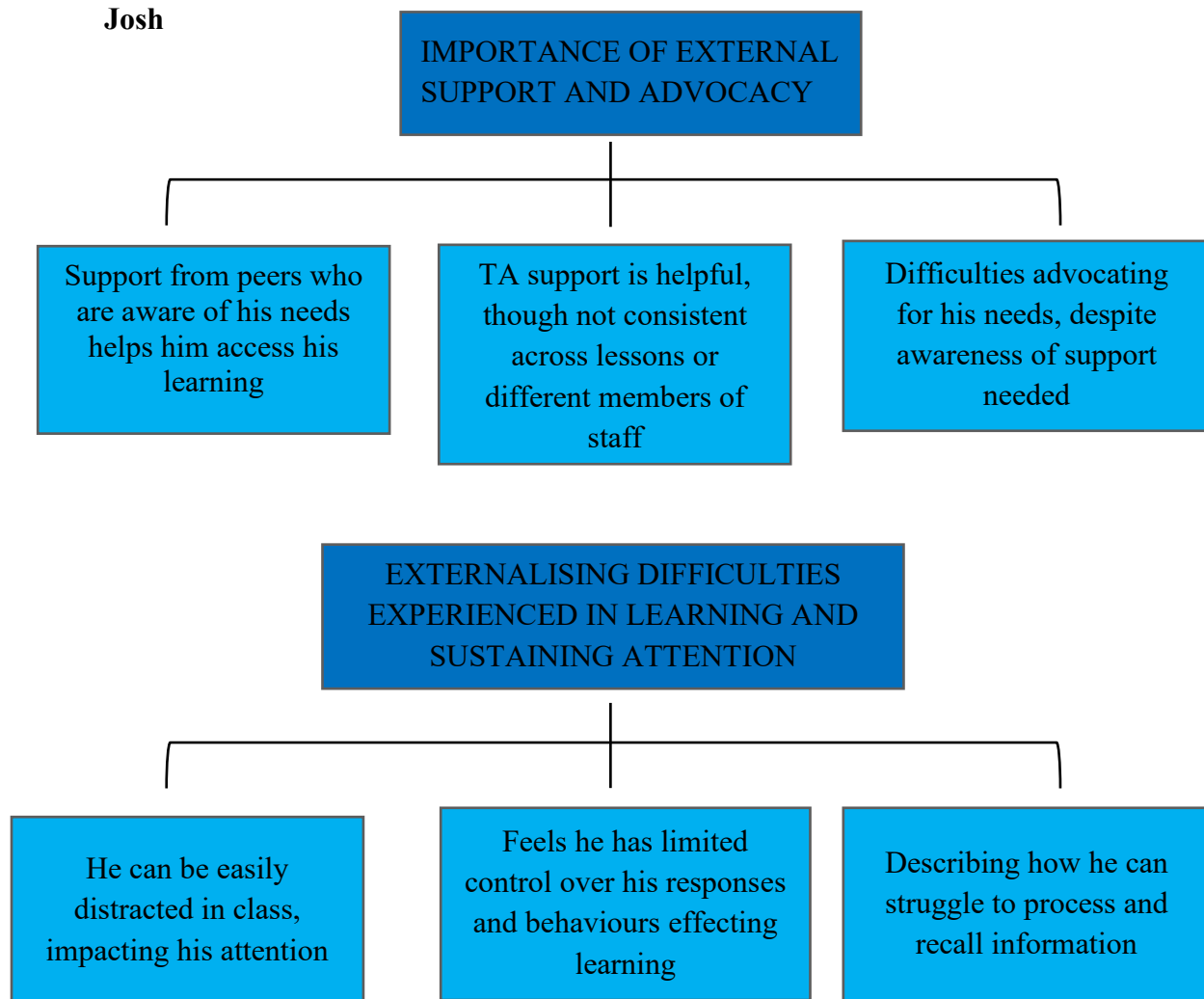


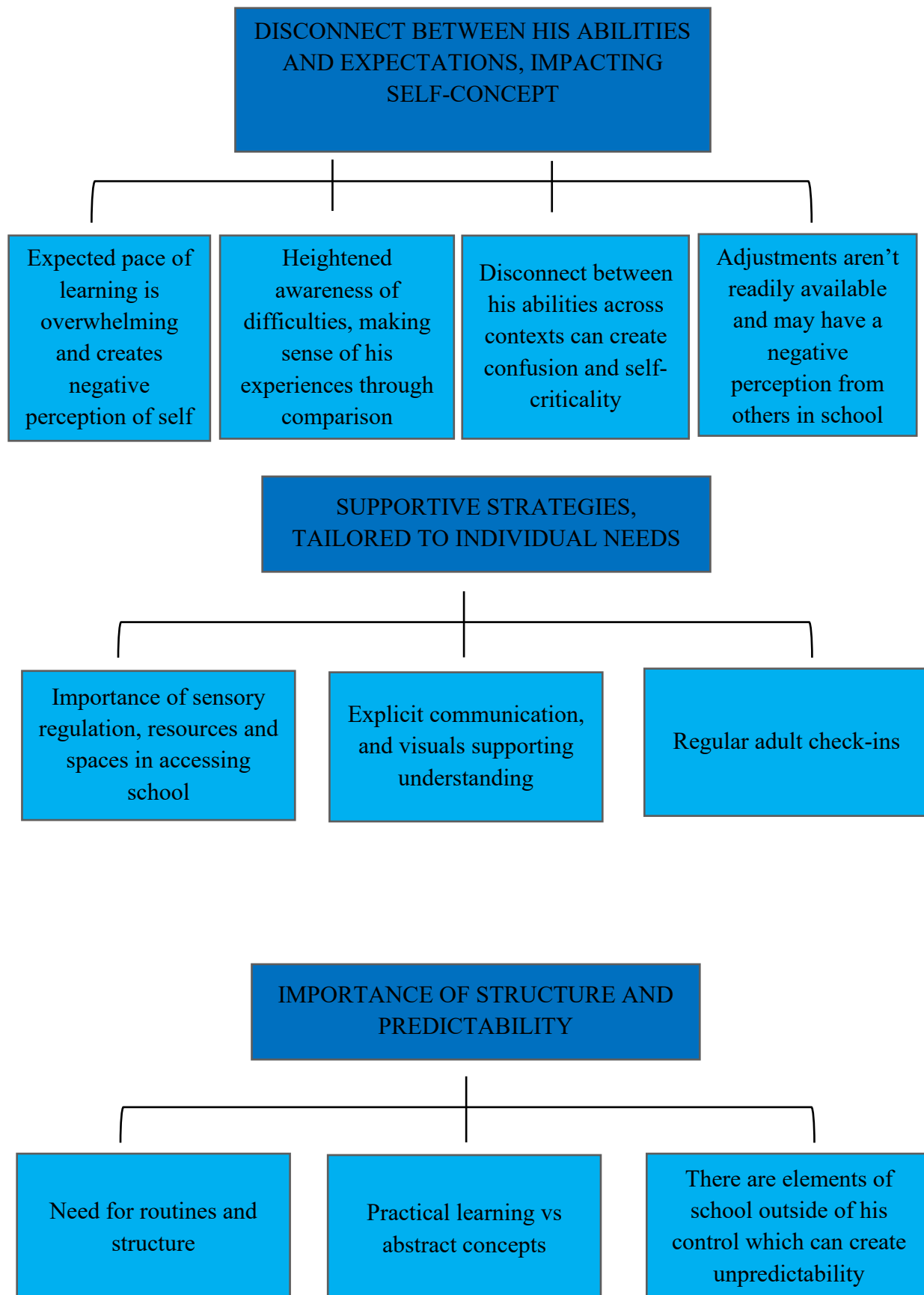
Thank you

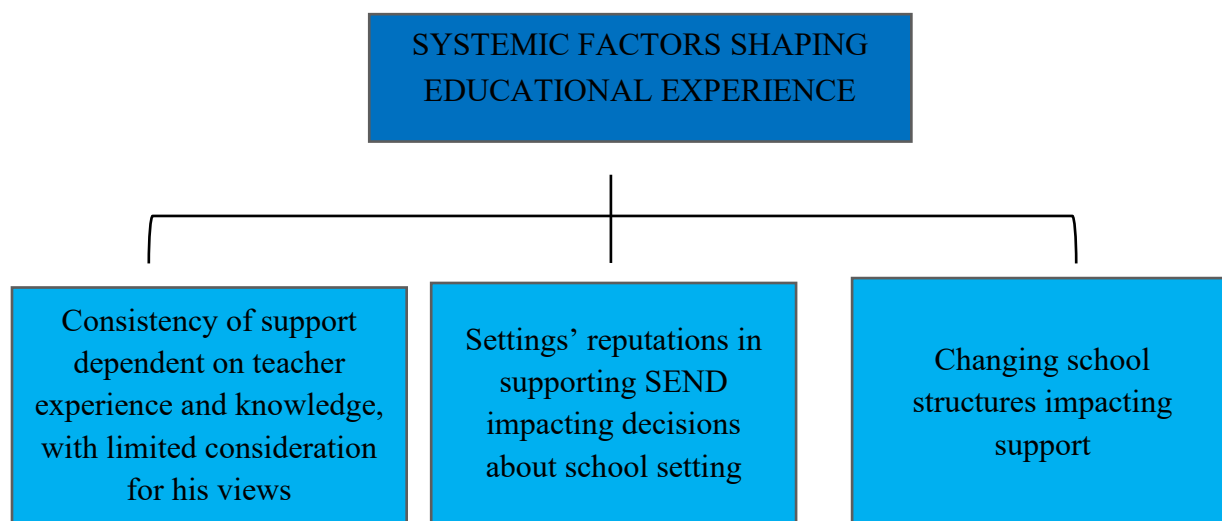
Appendix T

Thematic Map for Personal Experiential Statement for Each Participant

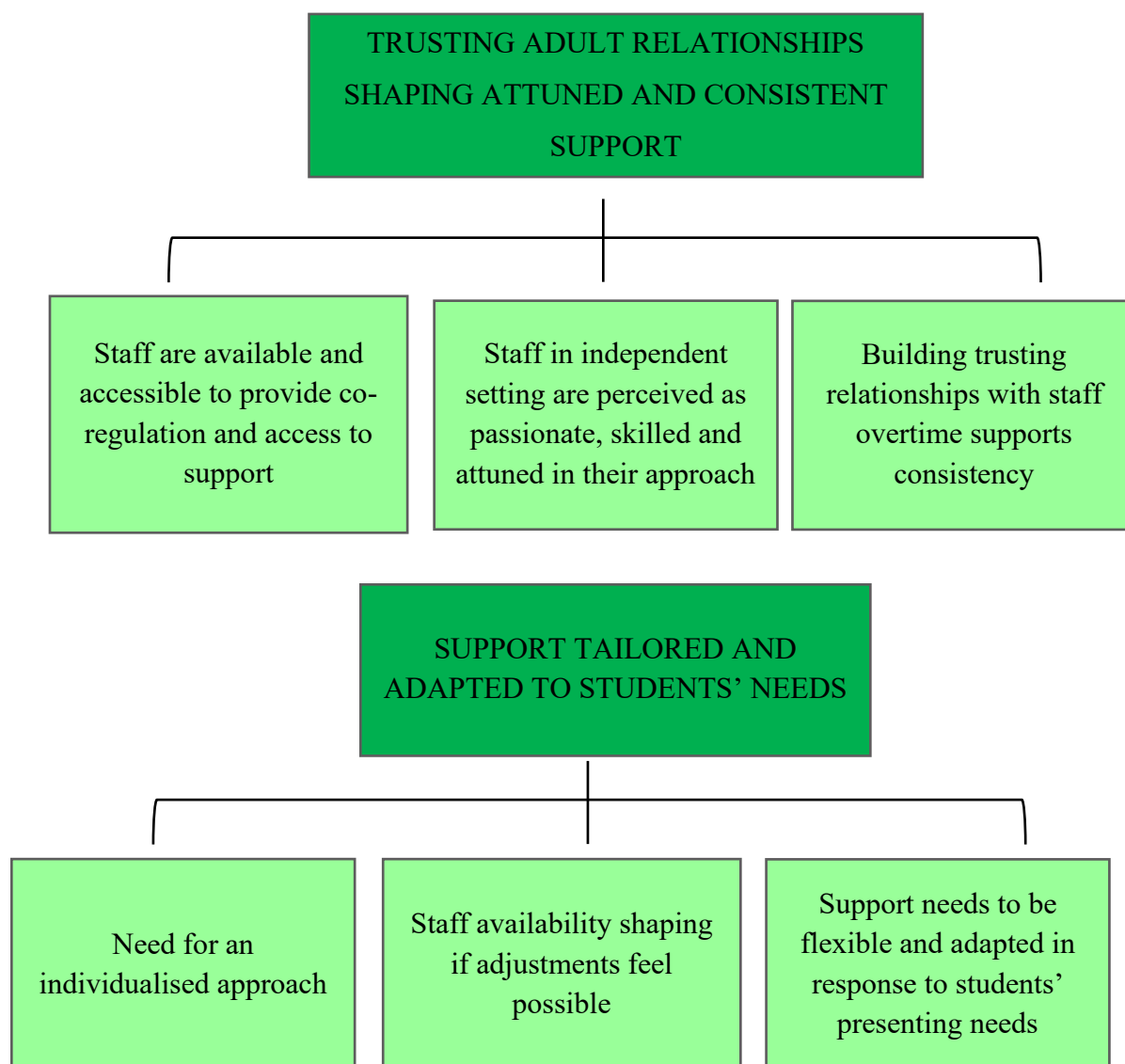
Josh

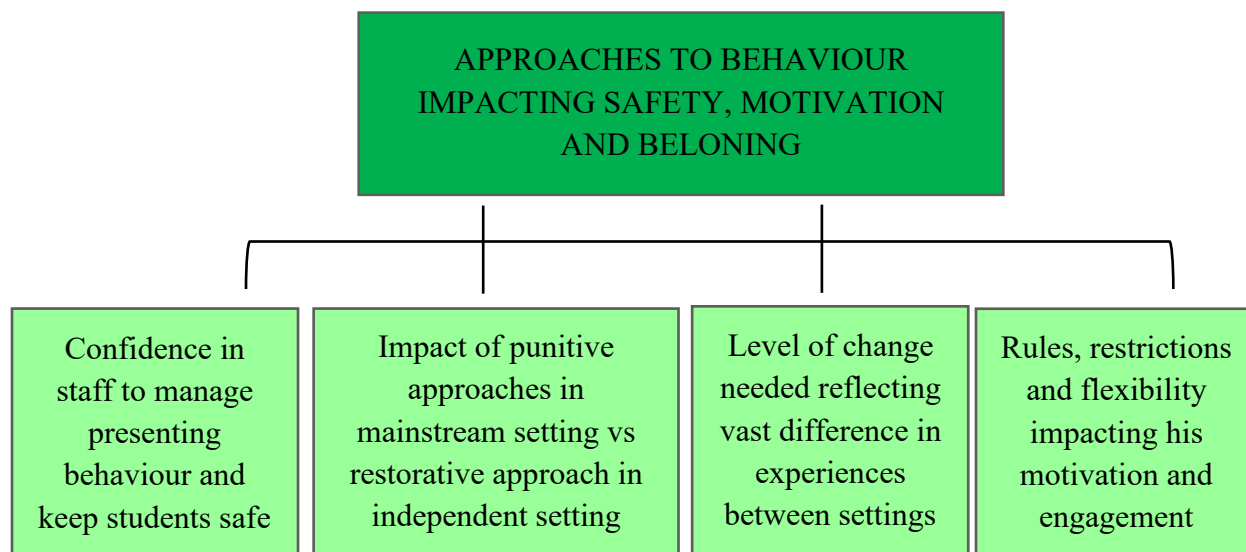
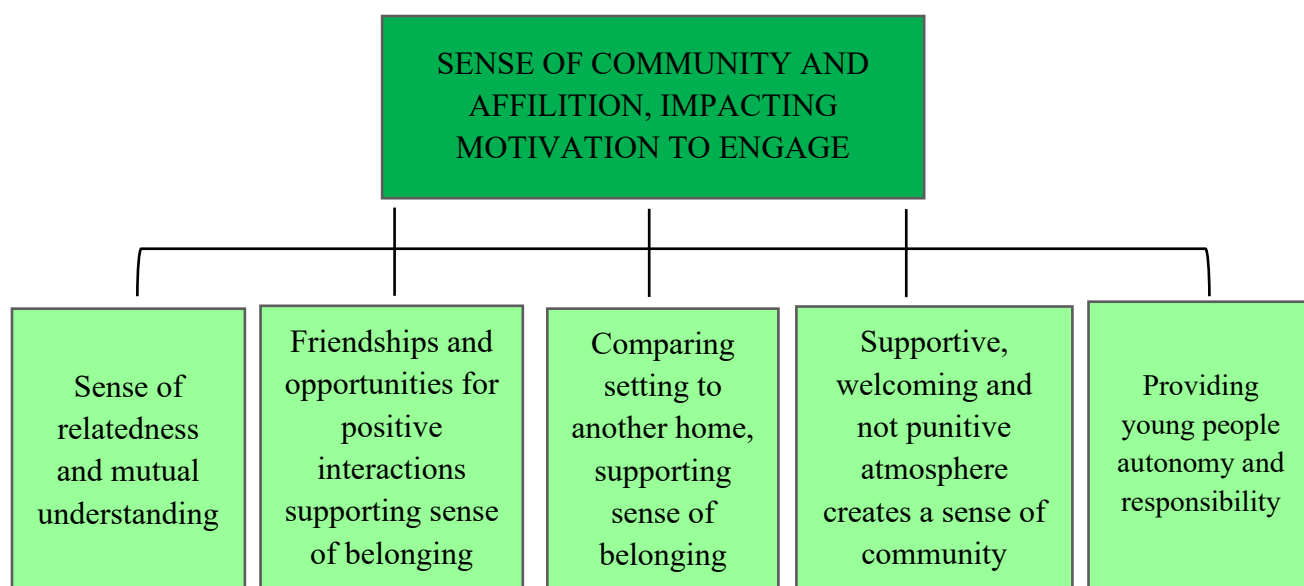
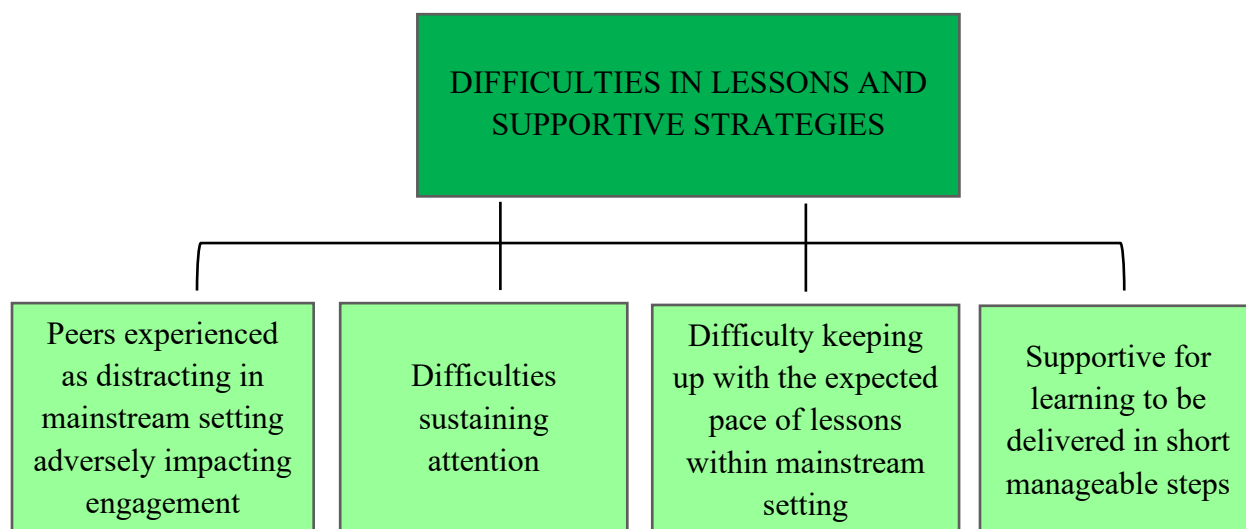


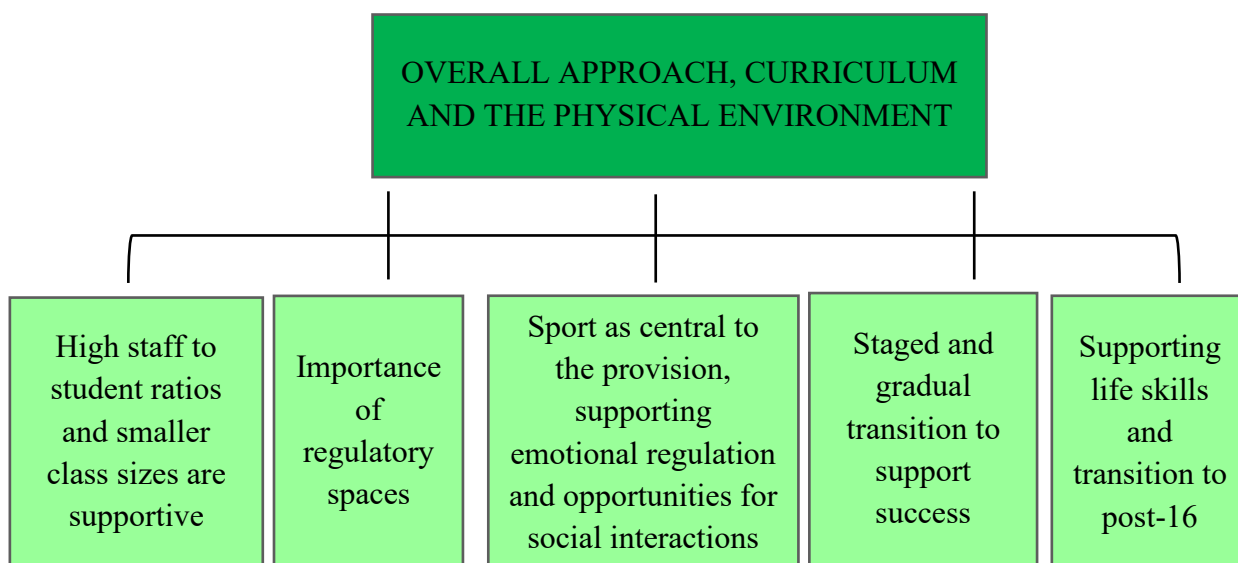




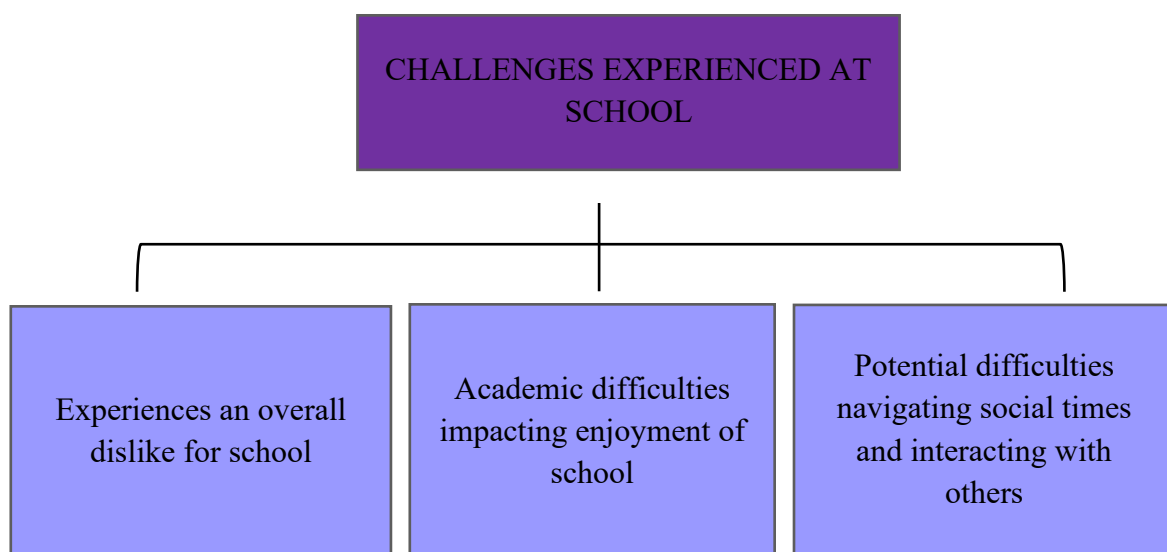
Oscar



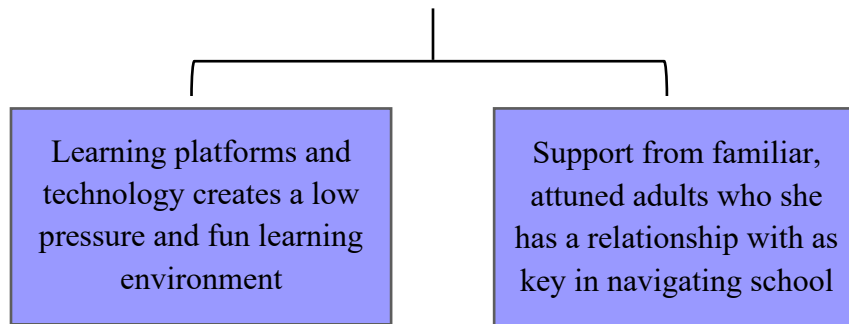




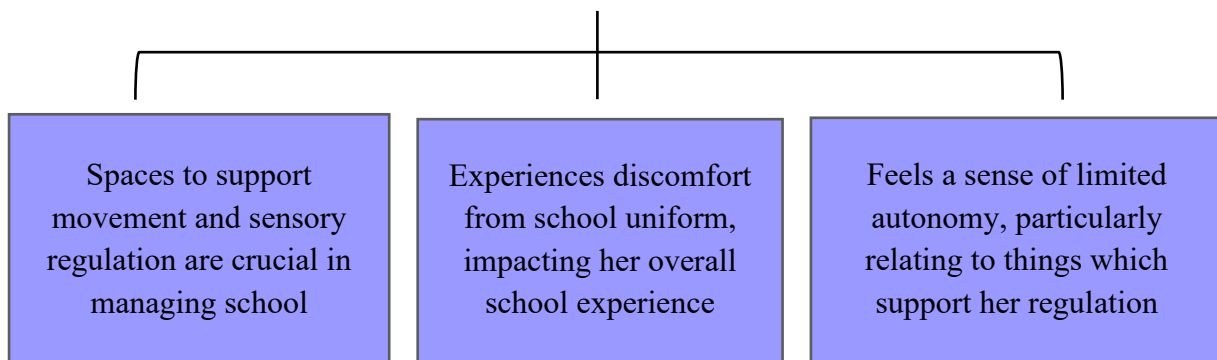
Lily



SUPPORTIVE ADULTS AND FUN IN LEARNING AS PROTECTIVE

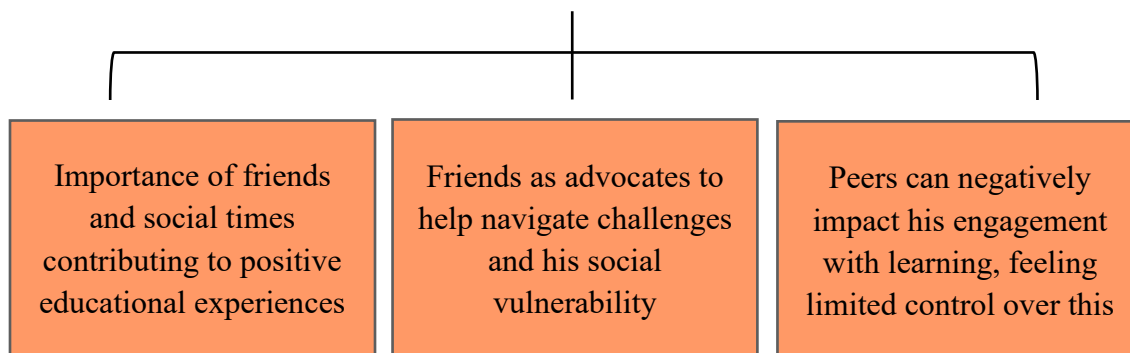


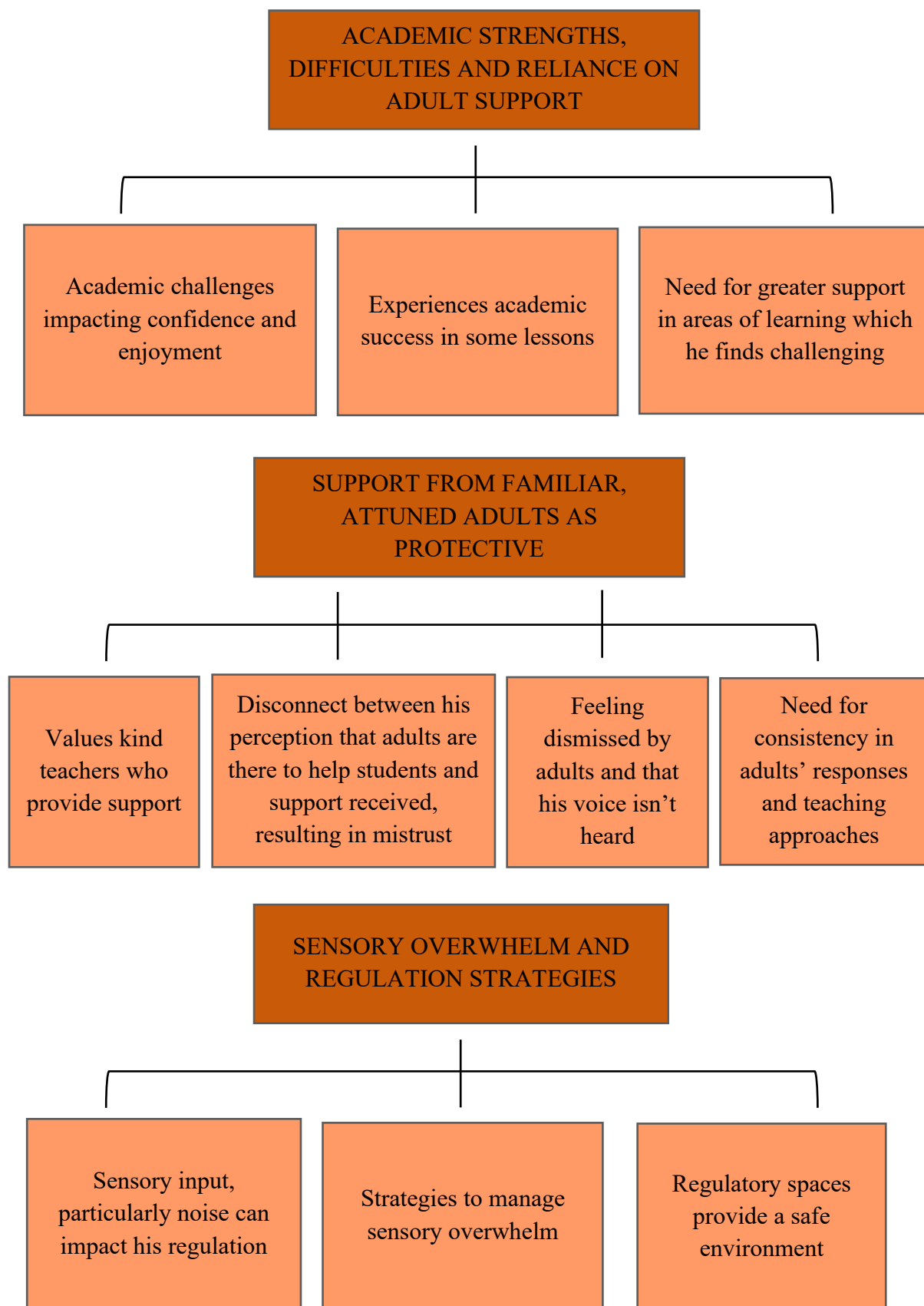
SUPPORT FOR SENSORY AND EMOTIONAL REGULATION SHAPING EDUCATIONAL EXPERIENCES



Thomas

FRIENDS AS PROTECTIVE, PEERS AS A SOURCE OF DISTRACTION AND ANNOYANCE





Appendix U

Example Research Diary Entries During Recruitment

13th August 2025- A POTENTIAL PARTICIPANT!

Today started with an email from a mother a young person due to transition to Year 9 in September 2025 in a mainstream setting, who is interested in taking part in this project. I feel today marks an important part of this research journey and while this young person is not a confirmed participant and has not formally consented, this is a breakthrough in what has been a long wait for participant responses. I feel ecstatic that the project may be possible and feasible after all and feel grateful this young person has shown their interest in the project.

14th August 2025 Supervision

Following feedback from my gatekeeper and the FASD community, we are extending the participant criteria to include specialist settings and specialist units, not just mainstream settings. This is justified as feedback highlights often by secondary school, these CYP have received a diagnosis, resulting in additional support through EHCPs and often specialist placements. We discussed how this does not change gatekeepers, recruitment strategy or methodology it just changes wording in forms (e.g. consent, debrief etc.), the recruitment poster and the project title/question wording (amended versions of wording attached). The amended wording throughout the application is highlighted within the attached ethics download from previous submission.

We have agreed that if I only receive 2 participants, it may be that I do a narrative inquiry. If I get to October and still have no participants, the project may adapt to include parental perspectives through reflective thematic analysis (see supervision notes for rationale, ontology and epistemology and literature search changes to include teacher perspectives).

November 7th Supervision

Currently I have one interview completed! And 4 potential participants potentially consenting to take part. We discussed how I currently feel frustrated relying on other people and lacking confidence about whether I can recruit enough participants and rich enough data for IPA and thesis requirements. X and I spoke about the complexity of recruiting these young people but how I want to stay true to my values of the research, amplifying CYP's voice as this is so under

presented in research. We discussed the use of thematic analysis, however the number of participants I have for CYP would not be enough for a competent thematic analysis.

21st November- Interview two

Today I conducted my second interview with a young person with FASD. I left this interview feeling lighter and with a reignited passion as to why am I doing my research and feel so passionately about amplifying these young people's voices. This interview was a unique experience because the young person had attended a mainstream secondary school for year 7-8 and transitioned to an independent specialist for Y9. He was therefore able to make clear comparisons between the support offered at each setting and how this impacted his sense of belonging, feelings of safety and motivation to attend school and do well. His responses about his experiences provided real hope about what works for these young people and therefore elements which could be reflected in mainstream as they were often simplistic such as adults being caring and passionate about their role. The feedback from his mum demonstrated the importance and appreciation for the research in raising awareness and amplifying these young people's voices! Despite recruitment challenges, this demonstrated why I keep trying!

Appendix V

Copyright permission from Canadian Medical Association Journal

RE: Thesis Figure Permission

Start reply with:

Warning: This email is from outside the UEA system. Do not click on links or attachments unless you e
sender and know the content is safe.

Hello Lauren,

You have the CMAJ's permission to use the 2 figures in your thesis.

Best,
Isabelle

Isabelle Laurendeau

Business Development Manager, CMAJ Group
Développement de l'entreprise, Le Groupe JAMC

500-1410 Blair Towers Place / 500-1410, place des tours Blair
Ottawa ON K1J 9B9

C (613) 325-5600