# Primary Caregiver's Experiences of School Accessibility for Neurodivergent Children.

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**Submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology**

**Date 17th August 2025**

# ACKNOWLEDGEMENTS

I would firstly like to acknowledge and thank all twelve participants who generously gave their precious time, emotions and energy to share their experiences and join me in interviews. The stories you have shared will undoubtedly remain with me, though I am saddened to have met under these often harrowing experiences, it has been a privilege to have met you. There is so much that each and every one of you has offered, to which I am truly touched. I hope this research continues to offer some support and I hope that other parents reading this know that they are not alone.

I would like to thank Barbara for the endless support and constant cheerleading throughout these years. Thank you so much for all the empowerment you encouraged me to build, for your time, wisdom, humour, and authenticity. But mostly, thank you for having confidence in me when I struggled, and reminding me that I would get here. I have been blessed to have you as a supervisor throughout this research and DCLIN journey. I would also like to thank Jodie for the passion and advocation throughout this project, it has been a joy working with you. I am so grateful to have been supervised by you, thank you for your kindness and understanding when I felt overwhelmed. I would like to thank Lizette, for her knowledge in methodologies, and particularly for her patience whilst I was in the journey of learning. To Eliza, thank you for your wonderful illustrations, all of your advice and time you have shared with me.

I would like to thank the trainees that have kept me sane on this insane journey. Thank you for all of your endless support, kindness, understanding, humour and light you have brought. There is no one else I would rather have done this with. I am so grateful to have made friends for life.

I would like to thank all of my friends outside of the course. Thank you for your understanding and kindness whilst I have endured this journey. I am blessed to have you all in my life. Thank you for the pockets of hope and encouragement. Thank you T, for your guidance and cheer.

Thank you to my family, for your support and endless love throughout my entire Psychology career, helping me achieve my dreams. To Sunshine, thank you for letting me share parts of your journey, I am blessed to have you and Sea in my family. Thank you God for carrying me through, may the glory forever be yours.

Finally, thank you to my partner, I would like to thank you for your constant understanding, patience and support throughout this journey. Thank you for allowing me to just be within this journey and embracing the carnage that has come with it. Thank you for being by my side throughout.

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# ABSTRACT

In the UK, many neurodivergent individuals are unable to access school. Literature has highlighted this is often due to their needs being unmet within schools, and compounded by a lack of knowledge and understanding of neurodivergence in society as well as professionals and systems surrounding them. It is considered that many systems and structures were created for neurotypical individuals, therefore causing detrimental effects for neurodivergent individuals accessing them. Though research has started to explore children's voices, there is limited published research exploring the impacts on parents who are key stakeholders in this experience, often caught between their child and school systems with legal parental responsibilities ensuring they access school if enrolled. Therefore, this research aimed to explore parents' experiences and the impacts of "school non-attendance" in the context of having neurodivergent children. Semi-structed interviews were conducted with 12 parents whose neurodivergent children had experienced occasions of not being able to access and engage with school. Data was analysed using constructivist grounded theory methodology. A co-constructed theoretical model was developed with findings highlighting that children and their parents experiencing school non-attendance are often disempowered by the services surrounding them, including governmental, school and mental health systems. Parents experienced attacks, blame and were often dismissed by systems involved with their child. These experiences often led parents fighting for their child's legal access to provisions. Parents were seen to be "left holding everything" alone from how the systems responding, causing them to live in "chaos and uncertainty". All of these experiences significantly impacted parents' wellbeing and health, with many "losing" their previous life and identity. These findings have significant implications for mental health services, schools, policymakers and other external stakeholders that are involved in supporting children and their families in the context of school non-attendance.

# Chapter One: Introduction

## 1.1 Overview

Within the United Kingdom (UK), a significant number of neurodivergent individuals are currently unable to access mainstream schools or have their needs appropriately met (Connolly et al., 2023). These experiences cause distress for many individuals impacting on their education, confidence, mental wellbeing, and physical health (Lawrence, 2025). Whilst recent research has begun exploring the impact on CYP, there is limited research exploring the experiences and effects on parents despite being affected by their child and schools (Mullally & Connolly, 2025). This research aims to explore the processes that underpin parents' experiences and the impacts of their neurodivergent child being unable to access school. This chapter introduces and situates the researcher in relation to the topic area, offers key terminology used, and presents background literature that provides broader context to the topic and research.

## 1.2 Situating the Researcher

Within qualitative research methodologies, it is recognised that researchers are inseparable to research construction and analysis of data, consequently methodologies like Constructed Grounded Theory (CGT) utilise the researcher as a tool (Charmaz, 2014). It is therefore imperative to situate the researcher, and for the researcher to engage reflexively to consider how their values, positionings, beliefs, privilege, and context interact with this research as it is seen as a joint co-construction with participants (Bukamal, 2022; Dwyer & Buckle, 2009; Charmaz, 2014). Therefore, the researcher will now share their relationship to the research, some of their contexts and epistemological position.

### 1.2.1 Researcher's Relationship to the Research

I describe my relationship to neurodivergence as an ongoing journey, recognising that I am neurodivergent and still discovering myself, areas of need and strengths. Whilst many individuals and professionals questioned neurodivergence in my teenage years, it was not something I fully came to understand until my mid-twenties. In school, though there were times I struggled, I did attend and complete mainstream school. I believe that I got through school by masking at a cost, as well as from my family support and their push to learn outside of school settings. My relationship with neurodivergence and school non-attendance drastically changed when a close loved one, Sunshine[1], was unable to access school due to their needs not being understood or met, causing extensive schooling trauma for them, with effects felt throughout our family (see Appendix A).

These experiences have positioned me as an insider-outsider researcher[2]. In one sense, I may be grouped as an insider researcher as I am neurodivergent and seen a loved one experience school non-attendance connected with neurodivergence. However, I may be regarded an outsider researcher as I was able to attend mainstream school, I am not Sunshine's parent, and eventually Sunshine was re-integrated back into mainstream school, which is different to some participants' experiences within the research. Mason-Bish (2018), reflects that the insider and outsider positionalities are dynamic and constantly fluctuating depending on context. It was a dance that I found myself navigating throughout, where I was considered more of an insider to some and an outsider to others. The positioning also changed depending on other contexts such as my cultural background, gender, class etc. Due to the changing positioning as a researcher, it was helpful and important to engage in reflexivity and awareness (Bukamal, 2022).

Insider statuses hold many benefits such as being able to build rapport through mutual understanding, acceptance and respect, some participants may find that this increases how open they may feel to disclose (Gary & Holmes, 2020; Mason-Bish, 2018). However, there are also challenges to insider statuses; insider researchers may make assumptions, overlook details or place importance on views that align with their experiences (Gary & Holmes, 2020). Plus, participants may make assumptions about the insider researcher's knowledge consequently not sharing or elaborating as they may with an outsider researcher (Bukamal, 2022). Reflecting on my insider-outsider research position

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[1] To protect their identity, they will be referred to as Sunshine which is chosen for the light, energy and joy they bring into my life.

[2] An insider researcher is considered to share particular attributes with participants in the research, whilst an outsider researcher is thought to be "when they do not belong", by having different attributes to the group of participants (Bukamal, 2022).

allowed me to be mindful of my interactions and meaning making when in interviews, as well as remain curious when asking questions and receiving answers whilst reflecting afterwards. To be aware of my own beliefs and biases and increase the research's reliability, I engaged in a reflective journal throughout, consulted experts by experience, supervisory team, colleagues, and sought "member-checking". I hoped by engaging in such reflection, this would negate some drawbacks of being an insider-outsider researcher.

### 1.2.2 Epistemological Position

The epistemological position adopted was critical realist, this was considered most appropriate for the research and consistent with the researcher's values and understanding of how they make sense of the world and knowledge.

Critical realism contends that the evidence observed can "come close to reality" but is always fallible due to the subjectiveness of the account of reality (Sturgiss & Clark, 2020). The accounts of reality are constantly changing due to individual's beliefs, understanding, meaning-making and context, though this does not change that there is a state of an independent reality and existence of knowable truth (O'Mahoney, 2016; Sturgiss & Clark, 2020).

The current research aimed to explore how parents' and primary caregivers' experience and made sense of school non-attendance and accessibility in the context of their child being neurodivergent. A critical realist stance was appropriate to explore this as it acknowledges the reality of events, power structures and history that surround primary caregivers, whilst recognising that the experience is mediated by meaning making and social context[3].

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[3] As a critical realist, it meant that the researcher was not seeking to "discover" proof or empirical data but instead aimed to offer co-constructions of parents' and primary caregivers' experiences, whilst engaging in curiosity to explore the "how" and "why" and underlying processes and structures.

## 1.3 Terminology

It is important to note that these terms may change in time and with preferences, see Table 1[4].

Table 1 – Key Terminology

| Term | Definition |
|---|---|
| **Neurodivergence** | Describes: when someone's brain learns, processes and behaves different to what is considered "typical" or normative, these individuals are often considered as **neurodivergent** (Connolly et al., 2023). There are many different types of neurodivergences. These include but are not limited to: Autistic, Attention Deficit Hyperactivity Disorder (ADHD), Sensory Processing Disorder / Sensory Integration Disorder, Dyslexia, Dyscalculia, Dyspraxia, Auditory Processing Disorder, Language Disorder, Visual Processing Disorder, Intellectual Disability as well as others (Connolly et al., 2023). The term "neurodivergent" holds several gifts like, promoting individual's strengths and abilities, creating more inclusion and acceptance by challenging stigma (Metu, 2024); however, limitations include oversimplification creating misrepresentation and ambiguity. The term neurodivergence and neurodivergent was chosen for this research as it represented the various types of neurodivergences that this research aimed to speak to. The term neurodivergence was utilised as it also appreciated where individuals may have had several different neurodivergences, whilst ultimately encouraging inclusion and recognising individual's strengths. The language in the project was reflected on for several months with consultants, supervisors and also with the participants. |

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[4] The term CYP will be used through out to represent children and young people/persons.

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|---|---|
| **Parent and Primary Caregiver** | Describes: the relationships with children, whereby biological, adoptive and foster parents are defined as having legal or social responsibility for a child. Primary caregivers may or may not be the parents, though they are considered as the individuals who provide the majority of daily support and care for the child. For the purpose of this research, they will be grouped together and termed as "parent", recognising their roles unless otherwise stated by the individuals in this research that they would prefer a different title, this will then instead be used, such as 'adoptive mother'. |
| **School Non-Attendance (SNA)** | Will be used in this research to describe when neurodivergent individuals are unable to access school. It is important that this term accurately represents their experiences, therefore this research will use it to highlight that non-attendance is connected to accessibility rather than choice as prior research has suggested (Lissack & Boyle, 2022). School Non-Attendance will encompass prior key terms similarly used throughout history within the related contexts and meanings, these include: school distress, emotionally-based school avoidance, emotionally-based school non-attendance, school refusal and absenteeism. |

## 1.4 Relevant Literature and Context

### 1.4.1 Introduction to UK School System and Education

In the United Kingdom (UK), education is free and compulsory, it is underpinned by the Human Rights Act (1998) which states "No person shall be denied a right to education". There are several other legislations central to the majority of schooling models, like the Equality Act 2010, Education Act 1996 and 2011. In the UK, the government shape and influence all legislation that surround education, physical health, social care, mental health and policing sectors; the government distributes power and choses the importance given to each of these sectors[5].

Each nation has some autonomy to choose how much governmental control is present, modify policies, curriculum, ways of assessing ability, and the overall structure of schooling (Sibieta & Jerrim, 2021). Maratos et al., (2023), have critiqued this arrangement as the education system and policies were seen to change “at the whim of which political party was in power at the time”. There are different institutions created to support education within the nations: “The Department of Education and Skills” (DfE) for England, the “Welsh Office” for Wales, the “Scottish Executive Education Department” for Scotland and the “Department of Education” for Northern Ireland (Bint a Zafar et al., 2025).

Dependant on location within the UK, children start primary school aged 4 to 5.5, transition into a secondary school from the ages of 11-12, and finish school between ages of 16 to 18 (Sibieta & Jerrim, 2021). Some individuals in England and Wales may attend a junior school between primary and secondary (Sibieta & Jerrim, 2021). There are a variety of schools: community schools and foundation schools (typically local authority maintained though some can be supported by religious/faith groups), grammar schools, academy/free schools, and specialist schools.

#### *1.4.1.1 Curriculum and Examinations*

In terms of curriculum, England has adopted approaches that emphasise “traditional” subjects and has standardised minimum content expected to be learnt whereas other nations have strived to create areas of learning with general aims, mission statements linking the subjects (Sibieta & Jerrim, 2021). Excluding Scotland, all UK nations have set broadly similar national curriculums, with researchers critiquing that this has led to more narrowed curriculums overall, teaching to perform in tests rather than having broader skills and a culture that induces fear rather than support and enjoyment in learning (Perryman et al., 2023). Scotland and Wales recently reintroduced tests for younger years, after initially

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[5] Despite shared histories and overarching UK-wider legislation with a collective goal of providing education (Farquharson et al., 2024), the devolution of nations in 1999, meant there are current differences across the UK (Knight et al., 2025).

abolishing them for pressures they placed on students and teachers, Northern Ireland instead rely on teacher assessments of children's abilities rather than written tests, whereas England throughout have examined younger children (Sibieta & Jerrim, 2021).

#### *1.4.1.2 School's Autonomy*

Schools in England are argued to have the highest level of autonomy due to recent increases in academies/free schools which can differ in staff pay and the national curriculum, these schools account for 37% primary aged pupils and 87% secondary aged pupils, local authority maintained schools in England have similar autonomy levels as the budget responsibility is often given to the school headteachers to decide (Sibieta & Jerrim, 2021). In contrast, Wales have slightly less autonomy than England as local authorities have more control; in Scotland local authorities and government are significantly involved removing school individual autonomy, and in Northern Ireland all schools are managed by boards of governors (Sibieta & Jerrim, 2021).

#### *1.4.1.3 General School Structures*

The structures of schooling systems, particularly in England, have been criticised as rigid, outdated, and with an ethos prioritising performance-based testing and productivity (Maratos et al., 2023). Robinson and Aronica (2015) highlighted parallels between current education and schooling in the 1880s'[6]. Despite technological advances and different ways of sharing knowledge, pedagogical practices remain similar with teachers being the "transmitter of knowledge and the pupils' role to receive" (Maratos et al., 2023). Though curriculums are argued that they should encourage children's self-esteem, wellbeing, and relatability with others, there is a large focus predominantly on equipping them for future employment and productivity within an industrial-based economy (White, 2004; Cuban 2013). The performative accountability movement seen in schooling has been argued to derive from both United States of America (USA) and the UK (Hargreaves et al., 2023). Over time, this has placed pressure and importance on receiving an education in "traditional"

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[6] Including, the buildings used, set up of schools, structure of the day as well as term times in line with harvest seasons.

topics like English and Mathematics, which has been contended to lead to social injustice for many who cannot access these subjects or didactic teaching frameworks, leading to inequalities later in life for these individuals (Farquharson et al., 2024; Hargreaves et al., 2023).

Despite the laws and legislation outlined for equitable education and accessibility for all children within the UK, many individuals are unable to access the school environment, educational models, pedagogical practices, and assessments, this is particularly prominent for SEN (Specialist Educational Needs) children (Connolly et al., 2023).

#### *1.4.1.4 Attendance*

All UK nations have a strong focus on attendance and place importance on education under The Education Act (1870), the first legislation to enforce school attendance. In England, the DfE including Secretary of State for Education, proposes laws and policies for parliamentary approval, however it is the Local Authorities that assume responsibility for administering the statutory duties connected with education and required of local government, this includes ensuring education provision, monitoring school attendance and means the local authority have power to initiate legal actions (Griffiths et al., 2022). Parents have a legal obligation to ensure their child accesses suitable education, including "regular attendance" if enrolled in a school[7], failure to do so can result in fines, imprisonment, parenting orders and more (Griffiths et al., 2022). Schools also are able to request the Local Authority to issue fines (Education Penalty Notice Regulations, 2007). All UK nations have their own version of this process for instance; in Northern Ireland they have the Education Authority that enforce school attendance through Education Welfare Service (Education and Libraries Order (Northern Ireland) 1986). The Covid-19 pandemic drew attention to topic of attendance[8].

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[7] "Regular attendance" is defined with what is prescribed by school.

[8] Due to the disruptions and school closures meaning many individuals did not attend school (Nathwani et al., 2021), when schools eventually reopened an increase in SNA was observed (McDonald et al., 2022). This was particularly seen within neurodivergent children who struggled the most with re-integrating back into school after such disruptions (McDonald et al., 2022). Whilst the experiences of unmet needs and SNA predates the pandemic, research has since focused on and highlighted neurodivergent individuals' experiences of schools and SNA (Totiska et al., 2020; Connolly et al., 2023).

### 1.4.2 Neurodivergence and School

In the UK, it is estimated that 15-20% of CYP are neurodivergent (Department for Education, 2025). There are many different types of neurodivergence, and each neurodivergence is considered a spectrum in terms of areas of needs and strengths, for example how one autistic individual presents could be completely different to how another autistic individual presents (Doyle, 2020).

Compared to "neurotypical" children, some neurodivergent individuals have certain needs which may make it harder to access the current schooling set up and frameworks previously outlined. Research has highlighted the multiple demands and barriers to the current UK schooling for neurodivergent children which can include: the frequent unpredictability in "complex multi-sensory environments"[9], the transitions within school[10], the rigid structures[11] and certain curriculum lessons that rely on abstract thinking and limited physical and practical opportunities throughout the day (Fielding et al., 2025; Lawrence, 2025; Sproston et al., 2017). These factors within the current schooling models make it difficult for neurodivergent individuals to access when their needs surround difficulties in transitions, executive functioning and abstract thinking, whilst needing certain sensory environments to focus and process (Fielding et al., 2025), as a result of this, many CYP are classed as having "specialist education needs (SEN)" which need to be supported for them to be able to fully access schooling and education.

As education should be equitable for all, legislation enforces rights for neurodivergent children with SEN to access school, requiring professionals to make reasonable adjustments to allow access (UK Equality Act, 2010). As part of this process, neurodivergent children can apply for an EHCP and seek SEN provisions to support their needs and make reasonable adjustments within school offering more of an accessible learning environment. The SEN support and level of initial provision can be decided by the

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[9] Including loud, busy, bright environments, having to wear specific uniform clothes, seeing unpredictable behaviour from peers and teachers shouting.

[10] Needing to transition to physical locations if in a secondary school with different classroom set-ups, changes in teachers and supply teachers, changing lessons and topics throughout the day.

[11] One-hour lessons, needing to sit still to engage in typical dyadic teaching model, seating plans, having breaks at certain times.

school and SEN Coordinators (SENCO)s if it is felt they are able to offer such level of support, however if the level of need and support is considered above this threshold further assessments are provided by local authorities within the UK to consider an EHCP and further funding to support provisions (HM Government, n.d. A). In 2025, the majority of EHCPs were for autistic individuals (Department for Education, 2025).

Despite the legislation and offers of provision and EHCPs, many neurodivergent children are still unable to access the current schooling environments and models (Gray et al., 2023). Reasons can include: long assessment waiting times (several years) in the UK delaying support being in place with schools arguing they are unable to make adjustments and provisions in the meantime, even with an EHCP in place, schools can contend that they are unable to offer such levels of adjustments and provisions outlined (Connolly et al., 2022). Without these provisions and reasonable adjustments, it often means that CYP are unable to access school and have an education; if children do attend school under these circumstances, it is often noted to have detrimental impacts on their mental and physical health (Lawrence, 2025). These experiences are argued to be compounded by school staff’s misunderstanding of neurodivergence and lack of training in this area, causing great distress (Martin-Denham, 2022). This often means CYP are referred to mental health services for support.

### 1.4.3 School Distress and Non-Attendance (in context of Neurodivergence)

As highlighted, on whole the current school system and set up is not accessible for most neurodivergent individuals to utilise unless there are appropriate reasonable adjustments in place and adhered to, which does not always happen (Connolly et al., 2022). In research by Fielding et al., (2025), one participant equated their experience with “jumping into a pit of hungry lions everyday no matter how much pain it causes… it gets worse” they described how every neurotypical child has “armour” to protect them which neurodivergent children don’t, they highlighted that they may get some pieces of armour from SENCOs or provisions but never enough or the full armour to protect them like everyone else. This often means there are detrimental impacts for neurodivergent individuals that do attend from needing to mask, and forcing themselves to remain in such triggering, destabilising environments, these heightened experiences mean students are unable to learn (Fielding et al., 2025). The impacts from trying to access such environments can lead to young people unable to access or attend school with experiences of being traumatised and distressed from the process of trying along with other significant declines in their mental and physical health, confidence, and independence (Brede et al., 2017; Lawrence, 2025).

It is important to note that this dilemma and systemic injustice has existed for decades, it has previously been understood and explained in research using several different terms including: absenteeism, school refusal or emotionally-based school-avoidance/non-attendance, truancy (Connolly et al., 2023). Recent research has highlighted how problematic such language is and has instead moved towards using “school distress”, critiquing prior terminology as locating the “difficulty” within the child or parenting, making it seem as if a choice (Fielding, 2025). It has instead been advocated that it is the environment that is not appropriate and therefore forces some neurodivergent CYP to be unable to attend (Connolly et al., 2023), which will now be termed “School Non-Attendance (SNA)” through the remainder of the research.

It is argued that neurodivergent individuals are over-represented in SNA and school exclusion compared to neurotypical peers (Martin-Denham, 2022; Brede et al., 2017). Connolly et al., (2023) recently found that in a sample of 1096 students who do not access school, 92.1% were neurodivergent students, of which 83.4% were autistic. Totiska et al., (2020) further argued that nearly half of all SNA for autistic students was a result of “school distress”; being unable to cope in such environments. Fielding et al., (2025) added neurodivergent young people experienced the whole school environment as problematic with “an onslaught of stress”, “sensory nightmare” and “constant changing”. SNA is noted to be more frequent and last longer neurodivergent pupils (Munkhaugen et al., 2017).

#### *1.4.3.1 Mental Health and School Distress*

Attending mainstream schools in particular was seen to have “devastating impacts” on neurodivergent CYPs’ physical and mental health (Lawrence, 2025). It was reported that neurodivergent CYP felt anxious, incompetent, lonely, sad, and different from everyone else (Fielding et al., 2025). It was also seen that neurodivergent CYP had started to engage in self-harm, with an increase in suicidal ideation and presented with more behaviours that challenge as means to communicate levels of distress resulting from attending and masking at school (Brede et al., 2017)[12].

Despite the level of distress and detrimental effects for neurodivergent individuals trying to attend schools (which are unable to accommodate needs and do not have reasonable adjustments in place), attendance policies are still applied and used to pressurise students with SNA and their families (Neilson & Bond, 2023; Mullally & Connolly, 2025). During these experiences, neurodivergent children and families highlight the lacking support available from mental health care services, schools as well as from wider health and social care professionals (Mullally & Connolly, 2025; Gray et al., 2023).

It is important to note that research has also highlighted that when neurodivergent young people and children's needs were understood, supported and met, students were able to access and engage in educational settings (Neilson & Bond, 2023). Effective strategies and reasonable adjustments to support access to learning included: person-centred flexible approaches, adjusting physical environments, familiarisation and consistency, good relationships and understanding from staff, access to safe environments, clear communication using visual supports, and joined up care with external professionals (Hoy et al., 2018; O'Hagan et al., 2024; Neilson & Bond, 2023; Brede et al., 2017).

### 1.4.4 The Role of Parents

Parenting is described as the enactment of a set of attitudes, practices and behaviours by parents to raise their child, whilst promoting their child's development, physically, emotionally and socially (Serafini et al., 2025). Trying to raise children is considered a "complex phenomenon", especially whilst also living amidst other demands

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[12] Parents often try to seek mental health services to support their child's presentation of increased distress and self-injurious behaviours connected with their experience of SNA (Martin-Denham, 2022). Parents highlight a variety of experiences from accessing neurodivergent or mental health services like CAMHS (Child and Adolescent Mental Health Service CAMHS), these range from helpful and supportive to disappointing and frustrating experiences both in relation to SNA (Bodycote, 2022).

and challenges of the modern world (Serafini et al., 2025)[13]. Whilst all parenting is considered as “the most difficult and rewarding job”, parents who raise neurodivergent children experience additional layers of challenges and demands, magnifying their role as a parent, without SNA experiences (Sinha & Rajan, 2024).

Parenting ideology and beliefs differ across cultures and genders with parenting styles and what is considered as a “good parent” varying (Pedersen, 2021; Smetana, 2017). In the UK, the government places responsibilities and legal obligations on those who hold parental responsibility[14], with repercussions if not met (HM Government, n.d. B; The United Nations Convention on the Rights of the Child (UNCRC)). Some of these legal obligations can be difficult for parents to attend to, for example, ensuring a child is accessing education, particularly if they are neurodivergent with SNA due to lacking reasonable adjustments. Despite these circumstances involving other stakeholders and systems who are also accountable with the SEND Code of Practice (Department for Education (DfE) and Department of Health (DoH), 2015) highlighting the need to support parents in early identification of SEN, high-quality provision, decision-making, choice, control and collaboration between agencies, research continues to highlight that parents are frequently penalised (Mullally & Connolly, 2025). The House of Commons Education Committee (2019) recognised the failings in executing the “Children and Families Act” (2014) causing “unlawful practice, bureaucratic nightmares, buck-passing, lack of accountability, strained resources and adversarial experiences”.

Parents are considered key stakeholders in SNA due to being positioned in a role between neurodivergent young people and the school system (Martin-Denham, 2022). Research has historically weaponised this role and blamed parents for children not attending school, through “poor parenting”, “being too busy or tired” and not being able to “tell their child what to do” (Înoue, 2022; Sheppard, 2007). Martin-Denham (2022) found parents of neurodivergent children in the context of SNA played the roles of: advocating for their child to access education and health provisions, completing referral forms to access services in

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[13] Research consistently highlights challenging demands and conflicting responsibilities that parents face and have to navigate like trying to establish a work-life balance whilst raising future generations (Nomaguchi & Milkie, 2020), these are particularly present within Westernised parenting (Rowe et al., 2023).

[14] Parents are legally responsible to provide a home for children as well as to protect and maintain children. Parents are also responsible for disciplining their child, ensuring their child accesses education, agreeing their child’s medical treatment, as well as looking after their child’s property.

hope to receive provision, volunteering at child's school to support, requesting and attending multi-disciplinary meetings, funding additional sensory equipment to support needs, and teaching at home if their child was unable to access school. It was highlighted that parents were often bounced between services and therefore had to go through the process of completing referrals and sharing their experiences several times with multiple different professionals and in some cases, they were still left with no support and therefore many faced this journey alone (Gray et al., 2023). These roles were in addition to other parenting responsibilities and demands, whilst further needing to support and regulate their child from distress caused by SNA along with their child's regressions present in these experiences (Lawrence, 2025).

This positioning between schools and their child, with a lack of wider support from external agencies that should be involved (Department for Education and Skills, 2001; Martin-Denham, 2022), placed parents in a very difficult position to navigate with increasing demands and pressure which parents of neurotypical children or neurodivergent children who can access school are unlikely to experience (Connolly et al., 2023; Sinha & Rajan, 2024).

### 1.4.5 The Impact of SNA on Parents

As parents were left failed by many services and alone holding responsibility, the experience and demands of SNA had great impacts on them (House of Commons, 2019; Lissack & Boyle, 2022). The rising demand for mental health services, with the lack of information on how to reach pathways and services added barriers to the accessibility of neurodivergent diagnosis and amounted to parents feeling isolated without support as the diagnosis is often required to access support from other external services (Martin-Denham, 2020; Anderson et al., 2017). Whilst these impacts have been occurring for parents for a significant amount of time, research has only recently begun to investigate and explore these in more detail.

At present, to the best of the researcher's knowledge, there appears only two published research papers solely exploring parents' experiences and impacts, one specific to employment (Blackwell, 2024) and the second, a broader exploration of their experiences

(Mullally & Connolly, 2025). This highlights the limited literature in this area and need for further research on parent's lived experiences.

Parents shared impacts on their physical health, mental health and wellbeing, including higher levels of anxiety and significant declines in their mood, researchers argued that this resulted from a loss in confidence in themselves and their parenting (Mullally & Connolly, 2025). This hypothesis could be supported by other research that found parents to experience tense relationships in school and be frequently blamed or dismissed for their child's experience of SNA, this level of professional gaslighting could lead to one questioning their own confidence and parenting styles (Connolly et al., 2023).

Another significant impact of a child's SNA for parents was difficulties accessing employment (Blackwell, 2024). If a child cannot access school, they need to be looked after and cannot be left unattended, per parental responsibilities, particularly in high levels of distress as most children who experience SNA are, meaning parents additionally are needed to support, regulate and supervise their child (Children and Young Persons Act, 1933; Lawrence, 2025). All these factors mean that most parents are unable to attend work consistently as it depends on the frequency of the SNA, this creates financial impacts for the parent leading to other significant impacts and loss (Blackwell, 2024).

Finally, research has suggested that romantic relationships and friendships are also impacted by the experience of SNA. Mullally and Connolly (2025) highlighted that the stresses and demands associated with SNA placed significant distance on parents connecting with their partners and friends.

### 1.4.6 Summary

Whilst this systemic injustice has taken place over the last few decades, research has only recently, since COVID, started to explore CYPs' experiences of school and SNA. Prior to this, students that could not attend school full-time were pathologized, blamed, and seen to be responsible for "truancy", as were parents (Aucott, 2014). It was rarely considered that the inaccessible environments which did not meet children's needs may have better explained this phenomenon (Connolly et al., 2023). Whilst recent literature has begun offering potential hypotheses through exploring multiple stakeholder's experiences like students and teachers, there is overall lacking research in this area (Fortuna, 2014). Though parents are key in the dynamic, their experiences are unheard and dismissed, consequently this remains to be a gap in literature (Mullally & Connolly, 2025).

# Chapter Two: Systematic Literature Review

## 2.1 Overview

This chapter provides a systematic literature review (SLR) exploring the current literature on parent's experiences of autistic children and school non-attendance, it highlights gaps in research, offering a rationale for this current research.

## 2.2 Aims

SLRs strive to answer research questions by synthesising research findings in a transparent and reproducible manner; SLRs aim to include all published evidence in the specific topic area and critically assess the quality of the evidence (Lame, 2019).

The SLR aimed to answer the following question: **What are parent's experiences of autistic children and school non-attendance (SNA)? [15]**

It was decided for the SLR to specifically centre on one neurodivergence, autism, this was due to the limited published literature found in preliminary searches that explored parent's experiences of all neurodivergence and school accessibility. Further, by focusing on the experiences of autism and SNA, it allowed the depth and complexity (Lissack & Boyle, 2022) that surrounded this topic to be further understood before this research presents broader neurodivergence.

## 2.3 Review Methodology

### 2.3.1 Search Strategy

The SLR was conducted between February 2025 and May 2025, with the initial searches taking place in February and being re-run in May, which led to one additional paper being added to the synthesis (Mullally & Connolly, 2025). In recent years, there have been SLRs that focused on parents' experiences and schooling "perceptions of school

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[15] It is noteworthy, that this SLR occurred after the empirical research and analysis were completed in line with Constructivist Grounded Theory (CGT) methodology (Charmaz, 2014).

involvement" (Goldman et al., 2019), "successful transitions from primary to secondary school" (Richter et al., 2019), as well more broadly "parents of children with autism spectrum disorder" (Sacca et al., 2019), yet to the best of our knowledge there was not a SLR that specifically focused on parents' experiences of SNA and autistic individuals, leaving a gap in literature.

SCOPUS, PsychArticles and PubMed databases were utilised and selected as their research focuses on scientific (medical, life and social sciences), technical, and psychological research and literature. Google Scholar was utilised afterwards to supplement database findings, whilst most results were already highlighted within the database findings, four pieces of research were additionally found[16].

As the SPIDER tool has suitable application to qualitative and mixed-methods research which this SLR intended to focus on, it was chosen as a tool over the PICO to support considering search strategies, terms and keywords (Cooke et al., 2012), see Table 2.

Table 2 – Spider tool used to establish search terms, inclusion and exclusion criteria

| | |
|---|---|
| Sample | Parents OR Caregivers of autistic children (under 18) who have experienced schooling. |
| Phenomenon of Interest | School Distress OR School Refusal OR Absenteeism OR Emotionally Based School Non-Attendance OR Emotionally Based School Avoidance. |
| Design | Interview OR Case Study OR Focus Group OR Survey OR Questionnaire |
| Evaluation | Experience OR Perspective |

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[16] After a few pages of irrelevant results were reviewed, the exploration stopped.

| | |
|---|---|
| Research Type | Qualitative OR Mixed Methodology |

Through the SPIDER tool, preliminary searches of the databases and meetings with experts by experience, the key concepts evolved to include historical language like moving from "absenteeism" to "school refusal" to "school distress". During the searches, the asterisk symbol was employed for truncation within the databases and the Boolean operators "AND/OR" were used. The final search terms applied in the searches are listed in Table 3[17].

Table 3 – Final Search Terms

| | |
|---|---|
| Concept One | Parent **OR** Caregiver **OR** Parental |
| AND | |
| Concept Two | Experience **OR** Perspective |
| AND | |
| Concept Three | Autis* (to reflect Autistic and Autism noting person-centred language currently used "Autistic Individual" and historically used "Individual with Autism) |
| AND | |
| Concept Four | School Distress **OR** School Refusal **OR** Absenteeism **OR** Emotionally-Based School Non Attendance **OR** EBSNA **OR** Emotionally-Based School Avoidance **OR** EBSA |

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[17] As discussed, the language that surrounds autistic individuals and SNA has changed over the years and will likely continue to. Whilst the researcher and supervisory team note harms and pathologisation from historic language (Lissack & Boyle, 2022), these terms had to be utilised in the SLR to find prior literature for the synthesis to take place.

### 2.3.2 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for the literature to be included in the SLR is listed in Table 4. Due to worldwide educational differences and support for autistic individuals, it was decided to focus the SLR on the UK (Hansen & Vignoles, 2005). The SLR specifically included research from 2015 as this was when the "Future in Mind" report released in the UK recommending mental wellbeing support for CYP, with a recognition on the impact on parents "you are only as happy as your least happy child" (McShane, 2015). Qualitative or mixed-method designs were chosen for the SLR as this methodology seeks "to understand a complex reality and meaning of actions in a given context" (Queiros et al., 2017), which would offer more exploration than solely quantitative methodologies.

Table 4 – Inclusion and Exclusion Criteria for Systematic Literature Review

| Inclusion | Exclusion |
|---|---|
| Meeting criteria of SPIDER tool: The research must reference parents' or caregivers' perspectives of their autistic child and school non-attendance. Sample must include a parent or caregivers. | Research does not reference/quote parents' or caregivers' experiences/perspectives of school non-attendance and autism. Sample does not include parents or caregivers. |
| Empirical papers that are published in peer reviewed journals | Not published in peer reviewed journals or are reviews/discussion articles/ other grey literature |
| Published from 2015-2025 | Published before 2015 |
| Using a UK sample | Using samples from outside of the UK |
| Qualitative or Mixed Methods | Quantitative Research |

The searches across three databases produced 5598 studies once the duplicates were removed. The research titles and abstracts were reviewed for relevance and included or excluded based on the criteria outlined in Table 4. The remaining 29 studies were read in full, and reviewed using the same criteria, leading to 9 studies being included in the SLR. To ensure an extensive search and ascertain any additional studies that the databases may not have captured Google Scholar was used, identifying an additional 4 studies. The PRISMA flowchart summarises the search process, see Figure 1.

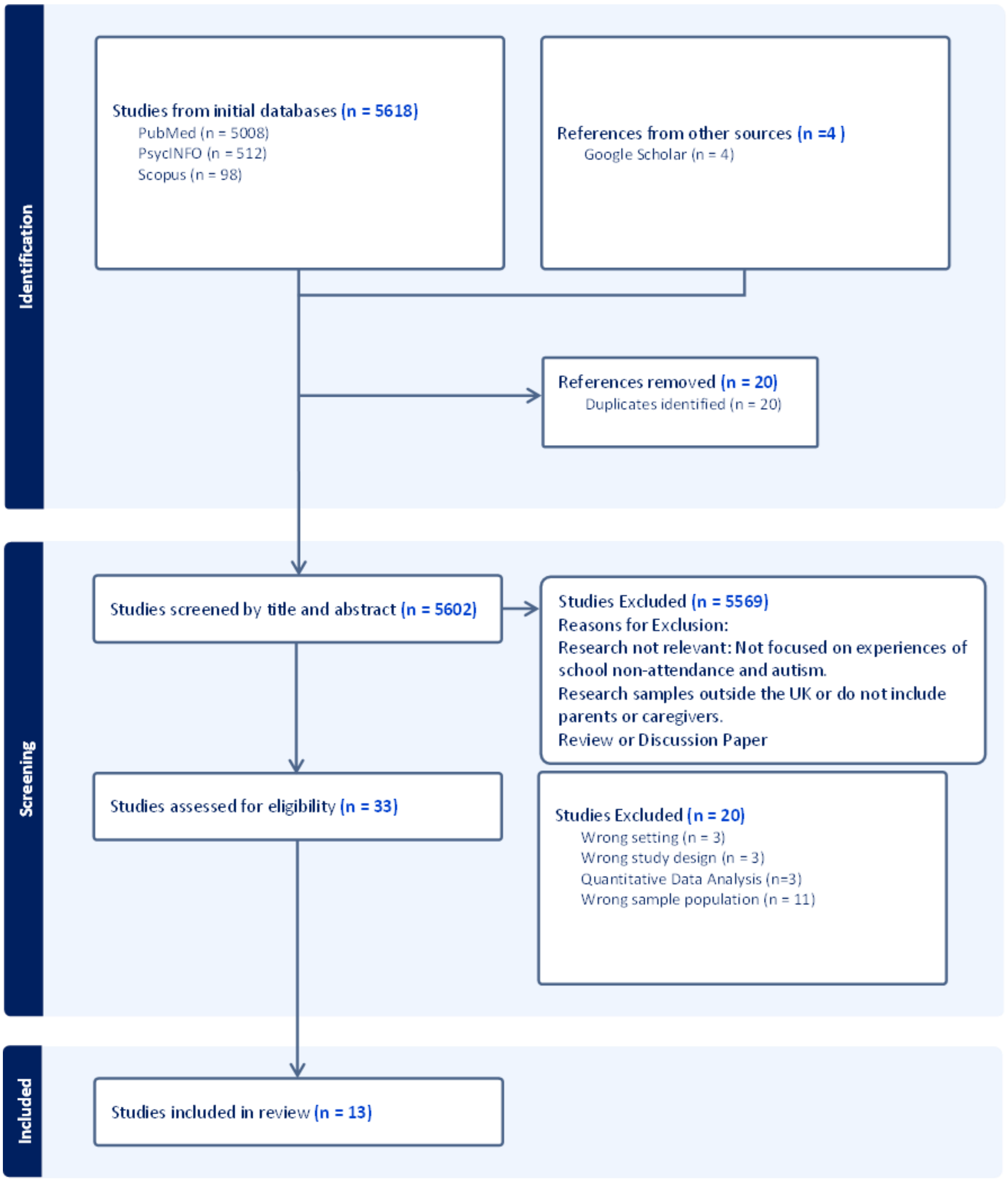

Figure 1 – Systematic Literature Review PRISMA Flow Chart

## 2.4 Search Findings

A total of 13 relevant studies were revealed through the initial literature search that met the SLR's criteria. These studies were chosen as they spoke to parent's experiences of having autistic children who are not currently accessing school. It is worthy to note that five of the thirteen studies did not solely focus on autism. It was decided that these studies would be included as they had high percentages of the sample representing autistic CYP, the studies had 83.4%, 83.4%, 81%, 79.8%, and 51%. It was concluded that the studies' findings therefore would offer perspectives of the experiences of a parent with an autistic child and school non-attendance. This decision will be further discussed in Appendix C.

The majority of studies chosen focused on several stakeholders (i.e. CYP, school staff, external professionals) as well as parents, this SLR will only be presenting and synthesising the findings specifically related to and reported by the parents and their experiences given the SLR's aims. Seven of the studies used qualitative methodology and six studies instead used mixed-methods approach with some qualitative aspects. In terms of the samples within the studies this ranged from 3 – 1121 parent participants. A summary of the chosen studies, their methodologies, findings, strengths and limitations can be found in Table 5.

Table 5 – Data Extraction of Papers included in Systematic Literature Review

| Authors and Year | Title and Research Aims | Participants | Research Methodology | Data Analysis | Research Key Findings | Strengths and Limitations |
|---|---|---|---|---|---|---|
| Brede et al., (2017) | Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school<br>**Aims:**<br>To understand factors surrounding school exclusion experiences and re-integration into education for autistic students with "complex needs". | Nine Students (Eight Males, One Female; All White British; Aged between 10 - 18; All have a formal diagnosis and EHCP/SEND plan)<br>Seven Parents (All Mothers)<br>21 Members of Teaching Staff | Semi-Structured Interviews and Questionnaires (Social Communication Questionnaire; Social Responsiveness Scale- 2; Spence Child Anxiety Scale for Parents; Extreme Demand Avoidance Questionnaire; Educational Experience Questionnaire) | Thematic Analysis - Data from Questionnaires were added to the participant's demographics to offer wider context of participants. | Two overarching themes were found investigating the experience of pre-exclusion experiences. Theme One - Gradual decline in school engagement: demands of school, school's failure to respond to their children's needs and staff using inappropriate methods to manage behaviour. Theme Two - Perpetual state of crisis: marked changes to behaviour and mental state, removal from school, stress of finding alternative provision. For successful reintegration into schools the following themes were identified: adjusting physical environment, providing strong trusting relationships, understanding and accepting child's needs and improving child's wellbeing.<br>**Findings reported from Parent's Experiences:**<br>All parents reported at least one fixed term of formal exclusions, and informal exclusions, most were argued to be a result of educational needs not being met. Parents reported increase in child's anxiety, and behaviours that challenge. Parents had to fight to get difficulties recognised. School lack of understanding contributed to their difficulties accessing schools. Inappropriate methods of restraint. Child in perpetual crisis which impacts the "entire house". Stress of finding appropriate placement. Reflecting on what works: listening to child and parents, understanding presentation, focusing on building foundations and "repairing prior damage" to access learning in future. | *Strengths:*<br>*- The research adds and builds on other literature within the area.*<br>*- Is transparent for readers highlighted areas of caution throughout the research when interpreting results or drawing conclusions in specific sections.*<br>*- Extensive effort was put into rapport building over time and making the space as safe as it can be when sharing experiences, paying attention to child consenting to taking part.*<br>*Limitations:*<br>*- Whilst this research has been successful in establishing factors that are key for reintegration within education settings, it has limited generalisability as it is based on the participants accessing the "Hub" and re-integrating with education there, the factors may change if they widened the sample to include those re-integrating into mainstream or those who have not accessed such provision or those from other locations with other alternatives.*<br>*- The sample lacks gender and cultural diversity and therefore speaks to predominantly a White British Males experience thus leaving questions around the experiences of those from more marginalised positions.*<br>*-The demographics are also limited for the parents and teachers.* |

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| Martin-Denham (2022) | Marginalisation, autism and school exclusion: caregivers' perspectives<br>**Aim:**<br>To find the barriers and enablers to mainstream schooling for autistic children, and to understand the effect of the journey to school exclusion on children and their caregivers. | Five Caregivers (1 Father, 4 Mothers) their children were between the ages of 6-17 and were predominantly male. | Semi-Structured Interviews | IPA | Finding One: Inadequate SEN Support and Inadequate staff training for schools. Finding Two: Psychological impact: Impact on child from school exclusion, victimisation, and use of restraint and Impact on parent. Finding Three: Health Imposed Barriers like being impacted by waiting lists or exclusion criteria. Finding Four: Effective Support - Meeting Individual Needs, being supported by health good practice, accessing voluntary organisations.<br>**Findings reported from Parent's Experiences:**<br>Inadequate SEN support. Psychological impact on child and parent. Barriers to getting a diagnosis. School were declining parents' requests for support. Parent being unheard. School system lacking knowledge. | *Strengths:*<br>*- Thoughtfulness around conducting the interviews where the participants can share stories as the expert.*<br>*- Clear Data Analysis. Deep analysis of participants' experiences represented by the IPA themes and theographs and reflected on impacts as well as the experiences.*<br>*Limitations:*<br>*- Small sample size means limited generalisability.*<br>*- Limited demographics for the parents in terms of age, ethnicities.*<br>*-Unclear recruitment* |
| Neilson & Bond (2023) | 'After a long period of being in hibernation – These little green shoots were growing'. Lived experiences of effective support for autistic young people who have experienced extended school nonattendance.<br>**Aim:**<br>To explore the experiences of autistic adolescents who had extended school nonattendance and effective support to meet their needs. In addition, parental perspectives were | 2 Young Individuals (17 & 14, one female, one male)<br>3 Parents (Mothers - no other specific demographics of Parents reported but all are parents to females aged between 10-17). | Participatory Inquiry, Narrative Interview with young individuals and Semi-Structured Interviews with Parents | Reflexive Thematic Analysis | Effective Support included: Time, Motivation, Control, Safe Environment, Relationships, Emotions, Diagnosis of Autism. Parents added: Holistic/Joined Up Approach as well as Change Starting within the Family Home. Researcher added: Understanding and Acceptance of Individual Lived Experience of Autism.<br>**Findings reported from Parent's Experiences:**<br>Parents spoke to the importance of safe environment and relationships when considering effective practice meeting child's needs in context of extended school non-attendance. The importance of positive relationships and child being seen and heard. They further identified holistic and joined up approach when professionals work together is more effective as they can see the wider picture. Formality of diagnosis reduced stressors of fines for attendance, validation not being bad parent. Spoke to accessing various support from CAMHS and home tutors. | *Strengths:*<br>*- Centres the young individuals voice in the research.*<br>*- Lots of time spent building rapport making individuals feel more comfortable and considerations to power and how this can typically play out in research.*<br>*- Had a meaningful impact and benefit for the setting it researched within.*<br>*-Member checking to ensure more reliability and validity of results.*<br>*Limitations:*<br>*- Limited generalisability due to one specialist provision being researched.*<br>*- Whilst member of staff aided supporting participants there may have been bias in who took part in the research and who did not etc.* |

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| | explored to consider potential contextual factors that supported the effective practice described by the young people. | | | | Frustrations around no onsite educational setting being available. | *- Limited demographics reported on in terms of ethnicity, diagnosis and no specific parent demographics were reported on.*<br>*- Small sample and noted there were times where the individuals had opposite experiences which would be helpful to have a larger sample to explore what factors or contexts may have led to the differences.* |
| Sproston, Sedgewick, Crane (2017) | Autistic girls and school exclusion: Perspectives of students and their parents<br>**Aim:**<br>The main aim was to explore experiences of the school exclusion process however the research also sought experiences of mainstream schooling, alternative educational provisions offered, and current educational provisions. | 8 Females (Aged between 12-17, 7 diagnosed, 1 no-diagnosis but assessment indicating likelihood of being autistic, no other demographics were reported other than siblings within household),<br>8 Parents (7 Mothers, 1 Father, no other demographics were reported) | Semi-Structured Interviews | Thematic Analysis | Themes associated with the experience of exclusions: Inappropriate school environments, Tensions in school relationships and problems with staff responses<br>**Findings reported from Parent's Experiences:**<br>Inappropriate school environments (impersonal environment mainstream). Believing pressures from school goes to teachers which goes to students (toxic culture). Focus on attendance and threatening parents with prosecution or receiving many texts. Lacking understanding and knowledge from schools. Parents being unheard/not listened to. Lack of support in schools. Want for effective communication. Battling for support | *Strengths:*<br>*- The research recognised difficulties young females face seeking a diagnosis such as lack of identification, costs etc and therefore the impact on recruiting and taking part in research. As a result, they opened recruitment for one individual that likely met the diagnosis threshold but had not been able to seek a formal diagnosis.*<br>*- Highlighted importance of hearing the young person's voice when researching their experience rather than other stakeholders.*<br>*- Built on foundations of previous research of autistic young people's experiences of school and highlights attention to female's experiences.*<br>*Limitations:*<br>*- By recruiting through pupil referral units, specialist schools and charities, it is likely that those who have been excluded from school and are not accessing support from charities, specialist schools or pupil referral units will have likely been excluded from taking part in the research.*<br>*- The lack of comparison groups meant it was not possible to determine whether factors were solely related to an autistic female's experience.* |

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| | | | | | | *- Lacking demographics of ethnicities and other demographics of parents too.* |
| O'Hagan, Bond, Hebron (2024) | Autistic girls and emotionally based school avoidance: supportive factors for successful re-engagement in mainstream high school.<br>**Aim:**<br>What are supportive factors that help autistic girls who experience EBSA re-engage and maintain their attendance in mainstream high school? | 3 Young People (aged 13-15)<br>3 Mothers and 1 Partner joined<br>3 Professionals. | Qualitative Exploratory Multiple Case Study Design - Semi-Structured Interviews | Thematic Analysis | Eight themes were found to be a factor associated with successful re-engagement: Relationship with key adults and wider staff team, relationships with peers and friends, belonging in the school community, diagnosis supporting girl's re-engagement, individual flexible approach, relationships with outside agencies, parent advocacy and incorporating the voice of the young person into their support plan.<br>**Findings reported from Parent's Experiences:**<br>What helps - staff having understanding and connection. All mothers had difficult journeys navigating systems for diagnosis and support and were pivotal to getting the diagnosis and support in place. | *Strengths:*<br>*- Deeper exploration of the experiences by using a case study.*<br>*- Also seeking multiple stakeholders' viewpoints to triangulate the data.*<br>*- Ensured that the case studies were from different schools which increases generalisability.*<br>*- Included member checking increasing reliability of research.*<br>*- Built on previous literature.*<br>*Limitations:*<br>*-Recruited via SENCO in schools which may bias who was chosen to participate.*<br>*- Limited demographics for the parents that took part and young individual's ethnicity and SES status.*<br>*-As it has a small sample size, it is particularly impacted by a lack of diversity including a diversity in range of abilities.* |

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| Gray, Hill, Pellicano (2023) | “He’s shouting so loud but nobody’s hearing him”: A multi-informant study of autistic pupils’ experiences of school non-attendance and exclusion.<br>**Aim:**<br>To understand proximal and distal barriers for inclusion and school attendance for autistic students. | 12 Young People<br>10 Parents (7 Mothers, 1 Father, 1 Foster Mother, 1 Adoptive Mother)<br>8 Teachers<br>9 Local Authority Professionals<br>6 Educational Psychologists<br>3 Specialist Autism Teachers | Semi-Structured Interviews, Social Communication Questionnaire, Wechsler Abbreviated Scales of Intelligence - Second Edition. | Reflexive Thematic Analysis | Three broad themes were found: The road to exclusion, exclusion and its aftermath, and moving on to alternative provision. Proximal factors included: sensory and social overwhelm, lack of understanding of autism by school staff, negative staff attitudes and responses, school's lack of flexibility, and adversarial home-school interactions. Distal factors included: fragmented educational experiences, complex bureaucratic system that parents struggle to navigate, lack of governmental funding, and limited professional involvement with delays in accessing alternative provision.<br>**Findings reported from Parent’s Experiences:**<br>Too overloaded in mainstream. Too much pressure leading to fall down and express overwhelm through unwanted behaviours. Teachers lacking understanding focusing on negative things. Experiencing unofficial exclusions or excluded from school events. Watching child deteriorate (behaviours, health and anxiety, suicidal). Constant contacts from school putting parents on high alert. Constantly battling to get support. Children and young people out of school for long periods of time between 1-3 years. Onus on parents to look for provision due to a lack of provision/support. Impacted parent's work and friendships. Having to navigate complex isolating legal processes to get support in place. Worried about their future. What is helpful: tailoring learning to meet needs, introducing boundaries slowly, flexibility. | *Strengths:*<br>*- Researched using multiple stakeholders to consider wider systems.*<br>*- Considered how to make research more accessible and spent time building rapport with young individuals and completing tasks to reduce social demands of the interview.*<br>*- Built on previous literature in this area and therefore was able to make practical implications.*<br>*Limitations:*<br>*- Limited generalisability as completed within one single local authority area.*<br>*- Lacking diversity in sample, and no demographics reported for parents or professionals who took part in the research.*<br>*-Whilst the teachers from the alternative provision were spoken to for the re-integration it would have been helpful to explore the mainstream teachers’ experiences, as much of the responses from the parents in particular spoke to their experiences of mainstream staff and how they interacted with them as parents etc.* |

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| Totiska et al., (2023) | School Attendance Problems Among Children with Neurodevelopmental Conditions One year Following the Start of the COVID-19 Pandemic<br>**Aim:**<br>To investigate school absence among autistic children and/or children with an intellectual disability, to understand different types and correlates of absence one year from the pandemic. The study also sought to understand barriers and facilitators of school attendance. | Convenience Sampling: Data was collected for 1076 Children, 67% Male, 90% White, 6% Multiple Ethnic Groups, 3% Asian/Asian British, <1% Black/African/ Caribbean/Black British.<br>The total number of parent participants is unclear whether this is also 1076 or less, though it is reported their ages ranged from 24-73, 41% had a disability. | Cross-Sectional Questionnaire (School Non-Attendance Checklist; Developmental Behaviour Checklist 2-Parent; The Strengths and Difficulties Questionnaire; Parent-Teacher Relationship/ Involvement Questionnaire; Family Assessment Device; The Pandemic Anxiety Scale). Parents were also asked to name three barriers and facilitators of school attendance in the questionnaire. | Multiple-Variable Regression, Qualitative Analyses for free text using bottom up approach to identify themes. | The research found 32% of children missed 10% or more of school days, with school refusal and ill health as the most frequently reported. Most frequently barrier was unmet needs, followed by child health and change. The most frequently reported facilitator was helpful routines with structure and predictability, followed by good school provision with understanding and adaption. Good parent-teacher relationships and child-teacher relationships were also frequently mentioned as a facilitator, and found to be statistically associated with lower likelihood of school exclusion and school refusal.<br>**Findings reported from Parent's Experiences:**<br>Most frequently barrier was unmet needs, followed by child health and change. The most frequently reported facilitator was helpful routines with structure and predictability, followed by good school provision with understanding and adaption. Good parent-teacher relationships and child-teacher relationships were also frequently mentioned as a facilitator, and found to be statistically associated with lower likelihood of school exclusion and school refusal. | *Strengths:*<br>*- The methods of recruitment appeared well thought through by reaching out to those on social media and those accessing charities and other third sector organisations, and having the questionnaire link open for a few months to widen access.*<br>*- The use of expert parent advisors within the research process.*<br>*- The research is rigorous and lots of thought has gone into reliability of the research.*<br>*Limitations:*<br>*- Some of the information presented in the demographic tables are unclear as they only reported specific variables and not all for instance child is a male (leaving out the rest of the sample) or parent respondent is female which can be misleading. It is also unclear how many parent participants were recruited overall, though the rest of their demographics are reported.*<br>*- The research acknowledged that a third of participants did not complete the questionnaire as it was quite lengthy, and they thus report that those from lower socio-economic deprivation were more unlikely to complete the questionnaire, meaning their voices were not heard.*<br>*- Only allowed to speak to three barriers and facilitators when there may have been more pressing barriers due to complexity of experiences.*<br>*- Due to using questionnaires to gather information on the experience, it did not allow for follow up questions to check understandings etc.* |

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| Blackwell (2024) | The impact of school challenges on parental employment among families with children on the autism spectrum<br>**Aim:**<br>To gain perspectives on the impact of school experiences on parental paid employment. | Purposive Sampling 7 Young People (aged between 6-14)<br>19 Mothers, 3 Fathers (aged between 20-60).<br>Predominantly a white British/Irish sample. | Semi-Structured Interviews | Thematic Analysis | Engaging in paid employment was a significant challenge for the parents. Parents employment decisions and dilemmas were greatly impacted by the extent the school were meeting their child's needs. School exclusions, school refusal and unmet needs, the flexibility of employers, impacted parental employment; there was a theme of parents working over time or in lieu to make up time lost.<br>**Findings reported from Parent's Experiences:**<br>Parents decisions and dilemmas around employment were greatly impacted by the extent to which needs of their children were met in school, with many parents in part-time work, ad hoc work, cutting hours down or not in paid employment. School (formal and informal) exclusions and refusal presented challenges for paid employment. Themes of not being listen to and getting phone calls regularly. Inadequate treatment of their children. Lacking school provision and support. Not having EHCP taken seriously. Difficulties getting EHCP and hours it takes. Difficulties getting child into school. Gendered division noticed with mothers taking on parental role and fathers in employment. Impact of supportive employers and flexible paid employment reducing stress as a result individuals do not want to move into new jobs, apply for promotions or do anything that may disturb this, or they would take on job roles below qualifications. If late to work individuals tended to work more hours than what they were late. | *Strengths:*<br>*- Didn't need to demonstrate or have official diagnosis to take part which widens the access.*<br>*- Builds on previous literature and considered school system as well as employers as systems and therefore is able to have implications for both.*<br>*- Much thought was given to the flow of the interview to build rapport and have a natural conversation to ease participants increasing how comfortable they feel in disclosing information.*<br>*Limitations:*<br>*- Predominantly white British/Irish sample and mothers, lacking diversity.*<br>*- Unclear on the rigor of the research and what processes were involved to increase reliability and consistency of the themes identified.* |
| Lissack & Boyle (2022) | Parent/carer views on support for children's school non- attendance: 'How can they support you when they are the ones who report you?' | Purposive Sampling 289 Parents/Carers, 51% had autistic children | Online Questionnaire | Reflexive Thematic Analysis | Views on Support Offered: Misplaced Support, (Mis)understanding complex problem, Lessons learnt from lockdown and hopes/recommendations for the future. How can support be improved: Prioritise wellbeing and partnerships, and adapting the system. | *Strengths:*<br>*-Completed pilot study for the questionnaire with 23 responses and feedback before publishing the research's questionnaire.* |

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| | **Aim:**<br>To investigate parent/carers' views on the support offered to them and their child for school non- attendance, and how they think the support could be improved to help their child attend school more consistently? | | | | **Findings reported from Parent's Experiences:**<br>Limited support. Impact on wider family. Lack of understanding. Prioritising attendance including prosecutions. Being Blamed and Unheard. Off-rolling. What is needed: Prioritising child's wellbeing, Partnerships with parents and young people too, Needing to adapt system, Stop using refuser in language (more understanding). | *-Clear practice and policy implications from research that considers an ecological, multi-systemic view of non-attendance.*<br>*- Builds on previous literature.*<br><br>*Limitations:*<br>*-Research completed during COVID-19 when schools were closed which may have biased results and types of support.*<br>*-Questionnaire was only open for three weeks. No demographics of parents reported.*<br>*-Due to using questionnaires to gather information on the experience, it did not allow for follow up questions to check understandings etc.* |
| Paulauskaite (2022) | Elective home education of children with neurodevelopmental conditions before and after the COVID-19 pandemic started<br><br>**Aim:**<br>To explore parents' experience of EHE as well as reasons for school de-registration before and after the COVID-19 pandemic started. Further, investigated child mental health outcomes (anxiety, internalising, and externalising problems) both in relation to the timing of | Convenience Sampling Participants were 158 parents (over 90% mothers, between 27-60 years old - average 44 years old, around 45% had a disability) of home educated 5–15 year-old children (average age was 11, there was a higher proportion of males, those of white ethnicities and those who | Online Questionnaire, Developmental Behavioural Checklist Parent Report 2, The Strengths and Difficulties Questionnaire, and free text to ask three barriers and facilitators of elective home education. | T-Test, Chi-Square Test, Descriptive Statistics, Content Analysis | Most frequent reason for de-registering pre-pandemic was that the child's additional needs were not met sufficiently in school, then the child's mental health deterioration and them being unhappy at school. From the free text response, safeguarding/risk reasons were cited as well as bullying. Post-pandemic the most frequent reason was the child's additional needs were not met sufficiently in school, then parents feeling that they could provide a better education at home. Most of the support came from the parents in educating. Parents reported being highly satisfied with Elective Home Education, but barriers included: competing demands and child's needs, but some parents reported that they did not experience any barriers. Facilitators included: being able to offer personalised education, and also availability of external resources.<br><br>**Findings reported from Parent's Experiences:**<br>Most frequent reason for de-registering was due to the child's additional needs not being met. Pre | *Strengths:*<br>*- Had a parent advisory group involved in the research development and analysis.*<br>*- Good recruitment strategies online, and also through newsletters and third sector partners.*<br>*- Questionnaire open for a few months to allow those time to participate.*<br>*- Reports larger sample size than previous literature and builds on past research*<br><br>*Limitations:*<br>*- In the analysis when making comparisons between the elective home education from the start and those in this after attending school were unbalanced groupings.*<br>*- Only allowed to speak to three barriers and facilitators when there may have been more pressing barriers due to complexity of experiences.*<br>*- Due to using questionnaires to gather information on the experience, it did not allow* |

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| | de-registration and in comparison, with school-registered children. | have formal recognition of special educational needs). | | | pandemic the top other reasons were the child's mental health and wellbeing. After the pandemic the next top reason was that the parents believed they could offer a better education. Pre-pandemic daily support was provided by their parent (84.1%) and this reduced to 68.3% of cases. Other family members supported learning and the young person too. Private tutors and online programmes supported child's learning. Barriers included: competing demands and difficulties due to child's needs, with some parents reporting no barriers. Facilitators included: being able to offer personalised and tailored education as well as availability of resources. | *for follow up questions to check understandings etc.* |
| Connolly, Constable, Mullally (2023) | School distress and the school attendance crisis: a story dominated by neurodivergence and unmet need<br>**Aim:**<br>To identify characteristics of children/young people experiencing difficulties attending school. To understand the level of support received for those experiencing school distress. | 947 parents of children who experience/experienced school distress, 149 parents of children who have never experienced school distress, 25 parents whose children have never accessed school. 97% Mothers. 93% White Ethnicity. | Case-control, Concurrent Embedded Mix Method Design. Online Questionnaire (Children-Autism Spectrum Disorder- Parent, Extreme Demand Avoidance-8) | Spearman Rho Correlation, T-Test, Kruskal-Wallis Test | School distress occurred significantly earlier and was more enduring in Autistic young people than non-autistic peers. School distress was commonly found in mainstream settings. Young people with school distress were significantly more likely to be neurodivergent. Sensory processing disorder, anxiety and demand avoidance were all significantly correlated with markers of school distress severity. Those in current school distress group had significantly higher levels of anxiety. The majority of parents were dissatisfied with the level of support their child was receiving from school and/or the local authority.<br>**Findings reported from Parent's Experiences:**<br>Onus on parents to get child into school. Emotional Impact on Parents. Seeing child deteriorate in physical health, mental wellbeing and behaviours. Lack of support for child. Parent doing paperwork or tensions with school. | *Strengths:*<br>*- Included a control group to make comparisons and large sample size.*<br>*- Recruitment strategies were good, using social media as well as accessing organisations and other recruitment websites.*<br>*- Broad criteria for neurodivergence which allows for those awaiting assessment/diagnosis in regard for the UK wait time.*<br>*Limitations:*<br>*- Predominantly a white sample, limited diverse sample.*<br>*- The research only ran for 14 days, limited time to take part, whose voice wasn't heard.*<br>*- Whilst the study had a control group, the sample sizes were unbalanced within these which may have influenced the analysis when exploring between groups effects.*<br>*- Needs to be clearer on what statistical tests were used in total.*<br>*- Due to using questionnaires to gather information on the experience, it did not allow* |

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| | | | | | | *for follow up questions to check understandings etc.* |
| Lawrence (2025) | Making the spoons last longer: Parents' views on flexischooling with their child with special educational needs<br>**Aim:**<br>To explore the experiences their autistic children are facing, and the rationales for choosing and undertaking flexischooling as a solution. | 31 Participants (No demographics are provided) | Online Questionnaire | Inductive Content Analysis | Strong relationship between parent's concerns regarding effects of school on their child's wellbeing and need for recovery during flexi-schooling. Flexi-schooling at home was used as periods of rest, or completing extra-curriculum activities that it would not be possible to access due to burn out from school. Flexi-schooling was seen as a way to enhance learning opportunities with parents supporting their children in this.<br>**Findings reported from Parent's Experiences:**<br>Parents reported that there were many challenges attending full-time school: being unable to cope with environment, finding it exhausting, needing to mask, and exhibiting distressed behaviour in response. Need flexi-schooling for time to rest, de-stress, have low demand time from school. Flexi-school allowed young people to take part in various activities that they would not be able to access otherwise, see friends and others giving sense of community and enhancing wider learning opportunities. Parents very active in the teaching/ supporting learning role. Time is used to access support and therapy that would be unavailable through schools. | *Strengths:*<br>*- Adds to previous literature on why individuals may choose flexi-schooling as well as advantages of this set up.*<br>*- Used several different recruitment routes including social media and third sector organisations.*<br>*Limitations:*<br>*- Due to using questionnaires to gather information on the experience, it did not allow for follow up questions to check understandings etc.*<br>*- Questionnaire was only open for 4 weeks, limited time to take part.*<br>*- No demographics are reported.*<br>*- Unclear summary of results in closing sections.* |

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| Mullally & Connolly (2025) | "I felt shamed and blamed": an exploration of the parental lived experience of school distress<br>**Aim:**<br>To explore the parental experience of school distress and the impact on their lives. | 1121 Parents of School- Aged Children in UK - 738 Experiencing Current Distress - 209 Experienced Previous Distress. 97.03% Mothers. 19 professionals (mainly school staff) also took part. | Case–control, Concurrent embedded mixed-method design. Online Questionnaire (Discrete Emotions Questionnaire, List of Threatening Life Experiences) | Descriptive Statistics - Chi-Squared Analysis/ Mann-Whitney-U/ Kruskal-Wallis - Thematic Analysis | Parents mental health impacted, heightened daily anxiety and lower mood which was not present before. Parents also had higher levels of negative emotions, and lower levels of positive emotions. Parents were blamed, disbelieved, threatened and disempowered by professionals. Other impacts were finance, careers, impacts on other children, friendships, families and relationships with partners. Parents with school distress experiences ranked it a significantly more life threatening event compared to others.<br>**Findings reported from Parent's Experiences:**<br>Significant impact on emotional and mental state (living in fear). Being unheard by professionals, schools and individuals in wider community. Being gaslit, bullied, and threatened. Having other agencies involved. Being disempowered. Misunderstanding of the complexity. Dereliction of duty. Protection from others and protecting self. | *Strengths:*<br>*- Large sample size and compares with a control sample.*<br>*- Much thought around language used and what fits and is appropriate to use.*<br>*- This research builds and elaborates on previous literature in this area and had good links with previous research offering hypotheses to explain results as well as making suggestions for future research.*<br>*Limitations:*<br>*- No age or ethnicity demographics were reported for parents.*<br>*- Use of Likert scales for majority of questions can lead to lack of context, loss of nuance and oversimplification as well as other bias.*<br>*- Limited recruitment of professionals only those attending a school anxiety conference invited.*<br>*- Research only open for 14 days - given pressures on parents and juggling not everyone would have had a change to take part.*<br>*- Due to using questionnaires to gather information on the experience, it did not allow for follow up questions to check understandings etc.* |

## 2.5 Quality Assessment

Quality assessment is integral to the SLR process (Yang et al., 2021). Consistent with Centre from Review and Dissemination (CRD)'s guidance for undertaking systematic reviews in healthcare settings (2009), the quality assessment for the 13 selected studies in this SLR took place before the synthesis started. It was decided to use the CASP tool (2024) to support this process as the quality assessment tool for this SLR as it has been commonly used for appraising qualitative studies, specifically in health and social care (Majid & Vanstone, 2018; Long, 2020). The ten questions within the CASP tool appraise the research's various methodological aspects, the strengths and limitations, the rigour, validity, appropriateness and value to the area of research (Long, 2020; CASP, 2024). See Appendix B for the quality assessments of each study included in the SLR and Appendix C for further discussion. On whole, this SLR argues the studies included are all of moderate to high quality rating on the CASP checklist. All the studies add value in this under-researched important area and offer good foundations for future literature to build upon.

Overall, at the time of this SLR, there was a lack of published research exploring the impact of autistic children's SNA on parents. This SLR identified two studies that explicitly explored the impact on parents (Mullally & Connolly, 2025; Blackwell, 2024). Though five studies took a broader lens and explored parents' perspectives of what their child had experienced and what portions of the experience were like for them (Martin-Denham, 2022; Sproston et al., 2017; Gray et al., 2023; Lissack & Boyle, 2022; Connolly et al., 2023). The remaining six studies largely focused on the parent's perspectives of what their child had experienced (Brede et al., 2017, Neilson & Bond, 2023; O'Hagan et al., 2024; Totiska et al., 2023; Paulauskaite, 2022; Lawrence, 2025). It is understandable why research focuses on CYPs' experiences given that they are at the centre of the impact, it is therefore essential to hear their voice (Hoy et al., 2018). Though it is equally important to appreciate the complexity of these experiences (Lissack & Boyle, 2022) and therefore important to seek to understand the wider systems and the individuals who are also largely impacted, like parents.

## 2.6 Method of Synthesis

The SLR employed a narrative synthesis methodology (Popay et al's., 2006) to summarise and synthesize the findings of the chosen thirteen studies. Initially, the studies were read thoroughly to familiarise the researcher. To start the preliminary synthesis the researcher wrote textual descriptions of the studies and utilised tabulation as outlined by Popay et al., (2006). All studies were then critically appraised. Then, as per Popay et al., (2006), thematic analysis techniques took place to identify main themes specifically reported by parents within the studies. Afterwards, the next stage of the identification and reflection on relationships within and between the studies took place, Clinkenbeard's (1991) tool of idea webbing supported this process. The final stage of assessing the robustness of the synthesis can be found in Section 2.8.

## 2.7 Synthesis Findings

The synthesis constructed four overarching narratives and ten sub-narratives. See Figure 2 where overarching narratives are in bold.

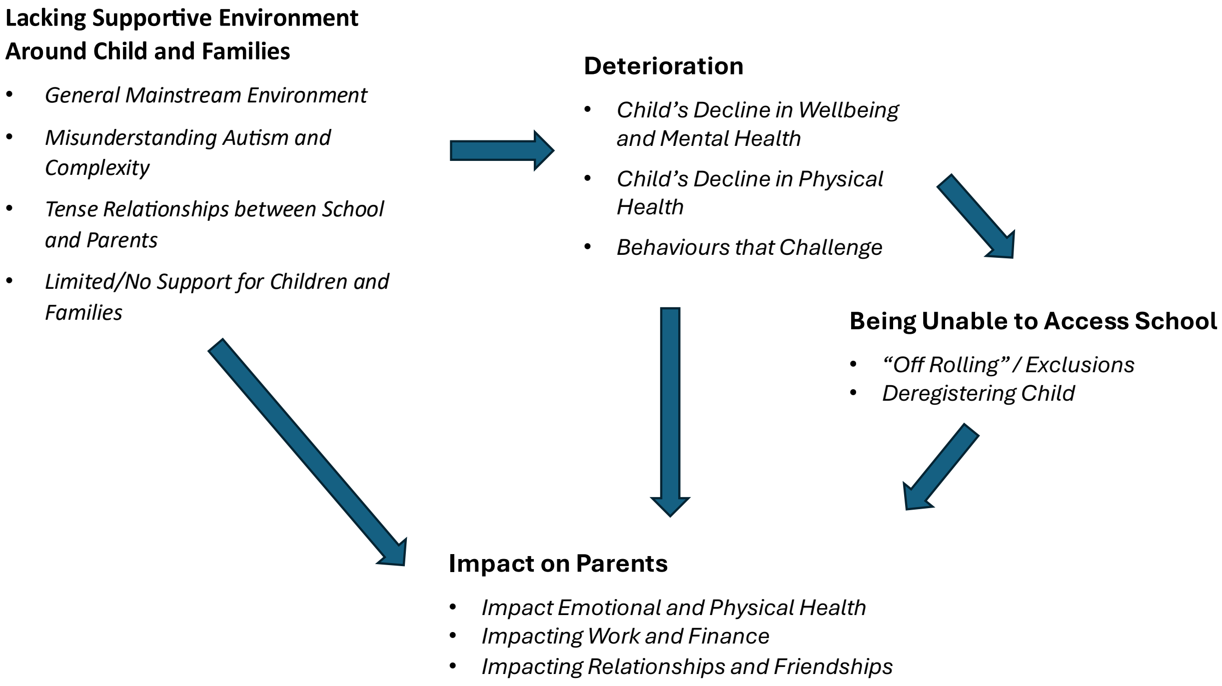

Figure 2 – SLR Synthesis Findings

## 2.7.1 Lacking Supportive Environment Around Child and Families

In all studies, participants shared experiences where they lacked supportive environments, that led to detrimental effects on their child's school attendance. Some studies reflected on the importance of having supportive environments, particularly in the context of reintegration when individuals have already encountered detrimental effects of an environment that lacks support and understanding (Neilson & Bond, 2023; Brede et al., 2017; Gray et al., 2023; O'Hagan et al., 2024). Factors that contributed to whether an environment lacked support or not are outlined in the subthemes below. All of these factors were felt to lead to the child's deterioration which is outlined in Section 2.7.2.

### *2.7.1.1 Mainstream Environment*

Five studies[18] specifically spoke to the mainstream environment often not meeting the needs of autistic CYP (Martin-Denham, 2022; Brede et al., 2017; Gray et al., 2023; Sproston et al., 2017; Lawrence 2025). Mainstream school environments were criticised as an "impersonal environment" (Sproston et al., 2017), that "will pay a lip service to inclusion – what they say and do are very different" (Gray et al., 2023), with many staff lacking understanding of autism and support (Martin-Denham, 2022), these findings will be further explored as separate themes in Section 2.7.1.2 and 2.7.1.4. However, it is noteworthy that one of the studies' participants attributed limited support in mainstream due to needing to manage "30 in a class" (Sproston et al., 2017). Overall, it appeared that the mainstream school's systems, environment and culture were not set up to meet the children's and young people's needs, thus creating a barrier to their school attendance and accessibility.

This was argued to be further compounded by the physical environment of the mainstream schools, which was found to be another barrier for attendance. The impactful sensory environment was highlighted by Sproston et al., (2017) and Brede et al., (2017) who found, "there was a lot of noise and visual distractions, and there was nowhere private for him to go to calm down". From encountering such environments, it often meant CYP were

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[18] O' Hagan et al., (2024) and Neilson and Bond (2023) also spoke to the theme of the mainstream environment, however the findings were not included in the synthesis as the theme was reported by the young people participating rather than the parents.

found to be “just too overloaded” (Gray et al., 2023) and “unable to cope” with the busyness of such environment (Lawrence 2025).

#### *2.7.1.2 Misunderstanding Autism and Complexity*

Nine studies reported the misunderstanding and lack of knowledge of autism (Mullally & Connolly, 2025; Martin-Denham, 2022; Brede et al., 2017; Gray et al., 2023; Sproston et al., 2017; Blackwell, 2024; Totiska et al., 2023; Paulaskaite, 2022), with Lissack and Boyle (2022) further emphasising the overlooked complexity and cross-over with SNA. Mullally and Connolly (2025), contended that there was thought to be a lack of teacher training in neurodivergence, with parents naming staff as “uninformed”. The lacking knowledge and understanding from staff was connected to an individual’s need not to be met, thus placing a barrier for school attendance and accessibility, with children feeling unable to cope (Totiska et al., 2023; Blackwell, 2024; Lissack & Boyle, 2022).

Several studies found the lack of knowledge meant teachers were unable to recognise needs or distress and therefore did not understand how to best support children at these times. Lissack and Boyle (2022) asserted that many parents believed staff “did not recognise the hidden difficulties” or masking in autism, which meant that difficulties were not recognised and ultimately ignored until crisis. Brede et al’s., (2017) parents also spoke to the “invisibility” of autism, with staff misattributing a child’s needs to them “being picky” rather than specific characteristics of autism. Parents wondered if the “invisibility” perpetuated the lack of recognition and knowledge. Sproston et al., (2017) reflected on parent’s frustrations towards the lack of knowledge and how it “really hurts” the child.

As a result of lacking knowledge in autistic presentations and needs, it meant staff “didn’t know how to get the best” out of the children (Gray et al., 2023) and were not aware of “the impacts it would have” on the children (Martin-Denham, 2022), despite some children having educational support plans (Blackwell, 2024). If there were strategies to support children’s needs in place, the plans were not executed well with reports that it “lacked any kind of comprehension” (Martin-Denham, 2022). Various studies found that CYP were being punished with inappropriate measures resulting from a lack of knowledge and understanding. Children were viewed as “badly behaved”, “naughty”, “rude”, or “lazy” and therefore were “constantly punished for the same things over and over” (Sproston et al., 2017; Gray et al., 2023; Brede et al., 2017; Lissack & Boyle, 2022; Blackwell, 2024). Parents reported that some of the inappropriate methods including emotional and physical abuse, use of restraints as well as “unofficial – even illegal exclusions” (Gray et al., 2023; Brede et al., 2017).

#### *2.7.1.3 Tense Relationships between School and Parents*

Eight studies highlighted difficult and tense relationships between the school and parents, these relationships involved parents being threatened, blamed or dismissed, which created another barrier in the environment for children being able to access schools (Mullally & Connolly, 2025; Connolly et al., 2023; Lissack & Boyle, 2022; Neilson & Bond, 2023; Gray et al., 2023; Brede et al., 2017; Martin-Denham, 2022; Sproston et al., 2017). However, an additional two studies focused solely on the importance of parent/school relationships, communication and how this may facilitate school attendance and access (O’Hagan et al., 2024; Totiska et al., 2023). The two studies which spoke to the importance of the relationships were in the context of exploring successful reintegration and facilitators of accessing school which may explain the difference in views.

Numerous studies found parents were often blamed for their child’s lack of attendance, presentations and behaviours. Schools would frequently attribute these to the child’s home life and parenting whereby they were seen as a “problem family”, or blaming parents own mental health, with recommendations that parents complete parental courses (Martin-Denham, 2022; Gray et al., 2023; Mullally & Connolly, 2025; Lissack & Boyle, 2022). The majority of parents (77.6%) reported experiencing professional gaslighting (Mullally & Connolly, 2025), with parents describing that they are made to feel useless like they are not trying hard enough (Lissack & Boyle, 2022). Many of the studies reflected that parents were regularly dismissed, disbelieved, ignored, or “treated like idiots” when sharing their child’s needs (Brede et al., 2017; Sproston et al., 2017; Lissack & Boyle, 2022; Mullally & Connolly, 2025). Together, Lissack and Boyle (2022) plus Gray et al., (2023) reported many parents felt in a “constant battle” for support or acknowledgement, with communication becoming more tense, described as “nastier and nastier from school”. Mullally and Connolly (2025) found that parents frequently selected negative adjectives when describing their experience with school staff, including “deceitful”, “critical”, “cold”, “wrong” and “derogatory”. Parents shared that once the relationship with schools is broken it is very hard to repair (Martin-Denham, 2022).

Staff were reported to believe it was the child’s choice to not attend school (Lissack & Boyle, 2022), with parents ultimately blamed for neglect and abuse (Neilson & Bond, 2023; Mullally & Connolly, 2025), various studies observed parents then threatened with punishment (Mullally & Connolly, 2025; Connolly et al., 2023; Lissack & Boyle, 2022; Neilson & Bond, 2023). Mullally and Connolly (2025) reported an overarching theme of dread, fear and vulnerability shared by the parents, with threats of being fined, prosecuted, or being referred to external agencies like children’s social services. Threats of prosecution impacted parent’s mental health (discussed in Section 2.7.4.2) and was argued to punish the vulnerable more than addressing wider truanting (Lissack & Boyle, 2022). Connolly et al., (2023) highlighted the positions that parents were put in when trying to get their child to school such as having to physically carry their child in crying and “kicking, screaming”, or seeing their child beg to not go. Parents reflected how difficult and “hard it was on many days” (Connolly et al., 2023). Despite these efforts, parents continued to be blamed or threatened, though Mullally and Connolly (2025) reported that whilst threats were made, only a small percentage of parents were fined or contacted by wider services

Despite most parents reporting tense relationships, there were examples of support and collaboration. The collaborative nature reported by the few individuals meant that parents and staff were able to share concerns and suggestions (O’Hagan et al., 2024) and “come up with solutions together”, thus maintaining a positive relationship (Lissack & Boyle, 2022). Totiska et al., (2023) found good parent and child-teacher relationships were a facilitator for being able to attend school, with Neilson and Bond, (2023) reporting that it can lead to individuals being “seen, and heard and understood”.

#### *2.7.1.4 Limited / No Support for Children and Families*

Ten studies found limited or no support for the children and families, to be a barrier for attending and accessing school, highlighting barriers when seeking support for diagnosis, provisions, and during periods of non-attendance and school distress (Mullally & Connolly, 2025; Connolly et al., 2023; Lissack & Boyle, 2022; O'Hagan et al., 2024; Neilson & Bond, 2023; Martin-Denham, 2022; Sproston et al., 2017; Blackwell, 2024; Paulaskaite, 2022; Gray et al., 2023).

Most studies cited that the onus was often placed on parents to get support, particularly when parents were "constantly told there wasn't provision" for their child by schools, and calls for help were unnoticed (Gray et al., 2023; Sproston et al., 2017; Lissack & Boyle, 2022). Parents were found to have been "pivotal" in initiating processes for getting diagnoses and further support, parents stated that they "applied for the EHCP" because the school wouldn't do it. No one would help me, so I did it myself" (O'Hagan et al., 2024; Sproston et al., 2017). It was the parents who were trying to contact schools for support and request referrals to services which were being rejected and thus bounced between services (Martin-Denham, 2022; Lissack & Boyle, 2022).

Neilson and Bond (2023) reported that parents described getting a formal diagnosis as a "gamechanger" which facilitated working together between different professionals, though they raised there still lacked observation of the "full picture". Martin-Denham (2022) raised that parents believed, if their child had been diagnosed sooner, it would have led to better access to support and provision. Despite this, the majority of studies found parents expressed dissatisfaction with the support from schools and local authorities and contended that limited or no support was in place despite having EHCPs and medical documents outlining their needs and implications if not met (Connolly et al., 2023; Martin-Denham, 2022; Blackwell, 2024; Paulaskaite, 2022; Lissack & Boyle, 2022).

Where inadequate support was observed, parents reported implications felt across the whole family (Lissack & Boyle, 2022). Parents described losing "all faith in educations systems", a sense of being "failed" and abandoned when the child and family "needed support most", leaving families "stuck" and not knowing what to do (Sproston et al., 2017; Lissack & Boyle, 2022). Parents highlighted that they were "fighting with a system that is ableist", and that the professional practices did not meet their children's needs (Neilson & Bond, 2023). However, Lissack and Boyle (2022) found that over half the parents believed that the support had been helpful to some extent even if the extent was reported as "little".

Connolly et al., (2023) also found a small proportion of parents' voices sharing that schools were supporting some reasonable adjustments for their children.

## 2.7.2 Deterioration

In eight studies, parents reported noticing a deterioration in their child when they were accessing school full-time. The deterioration was described in the context of the child's mental health and wellbeing, their physical health and was communicated through their behaviours. It was argued that this deterioration occurred due to needs not being met and a lack of a supportive environment and system at school (Connolly et al., 2023). The deterioration often led to children being unable to access school, discussed in Section 2.7.3. However, it is noteworthy that Gray et al., (2023) and Brede et al., (2017) emphasised that when these needs are met, children flourished in their wellbeing, and health.

### *2.7.2.1 Decline in Mental Health and Wellbeing*

Eight studies found that parents reported observing their child's mental health declining with an increase in their level of distress (Paulauskaite, 2022; Lawrence, 2025; Blackwell, 2024; Sproston et al., 2017; Gray et al., 2023; Brede et al., 2017; Martin-Denham, 2022; Connolly et al., 2023). Parents reported witnessing their child become anxious, frustrated, depressed, distressed, overwhelmed, burnt-out, leading to children being in a state of crisis thus self-harming and attempting suicide (Brede et al., 2017; Martin-Denham, 2022; Connolly et al., 2023; Paulauskaite, 2022; Lawrence, 2025; Blackwell, 2024; Gray et al., 2023). Parents shared that their child was often waking in the night crying, "rocking backwards and forwards", "shutting down", unable to communicate, with their child expressing they wanted to "live in heaven… away from all the nastiness in school" and some children acting on this (Connolly et al., 2023; Gray et al., 2023; Brede et al., 2017; Martin-Denham, 2022). Parents shared how difficult it was to see their child in such levels of distress (Brede et al., 2017; Martin-Denham, 2022). Studies highlighted that the levels of distress and decline in mental health related to attending school and lacking a supportive environment from schools or any wider support (Sproston et al., 2017; Lawrence, 2025; Blackwell, 2024; Connolly et al., 2023; Martin-Denham, 2022).

#### *2.7.2.2 Decline in Physical Health*

Three studies reported that distress felt by children had impacted their physical health (Lawrence, 2025; Connolly et al., 2023; Gray et al., 2023). The parents described how anxiety manifested in physical bodily responses such as vomiting, nausea, and incontinence, parents shared how symptoms appeared every night prior to school and impacted their child’s sleep (Connolly et al., 2023; Gray et al., 2023). Lawrence (2025) also reported that distress manifested in a child’s physical health whereby a child was unwell every few weeks which medical investigations ruled out other causes.

#### *2.7.2.3 Behaviours that Challenge*

Four studies found that parents reported their child was getting to heightened levels of distress, particularly before and after attending school, which led to an escalation in their behaviour described as “meltdowns” or “behaviours that challenge”. (Blackwell, 2024; Brede et al., 2017; Connolly et al., 2023; Lawrence, 2025). In these situations, the behaviour was explained as “lashing out”, “kicking”, “screaming”, “violent” and happened daily when attending school (Blackwell, 2024; Connolly et al., 2023; Lawrence, 2025). Brede et al., (2017) added barricading, destroying school property, attempts to end their life, and self-injury like banging their heads, pulling their hair out. These behaviours were considered to be communicating the high levels of “crisis” and exhaustion from attending the school environment (Brede et al., 2017).

### 2.7.3 Being Unable to Access School

Eight studies specifically spoke to individuals being unable to access school due to exclusions and “off-rolling”[19]. Exclusions and “off-rolling” took place when a child’s mental health had deteriorated, distress and behaviours that challenge increased, often in response to unmet needs and lack of support. These experiences were also frequently cited as the reason parents deregistered their child from school (Blackwell, 2024).

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[19] Off-rolling is described as a child being excluded for non-disciplinary purposes and is unlawful in the UK (Mullally & Connolly, 2025).

#### *2.7.3.1 “Off Rolling” and Exclusions*

Eight studies noted that parents had told researchers that their children had either been excluded or “off-rolled” and therefore unable to access school (Martin-Denham, 2022; Gray et al., 2023; Lissack & Boyle, 2022; Paulaskaite, 2022; Mullally & Connolly, 2025; Brede et al., 2017; Blackwell, 2024; Lawrence, 2025). Brede et al., (2017) found that children had often experienced multiple exclusions, with one individual being excluded 24 times within a 3-month period, causing distress and a decline to their mental health. Children were frequently reported as being expelled from school, with a small percentage being expelled permanently, and the majority excluded “unofficially” and “informally” such as sending a child home early or telling parents that their child “would be better off at home”, which had impacts on the parents, see Section 2.7.4 (Gray et al., 2023; Blackwell, 2024; Martin-Denham, 2022; Paulaskaite, 2022).

Children were “off-rolled” from schools, with parents encouraged to remove their child and home-educate, when schools reported being unable to meet the child’s needs (Lissack & Boyle, 2022; Paulaskaite, 2022). Lawrence (2025) inserted that parents saw this as avoiding their child being expelled. Parents shared that the “school did everything they could to get rid of my child”, adding that they were told it would be easier (Mullally & Connolly, 2025).

#### *2.7.3.2 Deregistering Child*

Four studies shared parents had opted to de-register their child from attending school after their child had deteriorated and struggled to access school with their needs met (Lissack & Boyle, 2022; Paulaskaite, 2022; Brede et al., 2017; Martin-Denham, 2022). Parents were seen to deregister their child to avoid exclusions and further negative experiences (Brede et al., 2017). Frequently, parents described thinking “long and hard”, believing there was no other option but to de-register their child (Lissack & Boyle, 2022). These decisions came after parents felt pressured by schools to remove their child, or they had noticed their child’s mental health and wellbeing deteriorating, or their child’s needs not being met in school, and losing “all faith” from a lack of help and support (Paulaskaite, 2022; Lissack &

Boyle, 2022). Martin-Denham (2022) reported that due to children unable to attend school, many parents resigned from employment, discussed in Section 2.7.4.2.

## 2.7.4 Impact on Parents

Eight studies reported that parents were greatly impacted by their child being unable to access school as a consequence of their needs not being met and a lack of support from school and external services. Mullally and Connolly (2025) reported that school distress had a “significant negative impact on every aspect” of parents’ lives. Whilst there were several reports that mentioned the entire household being affected (Gray et al., 2023; Brede et al., 2017; Blackwell, 2024; Lissack & Boyle, 2022), this next section will specifically focus on the impacts on parents.

### *2.7.4.1 Impacting Mental Health and Physical Health*

Five studies reported various detrimental impacts on parents’ own wellbeing and mental health, with two studies also finding impacts on their physical health (Gray et al., 2023; Lissack & Boyle, 2022; Mullally & Connolly, 2025; Connolly et al., 2023; Martin-Denham, 2022). Parents expressed how emotionally hard and heartbreaking these situations were with the addition of the “relentless” emails and calls about their child’s behaviour which meant parents were “constantly on alert” and feeling like everything’s out of control (Connolly et al., 2023; Gray et al., 2023; Martin-Denham, 2022).

Parents shared how they felt stuck with their lives being turned upside down, and that this experience was the hardest they had experienced in their life (Lissack & Boyle, 2022). Mullally and Connolly (2025) similarly found that parents reported the experience of school distress as the second most threatening life event, behind the death of a child or spouse. They went on to report parents lived in fear, had a significantly lower mood, lack of positive emotions, higher anxiety levels compared to parents whose children did not experience school distress, over 50% of participants had developed a new mental health condition since the distress began (Mullally & Connolly, 2025). Martin-Denham (2022) reported that some parents had been prescribed medication for anxiety since their child had started to experience school distress.

Many of the studies reported that parents disclosed feeling guilty for taking their child to school and knowing they were sending their child somewhere that would not meet their needs (Gray et al., 2023; Lissack & Boyle, 2022; Martin-Denham, 2022). Mullally and Connolly (2025), highlighted that the harm to parents' mental health was led by a loss of confidence in themselves and their parenting. Parents further stressed the emotional toll of not being able to access support for their child or themselves. One of the parents described it as "crying on my knees for help" (Martin-Denham, 2022; Lissack & Boyle, 2022). Gray et al., (2023) with Mullally and Connolly (2025) went on to find that once children were either accessing a provision that their needs were met or where a child was de-registered from schools or educated at home, that it had a positive impact on parents' emotions.

Two studies also found parent's physical health was significantly impacted by their experiences with one parent disclosing that they had shingles every single year resulting from stress (Gray et al., 2023; Mullally & Connolly, 2025).

#### *2.7.4.2 Impacting Employment and Finances*

Five studies stressed the level of impact of these experiences at school on parents' employment and consequently their access to finance (Blackwell, 2024; Gray et al., 2023; Mullally & Connolly, 2025; Martin-Denham, 2022; Paulaskaite, 2022). Mullally and Connolly (2025) commented that one of the most negative impacts was on parents' careers, with Gray et al., (2023) and Blackwell (2024) adding that parents often had to give up employment due to it being "impossible" to maintain a job at the same time. This meant that parents had big financial implications which also compounded their experiences (Paulaskaite, 2022; Martin-Denham, 2022). Blackwell's (2024) study specifically explored impact on parents' employment, and they concluded that parent's dilemmas around employment were significantly impacted by the extent schools met their child's needs.

Parents highlighted they were unable to work due to their child accessing school part-time or being excluded, as well as receiving phone calls in the day to collect their child (Blackwell, 2024). As a result of the unpredictability, some parents opted for shift patterns or part-time work, reducing their overall hours, so that there would be one parent around to support their child if needed, one of the parents commented that they were “barely surviving” as a result (Blackwell, 2024). Some parents were able to work through sympathetic employers or by finding flexible jobs to continue working while supporting their child, though it was reported that these parents often overcompensated and worked more than their employed hours to ensure “time was made back up” (Blackwell, 2024). If able to work, parents reflected they felt stuck in employment roles in case their routines were disturbed, this meant parents took on job roles below their qualifications, refused promotions or moving into new roles (Blackwell, 2024). Overall, parents were found to be constricted by conflicting demands, which meant the majority of parents were unable to be employed.

#### *2.7.4.3 Impacting Relationships and Friendships*

Two studies specifically reflected on the impacts on parents’ relationships and friendships (Mullally & Connolly, 2025; Gray et al., 2023). Mullally and Connolly (2025) found that a significant impact was on parents’ relationships with their partners, with several parents referring to breakdowns in their relationships due to the stresses both experienced as well as having limited time together. Gray et al., (2023) reported how parents described becoming “very quickly excluded” from others and experiencing social isolation. Mullally and Connolly (2025) added that parents not only described a loss of leisure time and friendships but further outlined that they were not believed by “just about everyone in their life” which further impacted their relationships.

## 2.8 Conclusion and Evaluation of Review Findings:

Thirteen studies were reviewed and synthesised within this SLR. The results highlighted the complexity when considering parents’ experiences of autistic children and school non-attendance, and lack of literature. The SLR found that there was often a lacking supportive environment within schools that results in the deterioration of a child’s mental and physical health leading them to not be able to access schools; all these factors directly impacted parents. The impacts of parents were found to be on their mental and physical health, their employment and their relationships with others.

To the researcher's knowledge, this is the first SLR to specifically focus on parents' experiences within the UK. Though this SLR offers value in synthesising research and highlighting the impacts on parents, results should still be interpreted with caution. Whilst there was literature that focused on parents' experiences of their child attending schools and their child's deterioration, there was still limited research that specifically focused on the impacts on parents, for instance the impact on social relationships was found in only two of the studies. This may be explained by the studies included in this SLR having different research aims and not specifically focusing on parents' experiences, though the studies were still included as they offered comments and insights. This highlights the lack of available literature within this area and poses as a potential limitation of the SLR. Whilst a strength of this SLR was the level of thought given to the search terms and language over the years as well as the SLR being re-run to try to reduce missed research, a choice was made to include five studies where not all the samples were autistic which also poses as a limitation. It was deemed important to include these due to the high percentages of the sample that were autistic and to not miss these voices, particularly given the lack of literature in this area and a need for recommendations.

## 2.9 Implications from the Review

There were several implications highlighted from the SLR. The SLR highlighted multiple concerns and reports of the children's needs not being met, in addition to a lack of knowledge and support from the environment. This became detrimental to children's attendance and mental and physical health. It would be suggested that schools and external professionals need more training in autism to develop their understanding as this currently acts as a barrier for children's needs being met along with misunderstandings of children's presentation leading to exclusions and off-rolling.

It is recommended that a consideration of needs is further explored and assessed when schools and clinical professionals first notice behavioural changes, or when children display distress. It is further proposed the topic of needs in school is thoroughly assessed when children and families try to access referrals to mental health or other clinical settings, this will allow professionals to work to ensure that needs are met. However, the SLR did highlight that not all individual's needs can be met for those who struggle within mainstream environments as they may require specialist provisions, which should be held in mind. Investment from the UK government is required to support this process.

The SLR further highlighted the tense and difficult relationships with schools as well as a lack of support from clinical professionals for parents, despite such significant impacts on them. The implications from this contend that parents' voices should be heard and respected when working together to best support children in accessing school and external services. Parents' voices can be considered as crucial when formulating what may be happening for the child, as they see the wider picture (Neilson & Bond, 2023). It also implied there needs to be better provision for parents to seek support for themselves and for them to have signposting of where they can also get practical and emotional support for themselves and their child to reduce isolation.

Due to the SLR finding such lack in literature, another implication includes the need for further research to take place to deepen understandings of the experiences and impacts for professionals and services to be better aware and so future provisions can offer packages of tailored support based on this. The research needed in this area should also aim to represent more diverse samples that represent the UK's population which was limited within the studies included in the SLR.

## 2.10 Rationale for the Current Research

As reported throughout the introduction and SLR, there is limited research on parents' experience and the impacts on parents from their autistic and neurodivergent children being unable to attend school, yet there has been vast research penalising and blaming parents in this area (Înoue, 2022). Though the SLR highlighted some of the complexity and nuances around these experiences, further research is required to extend the understanding by considering other neurodivergence in addition to autism to explore whether the experiences are related or different. Further research is also needed to specifically explore what parents' experiences have been, the impacts, why these experiences have happened and how they have come to make sense of their experiences. It is believed that if research could start to answer some of these questions, recommendations will be able to be advocated for services to better support children to access schools safely, with their needs being met from appropriate and tailored support, and stop harm that is currently observed for many.

## 2.11 Aims and Research Question

This current research aims to fill these gaps and build upon the literature by further exploring in greater depth the experiences of parents and primary caregivers currently trying to access school for their neurodivergent children. It is hoped that the research will be able to offer a theoretical model that may be useful to support others in understanding their experiences and the impacts.

Therefore, the research's purpose was to address the following question:

**What are primary caregivers' experiences of school accessibility for neurodivergent children?**

# Chapter Three: Methodology

## 3.1 Overview

This chapter details the chosen design methodology, researcher's epistemological stance, and rationale for using constructivist grounded theory in addressing the research question. The participant sample and recruitment, ethical considerations, data collection and analysis will be described. Finally, the use of consultations, self-reflexivity and the method of quality appraisal for the research will be outlined.

## 3.2 Design

A qualitative design was chosen as it lent itself to the exploratory nature of this research (Barker et al., 2002), whilst maintaining methodological integrity and rigor (Lim, 2024). Qualitative research offers openness to participants thus harnessing in-depth exploration which leads to rich detailed data that explores individual's understanding of specific phenomena and world (Sofaer, 1999). This is key in exploring the meaning-making of individual's experiences (Willig, 2008). Further, qualitative research can be useful when exploring a new topic area to generate a theory (Tenny et al., 2022). Based on this, it made sense to choose a Constructivist Grounded Theory (CGT) design, considering the lack of previous literature in this topic, focus on individual's meaning making and my own epistemological stance.

### 3.2.1 Epistemology Stance

Critical realism was the epistemological stance that informed this research (Bhaskar, 1989)[20]. The critical realist stance is considered relevant to research which explores social processes in natural settings, as this piece of research aims (Fletcher, 2017; Lawani, 2021).

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[20] Therefore, the existence of reality independent of human perception is assumed (Bhaskar, 1989), however it is recognised that knowledge and the experience of reality is subjective and constantly changing based on social construction, including individual's language, meaning making and social context (O'Mahoney, 2016; Groff, 2004). Critical realism acknowledges social and historical contexts which influence how people make meaning of life and holds the perspective that reality should be investigated cautiously and critically (Pilgrim & Bentall, 1999).

This current research aims to explore the experiences of parents of school accessibility for neurodivergent children. These experiences are likely to have been shaped by several social and historical processes including the actions of others, plus the context and social systems they are situated in (i.e. school, education, and local authority). The critical realist stance acknowledges the reality of events that surround parents, whilst recognising the experience is mediated by meaning making and social context.

The critical realist stance aligns with the CGT research design chosen for this research, as reality is considered to be "multiple, processual and constructed" (Charmaz, 2014; P13). Levers (2013) contends that CGT offers the opportunity to acknowledge there is a real world which both participant and researcher can have access to bits and pieces, which supports critical realist positionings. CGT acknowledges the interactive mutual role both participants and researchers have in making sense and co-constructing an account of reality (Willig, 2008; Charmaz 2014). This is consistent with critical realist stances in which the experience of reality is subjective and constantly changing based on social construction (O'Mahoney, 2016). As CGT proposes researchers as integral and inseparable to constructing the reality of the research, it does not seek to remove their influence, rather it urges researchers to recognise and reflect on this in forms of memo writing and journalling, this was particularly important based on the current researcher's insider-outsider position (Charmaz, 2014; O'Connor et al., 2018).

In line with these positions, this research strives to offer co-constructions of individual's accounts of experiences that recognises the context (including structural aspects) in which they are located (Charmaz, 2000; Clarke et al., 2023)[21].

### 3.2.2 Constructivist Grounded Theory (CGT)

CGT was identified as the most appropriate for this research based on the connections to the researcher's epistemological position, insider-outsider positioning, research question and lack of current literature (Charmaz, 2014). CGT seeks to study "how"

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[21] The research aims to do this by employing language that captures the contextually located and fluid advancing nature of the individual's reality (Sturgiss & Clark, 2020; Lawani, 2021). It was important to stay close to participants language as they may not describe themselves, actions and situations in ways the researcher may (Charmaz, 2014).

and “why” participant’s construct meanings and actions in specific contextually located positions and situations (Charmaz, 2006, P.130, Tweed & Charmaz, 2012). CGT was appropriate for the research and making sense of parent’s experiences as it seeks to analyse both structural aspects of individuals lives as well as their specific meaning making (Charmaz, 2000; Clarke et al., 2023). This further aligns with critical realist positionings. CGT differs from other variations of GT by placing emphasis on the meaning being co-created mutually by the participants and the researcher (Charmaz, 2006), therefore how knowledge is created in this research will be influenced by how the researcher has engaged in the world and connects to the researcher’s insider-outsider status (Keane, 2015). Therefore, it is important for the researcher’s influence, values, positionings, beliefs, privilege and context within the research to be critically reflected on and scrutinised in CGT (Charmaz, 2014) which is crucial for this research. Finally, CGT was used in hope to establish credibility, usefulness, originality and resonance for this research as outlined in the CGT quality criteria (Charmaz, 2014; McCall & Edwards).

Literature has noted several challenges that CGT presents with particularly for novice researchers in CGT. One challenge highlighted is the time-consuming process of coding which can highlight novice researchers’ lack of confidence, uncertainty and doubts, as well as absorbing researchers so that they may lose sight of undertaking the task (Bryant, 2019; Hussein et al., 2014). This research attempted to overcome this limitation by “not hurrying” developing the theory or codes consistent with Annells (1996) advice. Additionally, the researcher involved several supervisors and peers throughout the process, particularly around coding and theory development, who had completed several previous CGT projects. Reflexivity poses as a second potential limitation when using CGT (Bobbink et al., 2024), particularly if the researcher is not acknowledging or engaging in this crucial process to CGT (Charmaz, 2014). If reflexivity is not engaged with and lacks in CGT research, it can lead to the surfacing of the researcher’s own assumptions and interpretations of data (Hussein et al., 2014). This topic is further addressed in Table 13, whereby it explains how this was monitored.

CGT was chosen over other alterative qualitative methodologies, see Table 6. For the development and history of CGT, see Appendix D.

Table 6 – Consideration of other data analysis methodologies

| **Method** | **Considerations and Exclusion Reasons** |
|---|---|
| Interpretative Phenomenological Analysis (IPA) | Interpretative Phenomenological Analysis (IPA) is argued to have become a leading qualitative research method that is often used to explore, describe, interpret and situate the participants sense making of their personal life experiences (Tuffour, 2017). IPA views participants as experts of their own social and personal world, and similarly to CGT, it requires researchers to consider the impact of their own experiences on the research, including the design and procedures (Howard et al., 2019). Whilst, IPA would have allowed rich data analysis of how participants sense make of their experiences, CGT was selected over this methodology as IPA has been critiqued for not being able to answer "why" questions for phenomena (Tuffour, 2017) that CGT strives to explore (Charmaz, 2008). Further, IPA would not have allowed for a deepened understanding of how social processes interact for parent's when exploring school accessibility which was crucial for the research question, rather than focusing on the meanings of lived experiences (Burns et al., 2022). |
| Narrative Analysis (NA) | Narrative analysis (NA) focuses on exploring how participants have made sense of their lives, experiences and themselves through views of self-narrations as an identity and construction (Buruk, 2005). Ricoeur (1985) contended that participants use narratives to make sense of their lived experiences, and that the participants often drew on the forms of narrative available to them to "employ" they own story of self. Using narrative analysis may have been useful to explore what narratives and societal discourse that parents draw on to tell about their lives and themselves, however CGT was decided over this approach. Mainly due to the limited research within this area and the research aiming to develop a theory to support the gap in literature and to consider recommendations for policy, guidance in schools and other professional services. |
| Thematic Analysis (TA) | Thematic analysis (TA) is widely used in qualitative research and is considered a "valuable analytic tool", it identifies, analyses and interprets meaningful themes found within qualitative data sets to make sense of participant's shared experiences (Christou, 2023). Since it's origins, several different versions of TA have emerged including reflexive TA (Braun & Clarke, 2019). Though TA can be particularly useful in areas that have been under investigated (Christou, 2023), like the current research topic wanting to be explored, CGT was ultimately chosen as the current research strived to develop and generate a theory grounded in data that focused on the social processes which TA does not offer (Braun & Clarke, 2020). |

## 3.3 Ethical Approval and Considerations

Ethical approval for the current research was granted by The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority on 26/04/2024 (Registration protocol number: LMS/PGR/UH/05617) (Appendix E). This research adheres with the BPS Code of Conduct, Ethical Principles and Guidelines (British Psychological Society, 2018).

Ethical considerations, such as informed consent and confidentiality, were made throughout this research. These are presented in Table 7.

Table 7 – Ethical Considerations

| Ethical Consideration | How these were actioned and responded to |
|---|---|
| Informed Consent | A research advertisement poster (Appendix F) was initially shared on various social media platforms (including Facebook and Twitter), and shared through several organisations connected with neurodivergence, it was further shared through word of mouth, and others sharing the poster. The individuals that clicked the link within the poster were shown a participant information sheet (Appendix G). This outlined the purpose of the research, what their involvement in the research consisted, potential benefits and risks from taking part, as well as how their data would be stored and used. A consent form (Appendix H) was also connected to the poster after the participant information sheet, for individuals wanting to participate, which outlined what they were consenting to by participating in the research. It was made clear in these forms that due to volumes of interest in this topic area, not everyone would be able to be invited to an interview.<br>Once individuals completed the initial questionnaire volunteering to participate in the research, those the researcher selected to be interviewed were contacted with further reminders of the participant information sheet and consent form to ensure their awareness of the requirements and confirm whether they consented or no longer wanted to take part in the research. Prior to the interview, these topics were reviewed again to get their consent |

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| | a final time, the researcher answered any questions, and mentioned that the interview could be paused or stopped at any point, their consent was verbally recorded on Microsoft Teams. Participants were asked for consent for the recording of the interview to be kept until transcription had taken place, and for the transcriptions to remain until research completion.<br>Participants were also asked for consent to be contacted again in the future with any follow up questions, or to review a final model of the data once analysed. Participants were reminded they had seven days after the interview was completed to withdraw from the research, after this it would not be possible due to their data being coded and merged with others. |
| Confidentiality | The terms of confidentiality were outlined to participants in the consent form, participant information sheet and at the start of the interview. Data was collected and stored in line with the Data Protection Act (2018). The demographic information collected in the initial questionnaire was stored separately to any other data. Interview recordings and transcripts were stored securely on the University of Hertfordshire encrypted OneDrive server. All participant names were removed from transcripts and updated with participants chosen pseudonyms for themselves. All children were labelled as “X” to add another layer of protection for them within the research, and all other personal information or locations were removed and generalised to “School/Location A/B” when needed to highlight a change in living location or school situation while maintaining overall anonymity. In the researcher’s memo-writing and reflective log, they referred to participants as their pseudonyms and these reflections were also stored separately. The participants were told that the audio interview recording would be deleted upon completion of the transcripts and that the transcriptions would be deleted upon completion of the research. |
| Potential Harm and Distress | The researcher was aware when considering the content of the interviews that sharing experiences may be distressing for participants, considering previous research highlighted that parents’ experiences of trying to access school for their autistic children has had a negative impact on their mental health and shared that the events have been “harrowing” and “traumatic” (Clearly et al., 2024). At the start of the interviews, participants were reminded that they |

| | |
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| | can pause, take a break, or stop the interview at any point should they need. When reviewing topics that may be covered in the interview, the researcher acknowledged to the participants that these may be difficult to speak to, and therefore all emotions were welcomed so that they were comfortable sharing these experiences. When asking questions, the researcher made sure to ask for permission each time saying, "Please can I ask", to support those who may not want to answer, as the researcher was mindful of issues surrounding power in the interviewer-interviewee relationship. To try to minimise potential distress, sensitive interviewing techniques were used, including thoughtfulness around timing and locations of interviews, building rapport using effective empathetic listening, use of respect and validation of their stories and ensuring positive closure of the interview (Dempsey, 2016). All interviews offered a verbal debrief at the end, in addition to a debrief sheet (Appendix I) emailed to all participants. |
| Token of Appreciation | Following discussions with the board of ethics and the researcher's supervisory team, as a token of appreciation to participants for their time they were invited to opt in or out of a gesture of thanks in the form of being entered into a raffle, to get one of the £20 vouchers available. This was shared at the end of the initial questionnaire. Researchers recognised this voucher was not remuneration, what the participants offered and contributed to the research was worth substantially more. In the initial sample, both approval and rejection responses for being entered in the raffle draw were observed. |

## 3.4 Consultation with EbE

The researcher specifically sought experts by experience (EBE) as consultants, recognising the knowledge and value these individuals have. The researcher found and recruited several EBE consultants by reaching out to these individuals that had platforms and were speaking to the lived experiences of SNA and neurodivergence, through their social media, websites, and by word of mouth. Given the distressing nature and topic of SNA in the context of neurodivergence it felt important to reach out to individuals that were already sharing their own and hearing others stories. The researcher had hoped to have several EBEs, however some of the individuals that agreed to take part in this role where no longer able due to their own current experiences of SNA and the demands attached with this. This highlighted the experiences and contexts that surround parents whose neurodivergent children have difficulties accessing school. In the end, the researcher was able to only access one EBE consultant who remained throughout the project, they were instrumental to the research offering their expertise, skills, reflections and time. The consultant was in a position of advocacy and shared many experiences with other parents they had met. The consultant supported the development of the interview schedule and topics by ensuring the questions were relevant and used appropriate language; they gave feedback on the eligibility criteria such as offering reflections whether we should or should not interview those currently accessing specialist provision, the CGT model created in the research, as well as ensuring meaningful dissemination plans. The consultant was paid a small amount for their role within the research.

## 3.5 Participants

### 3.5.1 Recruitment

Participants were recruited through various social media platforms, including Facebook and Twitter. The research advertisement was posted with a link to a questionnaire to complete to express interest. The research advertisement was also sent to various autism and ADHD charities and to several “Special Educational Needs and Disabilities Information, Advice and Support Services (SENDIASS)”. After the research advertisement was shared in these spaces, it was then shared through word of mouth. Participants expressing interest were emailed the participant information sheet and consent form, plus a reminder of the research to see if they still wanted to participate. Participants wanting to take part in the research were offered interview times and asked how they wanted to complete the interview, i.e. telephone, video or in person if local to the researcher. All interviews were conducted via telephone, or Microsoft Teams.

Consistent with CGT methodology (Charmaz, 2014), as used in wider research (Clarke et al, 2023), a purposive sampling method was initially employed, with hope to produce a sample that reasonably represented the population and would enable the research questions to be answered (Rai & Thapa, 2015). Subsequently, importance was placed on ensuring participants were recruited from a variety of experiences. For example, the researchers wanted to ensure there was variety in the number of children primary caregivers had, how their child was being educated and their role within this as well as the type of primary caregiver they were. The researchers wanted to ensure there was a range of experiences for the children as well in terms of schooling years and type of neurodiversity. The researchers were mindful of much research using "WEIRD" samples (Henrich et al., 2010) and therefore hoped that this research would try to avoid WEIRD recruitment practices. Subsequently, importance was also placed on ensuring participants were recruited from a range of different backgrounds and intersecting identities. This was why participants were not chosen using a "first-come first-serve" basis which may have indicated more of a privileged positioning of having time and resources. The recruitment process is outlined in Figure 3. It is worthy of note that many individuals from more diverse backgrounds and intersectionalities were initially contacted but did not respond after they had completed the initial interest questionnaire. As many parents that participated in the research raised how difficult it was to get their own physical space, time and energy to engage in the interview, it was wondered how power, privilege and resources may have stopped some individuals from fully accessing taking part in the research.

Whilst this research hoped to recruit primary caregivers (acknowledging parents but also other relationships in these positions), the research was only able to recruit biological and adoptive parents. This was observed in the initial sparse limited responses to the first questionnaire for recruitment despite advertisement clearly expressing a desire for primary caregivers, as well as no responses from those that were contacted by the researcher. This is additionally reflected on in the limitations of the research.

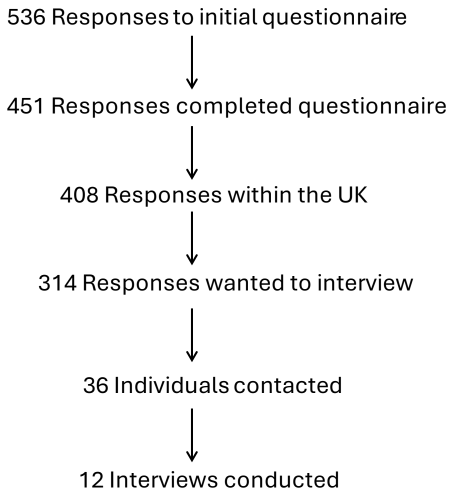

Figure 3 – Recruitment Flow Chart

### 3.5.2 Theoretical Sampling

After the first phase of recruitment when tentative codes were constructed, theoretical sampling was undertaken in line with the CGT methodology (Charmaz, 2014). Theoretical sampling is a process that allows further data to be collected which will explore concepts appearing from preliminary analysis; it is used to develop and refine categories and their boundaries, as well as mapping relationships between them (Charmaz, 2014). Memo-writing supported further sampling, as it offered space to start to theorize ideas about codes and their relationships as they strike the researcher whilst coding (Glaser, 1978) This allowed the researcher to follow up emerging ideas and questions which arose during the preliminary analysis of the first few interviews (Butler, Copnell, & Hall, 2018). As part of theoretical sampling, participants were further recruited from outside of England but within the UK and further recruited participants whose children were not currently able to access any mainstream school hours or awaiting specialist provision. The memo-writing also led the researcher to add more questions including “what strengths, resources and skills have you relied on” as the researcher noticed participants referencing “getting through it” despite no services or schools supporting them, and wondered what supported them to “get through it”. It also allowed further exploration on topics such as “in the trenches” and “everything being a blur”.

In GT, theoretical sampling continues until data reaches theoretical saturation of the emerging conceptual categories (Charmaz & Thornberg, 2021). The concept of saturation is discussed in Section 3.5.5. All participants were invited for member-checking, in the form of a focus group, to explore whether the constructed end model and categories resonated with them and in hope to seek further opinions, and increase credibility (Birt et al, 2016; Doyle, 2007).

### 3.5.3 Inclusion and Exclusion Criteria

It was important to apply the inclusion and exclusion criteria effectively when postulating the target population and sample boundaries to identify eligible individuals, as it can increase the external and internal validity of the research, as highlighted by Velasco (2010).

This research aimed to recruit primary caregivers of neurodivergent children that were unable to access mainstream schools fulltime throughout their child's life, predominantly due to their needs not being met.

Table 8 – Inclusion and Exclusion Criteria for Research's Sample

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| Primary caregivers of neurodivergent children. Children did not require an official diagnosis; their caregivers were also able to participate in the research if their child identified as being neurodivergent.<br>The reasoning was that previous research has highlighted no significant differences in autism characteristics in those who identify as autistic and those who had a confirmed diagnosis (Brice et al., 2021). It felt important to recognise in line with the UK waiting times for assessment, that individuals could be waiting for a referral to | Currently living outside of the United Kingdom as mainstream schooling differs as well as other wider contexts such as governmental policies etc (Mincu, 2022). |

| | |
|---|---|
| be made, waiting for a diagnostic assessment, or having a referral rejected due to lack of information from services prior to an accepted referral (Connolly et al., 2023). | |
| Primary caregivers of neurodivergent children who have experienced being unable to access mainstream school full time: i.e. they may have started home education after accessing mainstream school, are awaiting new school allocation or are accessing mainstream schools on reduced hours with or without an EHCP etc. | Primary caregivers whose children are currently accessing a specialist school full time with adapted plans to better support their needs. |
| Currently living in the United Kingdom | |

### 3.5.4 The Sample

Participant demographics were completed within the initial questionnaire (Appendix J) that was sent out with the advertisement, should individuals have been interested in participating. All demographics provided by participants were rechecked at the start of interviews. Twelve participants took part in this research, they were interviewed across nine months. For participants to see how their participation influenced the research, they chose their own pseudonyms for the research write-up. To further protect their anonymity, pseudonyms are not presented alongside demographic information. Additionally, age ranges have been provided to aid anonymity, their ethnicities are presented separately from demographic information. See Table 8 and 9.

Participants' children's demographics are also reported separately to participants. See Table 10. To aid further anonymity of their children, their ethnicities are reported separately, see Table 11 and locations are not shared. All participants' children lived at the same address as their primary caregivers.

Table 9 – Participant Demographic Information

| Participant Number | Age | Gender | Relation to Child | Location | Number of Children Unable to Access School |
|---|---|---|---|---|---|
| 1 | 50 – 54 | Cis-Male | Father | South East England | 1 |
| 2 | 40 – 44 | Cis-Female | Mother | London | 3 |
| 3 | 60 – 64 | Cis-Female | Adoptive Mother | Yorkshire and the Humber | 2 |
| 4 | 45 – 49 | Cis-Female | Mother | Northern Ireland | 2 |
| 5 | 35 - 39 | Cis-Female | Mother | East Midlands | 1 |
| 6 | 50 – 54 | Cis-Male | Father | South West England | 2 |
| 7 | 35 – 39 | Cis-Female | Mother | North East England | 1 |
| 8 | 40 – 44 | Cis-Female | Mother | Yorkshire and the Humber | 1 |
| 9 | 50 – 54 | Cis-Female | Mother | Scotland | 1 |
| 10 | 40 – 44 | Cis-Female | Mother | East of England | 2 |
| 11 | 35 – 39 | Cis-Female | Mother | South West England | 1 |
| 12 | 40 – 44 | Cis-Female | Mother | West Midlands | 1 |

Table 10 – Participant Demographic Ethnicity Information

| Ethnicity | Number of Participants |
|---|---|
| White: English, Welsh, Scottish, Northern Irish or British | 10 |
| Asian or Asian British | 2 |

Table 11 – Participants' Children's Demographics

| Age | Gender | School | Neurodivergence | Diagnosis? |
|---|---|---|---|---|
| 9 | Cis-Female | Primary School | Autism, Dyspraxia, PDA | Professional Diagnosed |
| 9 | Cis-Female | Junior School | Autism, SPD, Dyslexia, PDA | Professional Diagnosed |
| 11 | Cis-Male | Home Educating | Autism | Professional Diagnosed |
| 9 | Cis-Male | Primary School | Autism, Language Disorder | Professional Diagnosed |
| 15 | Cis-Female | Secondary School | Autism | Professional Diagnosed |
| 19 | Cis-Male | Secondary School/College | Autism | Professional Diagnosed |
| 11 | Cis-Male | Secondary School | Autism, ADHD | Professional Diagnosed |
| 14 | Cis-Female | Secondary School | Autism, ADHD, Afrid | Professional Diagnosed |
| 18 | Cis-Male | Secondary School/College | ADHD, Autism | Professional Diagnosed |
| 11 | Cis-Female | Secondary School | Autism, ADHD, SPD | Professional Diagnosed |
| 8 | Cis-Male | Junior School | Autism, PDA, Speech Difficulties | Self-Identified |
| 13 | Cis-Female | Secondary School | Autism | Professional Diagnosed |
| 13 | Cis-Male | Secondary School | Autism | Professional Diagnosed |
| 7 | Cis-Female | Primary School | Autism, ADHD, Selective Mutism | Professional Diagnosed |
| 5 | Cis-Female | Primary School | Autism, ADHD | Self-Identified |
| 6 | Cis-Female | Primary School | Learning Disabilities, Autism, ADHD | Professional Diagnosed |
| 9 | Cis-Female | Primary School | Speech, DCD, Autism, PDA, Auditory | Professional Diagnosed |
| 16 | Trans-Male | Education Otherwise Than At School (EOTAS) | Autism, ADHD, PDA | Professional Diagnosed |

| | | | | |
|---|---|---|---|---|
| 13 | Cis-Male | Home Educating | Autism, SPD | Professional Diagnosed |

Table 12 – Participants' Children's Demographics Ethnicity

| Ethnicity | Number of Participants |
|---|---|
| White: English, Welsh, Scottish, Northern Irish or British | 8 |
| Asian or Asian British | 4 |
| Mixed or Multiple Ethnic Groups: White and Black Caribbean | 2 |
| Mixed or Multiple Ethnic Groups: White and Asian | 2 |
| Mixed Heritage (Defined as this by parent) | 1 |

### 3.5.5 Sample Size

In GT, data collection continues until data is considered to have reached theoretical saturation of the emerging conceptual categories whereby no new theoretical insights or properties of pattern could be found in additional data gathering (Charmaz & Thornberg, 2021; Charmaz, 2006). Aldiabat & Le Navenec (2018) described reaching data saturation in GT as "mysterious, subjective, non-linear and gradual", and acknowledged the concept of theoretical saturation and how it is articulated has received various criticisms with several researchers in disagreement about the definition, level of ambiguity and minimum criteria (Unlu & Qureshi, 2023). Critical realist positions which see multiple constructions of reality, may also critique early definitions of theoretical saturation in GT and could find it to be problematic as they would argue it is always possible to see new theoretical insights if new data were to be gathered and that saturation is not objective (Low, 2019; Unlu & Qureshi, 2023).

Subsequently, this current research used various guidance to critically consider whether theoretical saturation had taken place. Whilst many researchers contend the there is no "set" number of interviews to achieve saturation (Unlu & Qureshi, 2023), researchers have argued a minimum of ten (Charmaz, 2014). The researcher was mindful to use this as a tentative guide and focused on the use of theoretical sampling, preliminary data analysis and memo writing to consider theoretical saturation as used in CGT rather than using a set number of interviews (Charmaz, 2014). Theoretical saturation was also considered in line with some of Low's (2019) explanations[22] whereby it is questioned in terms of robustness and rigor of the theory. Though ultimately Charmaz's (2006) CGT concept of data sufficiency was used, whereby it was seen as a dynamic and ongoing process rather than a predetermined amount of data. Participants were recruited until new data did not provide any new properties of theoretical categories or new theoretical insights, and when a meaningful coherent co-constructed theory was created that accounted for the majority of data (Charmaz & Thornberg, 2021; Charmaz, 2006). Consistent with CGT, it is the interaction between the researcher, participants and experiences that construct the theoretical saturation (Unlu & Qureshi, 2023). This research is mindful that saturation is subjective, therefore there are other possible ways of constructing the theory in the different contexts with other researchers (Unlu & Qureshi, 2023).

Deliberating on these explanations, the current research was considered to have reached theoretical sufficiency within twelve interviews.

## 3.6 Data Collection

### 3.6.1 Interviews

Semi-structured interviews were chosen for data collection, they are a widely used and accepted method in gathering qualitative data (Seidman, 2013), interviews invite participants to freely share their stories which is in line with CGT methodology and the researcher's epistemology (Clarke et al., 2023; Cunningham et al., 2017). This research specifically used intensive interviewing techniques in line with CGT; intensive interviewing recognises that the interviewee has substantial experience and knowledge, therefore its structure offers an open-ended in-depth exploration of these areas and interpretations of

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[22] Low (2019) contended that research can be considered robust and coherent by addressing "how and why" questions, use of theoretical sampling that generates connecting categories to create a conceptual model which is held in social context and accounts for sufficient data.

participant's experiences (Charmaz, 2014). During intensive interviewing, responses and discourses can emerge from the participant's multiple identities and social connections (Charmaz, 2014). Interviews were completed over telephone and Microsoft Teams, this was to reach various participants from different parts of the UK and in hope to widen access and offer more flexibility when the interviews could take place.

### 3.6.2 Interview Schedule

In line with CGT, the researcher initially created the semi-structured interview schedule with questions that aimed to support fulfilling the research objectives, whilst also being aware of some current experiences associated within this research area that were shared by the EBE consultants in the project, as Charmaz (2014) suggests. The interview schedule was influenced by Charmaz's (2014) types of CGT questions, and further developed by the researcher, their supervisory team and EBE consultants. To explore participant's interpretations of their experience, the interview schedule started with open-ended questions to ease the participants and then focused questions to encourage detail discussions of the topic; it hoped to support unanticipated statements and stories to emerge by using non-judgemental, open-ended questions (Charmaz, 2014). An intensive interviewing technique was harnessed throughout to allow openness and delve deeper into participants' experiences (Bobbink et al., 2024; Lindqvist & Forsberg, 2021). The interview schedule aimed to follow the journey that parents encountered, therefore it focused on the start of their journey, their experiences whilst their child was unable to access school, how they made sense of their experiences, impacts, how they understood others responding to their experience, experiences of what was supportive or unhelpful to accessing school, and what changes they would like to see (refer to Appendix K).

In accordance with CGT, the interview schedule was developed and seen as "a flexible tool to revise" over the process of interviewing and theoretical sampling (Charmaz, 2014). The changes to the interview schedule allowed for refining concepts and categories as well as exploring further gaps and unanswered questions. As a result of this, questions were added to the interview schedule, such as "What strengths, resources, and skills have you relied on?".

The researcher engaged in reflexive journalling throughout the stages of creating the interview schedule and pilot interview which was important to consider and reflect on any assumptions and biases, in line with CGT (Hussein et al., 2014). The researcher also used Charmaz's (2014) reflective questions to consider the interview schedule, see Table 12.

Table 13 – Reflective Questions to Support Interview Schedule (Charmaz, 2014)

| | |
|---|---|
| To what extent does the interview guide elicit the research participant's views, concerns and accounts of the experience? | To what extent does the interview guide reflect my views and interests instead of the participant's experience? |
| Will the interview guide address the purpose of the research? | How can I shape my questions to open the conversation to what the research participant has to say and simultaneously fulfil my research objectives? |
| How well have I paced the questions? Have I eased the research participant into the tough questions? | Have I asked the right background questions for what we need to do in this interview? |
| Do I have enough information about the research participant to delve into their experience? | Have I adequately prepared the research participant for what this will ensue? |
| How would these questions sound to someone who has had this experience? | What do my questions assume? To what extent will the research participant share my assumptions? |
| Have I worded the questions in terms that the research participant would use or understand? | Are the questions clear and concise? |
| Have I thought of probes that will follow up on the general questions? Are any of my probes too intrusive? | |

### 3.6.3 Pilot Interview

A pilot interview was completed with an EBE parent to assess the interview schedule and relevance of questions. It was further used to consider appropriateness of wording with hopes to ease participants and build rapport in interviews. Feedback from the pilot interview and EBE consultant led to amendments in research questions and the order of the interview schedule. After the pilot interview, it was decided to start more broadly by exploring opening with “How many days a week and hours, on average, does XX utilise mainstream schools? How long have they accessed school in this way”, this meant the participants were not expected to start with their own experiences and impacts which was considered an eased approach in. This approach is in line with CGT, starting broadly and then inviting further detailed discussions of the topic for stories to emerge (Charmaz, 2014). It was also decided to add additional questions at the end of the interview like “Is there anything else you think I should know to understand school accessibility for neurodivergent children better?”. This offered space for parents to discuss what they felt was significant and important for the researcher to know in relation to the topic where opportunities may not have come up in the questions. After these additional questions and reflections, the interview structure was shared again with EBE consultants and the supervisory team. The pilot interview was not included in the data analysis.

### 3.6.4 Interview Procedure

Five interviews were conducted via telephone, and seven on Microsoft Teams, the duration ranged between 40 and 105 minutes. At the start of the interview, participants were reminded of the interview topic and the researcher shared that they recognised this topic could lead to a range of emotions which were welcomed within the interview if the participant wanted. The researcher welcomed any further questions the participants had. The participants were also reminded that that they can pause, take a break, or stop the interview at any point should they feel the need. At the end of the interview, the recording was stopped, and the researcher offered a verbal debrief to the participants where they could ask any further questions of the researcher. Once the interview was completed, a debrief sheet was shared with participants. Throughout the interview, the researcher used effective empathetic listening, respect and validation of their stories to support a closure of the interview. The participants were encouraged to set the pace and tone of the interview, which the researcher strived to mirror to offer comfort to participants; the researcher used “uh huhs” and clarifying questions to support a story continuing if the participant could and wanted to (Charmaz, 2014).

### 3.6.5 Transcription

All interviews were transcribed verbatim by the researcher within three weeks of the interview. It was important to the researcher for all interviews to be transcribed in line with CGT and other research, in hope to allow the researcher to immerse with the data, witness how participants construct their experiences and allow the researcher to engage with memo-writing (Clarke et al., 2023; Charmaz, 2014). Afterwards, all transcriptions were input into NVivo12 software for data analysis.

## 3.7 Data Analysis

In line with CGT methodology, the data was analysed through initial coding, focused coding and theoretical coding. Memo-writing and reflexivity practices were employed to support this process. These are outlined in Table 13 for ease of the reader.

In order to then explore the quality and validity of the data analysis of the research, the CASP qualitative checklist was used (CASP., 2018). This is the same qualitative checklist that was previously used to critically evaluate the credibility, rigor, and relevance of the journals in the SLR. Refer to Section 5.6 for the outcomes and full details of this process.

Table 14 – Data Analysis Processes

| Process: | Explanations and how these were practiced: |
|---|---|
| Initial Coding | Coding is seen as the critical link between collecting data and the development of an emergent theory that offers explanations of the data; initial coding is the first stage, where the researcher remains close with the data and stays open to exploring the theoretical possibilities detected in the data (Charmaz, 2014). As in CGT, the researcher coded the data with words that reflected action, the codes were considered provisional, potential theoretical cues, comparative and grounded in the data (Kenny & Fourie, 2015; Charmaz, 2014). This research used line-by-line coding and coded using gerunds to capture the processes and actions (Charmaz & Thornberg, 2021; Charmaz, 2014; Cunningham et al., 2017). Coding in this fragmented manner, aided defining implicit meanings and actions, supported making |

| | |
|---|---|
| | comparisons between data and highlighted emerging links between processes for the researcher to further explore as well as identifying gaps within the data (Charmaz, 2014). Initial coding for the first few interviews were shared with the supervisory team and other colleagues to compare codes and check accuracy. For examples refer to Appendix L. |
| Focused Coding | Focused coding is the second stage, whereby codes are used to sift, sort, synthesise and analyse larger amounts of data, this coding develops the theoretical direction by exploring how initial codes account for data and creating conceptual codes (Bobbink et al., 2024; Charmaz, 2014). The researcher reviewed the initial codes that emerged more frequently, or those that appeared significant in portraying meaning, in line with CGT (Charmaz, 2014). Throughout coding, the researcher continued to engage with memo-writing and adding to the reflexive journal, this supported the process of creating more focused codes. The focused codes were continually refined and developed, with constant comparison across all data and stages of analysis. An extract of focused codes were reviewed with the supervisory team to check applicability, quality and coherence. The focused codes provided the makings of a frame, including summarising key ideas and social processes, for later analysis (Charmaz & Thornberg, 2021). For examples of focused coding, refer to Appendix M. |
| Theoretical Coding | Theoretical coding is considered a final stage of coding constituting the refining of constructed categories and detailing their relationships, which leads towards a formulation of concepts and the relationships between them thus forming an overarching theory (Timonen et al., 2018). Theoretical coding is seen as “weaving the fractured story back together again” (Glaser, 1978), to tell a “coherent, comprehensible and analytical story” (Charmaz, 2014). It was an iterative process, where the data was constantly revisited, with further comparisons between codes that led to rewording categories that best fit the data (Aleuma et al., 2015).<br>When creating the overall model, the researcher used the technique “diagramming” (Charmaz, 2014), to draw the visual representations and conceptual maps which explored the relationships and directions between the categories, and the context they are positioned in. See Appendix N for the various iterations of the model. The preliminary model was reviewed during the member-checking |

| | |
|---|---|
| | process with participants, it checked the categories and language within the model were meaningful and sufficiently represented the co-constructed response to the research questions. This added to the validity of the overall model. The supervisory team and consultant also supported the development of the model. The interviews were reviewed again to consider whether the final theoretical model may account for their experiences and the social processes. |
| Memo-Writing | In line with GT, memo-writing started at the beginning of the research, it occurred during the initial planning phase of the research as well as throughout the interviews and analysis, it was engaged in as a continuous and systematic notetaking through the entire research. Memo-writing is seen as "documentation of the researcher's thinking process and theorizing from data" (Thornberg, 2012), each memo is preliminary, modifiable and open to revision (Charmaz, 2006). Memo-writing is argued to be a crucial link between the data in interviews and the construction of codes and categories (Mohajan & Mohajan, 2022). Memo-writing supported the researcher to identify points of connections as well as unanswered gaps within the interviews and relationships between the codes, focused codes and categories. It encouraged the researcher to explore and scrutinize codes and categories, leading to continuous reflection and refinement (Charmaz, 2014), it was a record of "analytical discussion" between researcher and data (Khanal, 2018). (See Appendix O). |
| Reflexivity | Engaging in reflexivity is fundamental within CGT, it is important to engage in strong reflexivity throughout the entire research process (Charmaz & Thornberg, 2021). Reflexivity offers scrutiny to the research, the decisions and interpretations, it examines the researcher's interests, positions, assumptions and how these interlink with the research process (Charmaz, 2014). It was particularly important to engage in this process from the start of the research, given the researcher's insider-outsider positioning. The researcher utilised memo-writing as an opportunity to enhance reflexivity within a CGT framework (Rieger, 2019). For example, when participants brought up the theme of experiencing school as an outdated system built to get individuals into work; the researcher reflected on their interpretations on this, having not thought about this previously. The researcher also kept a journal from the beginning (Appendix P), to notice their relationship to the research process, the participants, societal discourses and explore any assumptions, values, or power that may be |

| | |
|---|---|
| | present. Within this, the researcher also reflected on the context and structures within in the UK and wider world during the time research took place. Throughout the research process, the researcher reflected with the supervisory team and shared awareness of their own interpretations. During the analysis, each stage was reviewed and discussed with the supervisory team and other colleagues. |

# Chapter Four: Results

## 4.1 Overview

This chapter presents the research findings, including an overview of the co-constructed CGT model, as well as the categories, sub-categories and relationships between them. Participant quotes have been used to demonstrate and offer insights in each category.

## 4.2 Overview of the Model

Figure 4 showcases the model which illustrates a theoretical understanding of parent's experiences of their neurodivergent children trying to access schools. This model was co-constructed through the twelve participant interviews, the member-checking focus group including six of the participants, the researcher's meaning-making through their memo-writing, journalling and frequent discussions with their supervisory team and consultants.

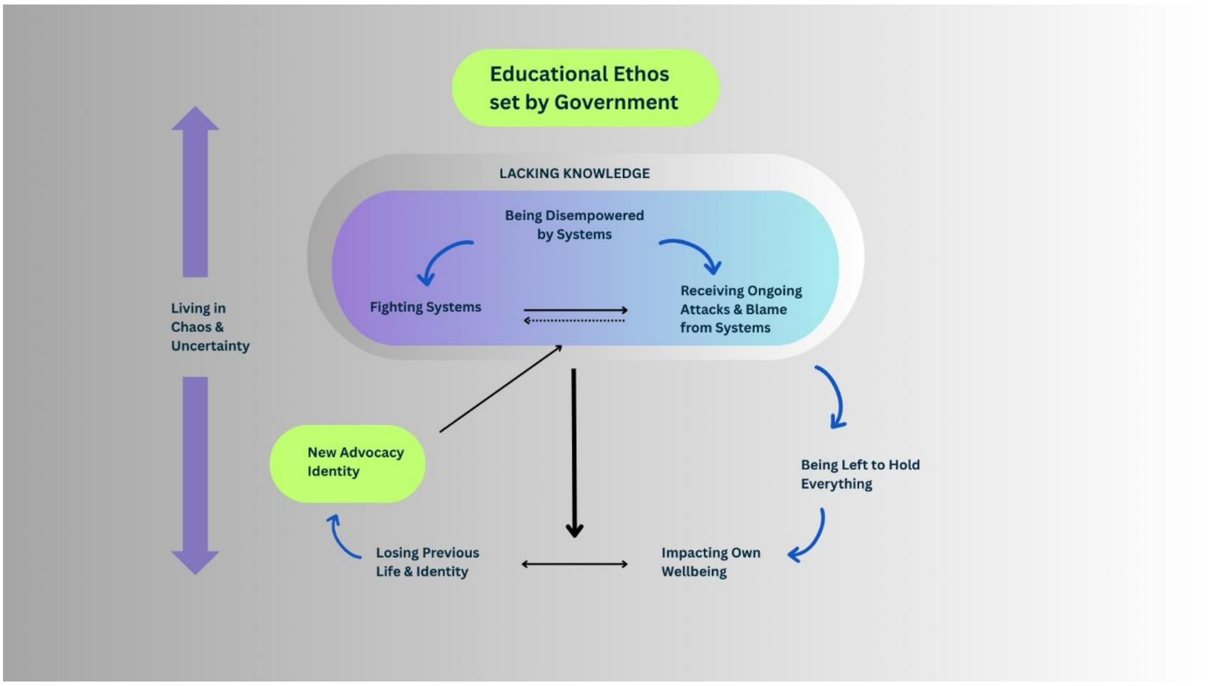

Figure 4 - Constructivist Grounded Theory Model of Parents Experiences of SNA in the context of Neurodivergence

The model contains seven overarching categories[23], with several subcategories, displayed in Table 14. Participants felt that all systems they had contact with were given "too much power" and authority by the government directives and legislation, these included schools, mental health and social services, etc. The government was seen to drive the agendas and influence the importance of education, older educational models plus attendance. However, school systems and other external professionals still held power and independence on how to respond, this was described as being influenced by the schools and services demands, pressures and their over-arching ethos. This offered an explanation to some of the varied responses from school systems and professionals. Parents explained that on most occasions parents are unnecessarily being ***disempowered by the systems*** and ***attacked*** particularly where it was experienced that systems misused power held. The way power operated in systems frequently meant that parents were left having to defend themselves and their child, described as a sense of "***fighting***" an "uphill battle". In some cases, it was viewed that the more parents defended and "fought", the more systems responded by further attacks and disempowerment for parents, this is indicated in the model by a larger arrow. It was considered that professional systems all lacked knowledge of neurodivergence when responding, and parents advised they themselves lacked knowledge of neurodivergence and their and their child's rights.

These experiences of ***disempowerment, being attacked*** and ***having to fight*** were considered central to parent's experiences and frequently resulted in parents ***being left to hold everything*** causing them to ***live in chaos and uncertainty***. From these collective experiences, parents shared it meant that their own ***wellbeing was profoundly impacted***. Consequently of these factors, parents shared a sense of ***losing their previous life and identities*** and forced into a different life with these demands and experiences. It was noticed that the majority of parents had used their own personal strength and moved into advocacy roles or voluntary work, often leading to experiences and feelings of empowerment[24].

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[23] Missing the Mark - Eliza Fricker has illustrated each of these overarching categories for this thesis, they will be found through the results section in line with each category.

[24] This theoretical understanding and model are located within the participants context, time, and positioning as well as the researcher's understanding of this and "meaning-making" of the participant's understandings including the "how and why" plus the participant's actions. (Charmaz, 2008; Tweed & Charmaz, 2012).

Table 15 – Categories and Subcategories within the CGT model

| **Categories** | **Sub-Categories** |
|---|---|
| **Category 1: Being Disempowered by the Systems** | 1A: Being Impacted by Outdated School Models and Policies Driven by Economics |
| | 1B: Being Impacted by School Ethos, Culture and Pressures they Face |
| | 1C: Being Impacted by What is Happening Within Professional Systems |
| | 1D: Experiencing Schools and Services as Gatekeepers for Support and Referrals |
| **Category Two: Receiving Ongoing Attacks and Blame** | 2A: Being Attacked |
| | 2B: Being Ignored as a Parent (Unheard & Dismissed) |
| | 2C: Being Enthralled to Professionals |
| **Category Three: Fighting the Systems** | 3A: Advocating and Fighting for Child's Rights to Education and Health Provisions |
| | 3B: Pushing for Change and Supporting Others |
| | 3C: Having Prior Knowledge, Skills, Positionality Impacting Experience of Fighting |
| **Category Four: Being Left to Hold Everything** | 4A: Doing Professional System's Jobs |
| | 4B: Trying to Make Sense of Situation "Learning as you Go" |
| | 4C: Recovering Child |
| **Category Five: Living in Chaos and Uncertainty** | 5A: Unknowing of What to Expect for the Day |
| | 5B: Struggling to Juggle Everything |
| **Category Six: Impacting Own Wellbeing** | 6A: Being in the Trenches – Lasting Impact of Trauma Encountered |
| | 6B: Internalising System Response |
| | 6C: Witnessing Impact on Child Accessing School |
| | 6D: Lacking Space and Support for Self |
| | 6E: Losing Money and Family Experiences and Opportunities |
| **Category Seven: Losing Previous Life and Identity** | 7A: Impacting Relationships, Missing Friendships – Feeling Removed from Society |
| | 7B: Losing Work and Professional Identity |
| | 7C: Reassessing Values, Expectations and Upheaving Entire Life due to Lack of Choice. |

## 4.3 Category One: Being Disempowered by the Systems

This category shares how the set-up of systems often meant the young people and their families accessing them were repeatedly ***disempowered*** (Figure 5), ultimately leading to ***detrimental effects on mental health and wellbeing***. The outdated school models and policies considered to be driven by economics created an environment that many neurodivergent young people could not access due to their needs and learning styles likely not being met. The government was seen as being responsible for the level of pressures that schools attend to, thus creating school cultures of pressure to perform which is then "put on the children". The schools were seen as having some control and independence in how they responded to SNA with children and their families, though in most cases is seen as ***attacking*** and ***gatekeeping***. Children and families were often further disempowered through external services and professionals which was seen to perpetuate the difficulties faced in other systems.

Figure 5 – Illustration by Missing the Mark (Eliza Fricker) depicting theme "Being Disempowered By the Systems"

### 4.3.1 Being Impacted by Outdated School Models and Policies Driven by Economics

Several parents highlighted beliefs within the UK that the entire education systems is *"outdated" (Josie)* like a *"tradition… it has always been" (Petra)*, this included pedagogical models and policies connected with the system. This was highlighted by school enforcing uniforms because *"30 years ago everyone went and worked in an office, they wore shirts and ties" (Petra).*

Parents reflected that the education system continued to be based on historical obsolete economic driven models prioritising productivity *"It's drive, drive" (Lucy)* with a focus on getting children into employment like in industrialisation periods. *"This is crazy… we're meant to be educating their future brains of Britain, and we're treating them like they're still in factories, so it just it's very frustrating" (Lucy).*

Parents called for schools to start being *"wellbeing driven*" rather than *"economically driven"* highlighting that it should not be *"about what you can output, it's not about being economically viable" (Mark)*. It was asserted that these economic models favoured obedience, compliance and conformity, which the educational system was similarly seen to value and prioritise. *"Rather than allow the individuals to express themselves and grow in confidence social skills… it was about attendance… uniform behaviour… compliance, obedience" (Mark).* It was commented that the system was seen as a product of *"every single echelon of capitalist countries" (Lucy)* where value is measured by an individual's "productivity" and outcomes. This was argued to be embedded, and their child experienced this from primary school years.

Yet, parents still strongly felt the importance and value placed on education particularly within a school setting seen by *"We have to get you to school otherwise you're not going to get the full educational experience" (Mark)*. It was considered that if their child missed out an education in school, they would be impacted further in life. Such messages and placement of importance was considered to be reinforced and experienced throughout the wider society.

These outdated models were argued to be imposed in the education systems by the current government; through enforcing the current curriculums, ways children are assessed, and guiding policies for managing children's behaviour and attendance. Parents believed the pressures and disempowerment came from the system *"as a whole"* with particular accountability for those at *"the top"*, advising that some teachers *"do their best but their hands are tied" (Josie)*. Parents believed that the government was seen to apply pressure on schools and influence certain policies like attendance. *"That pressure, you must go into school must attend it's very explicit in school, it's explicit in media, the Secretary of Department is like attendance is her biggest thing. I'm going to get attendance up" (Lucy)*.

The educational system was viewed as *"fundamentally flawed" (Fahmida), "no longer serving"* with *"fundamental change needing to happen" (Anna)*. Many parents argued that the entire system was not created with understanding of "*nuances with children that may be presenting as slightly different" (Anna)* or *"neurodivergent individuals, which is a huge problem" (Fahmida).* Neurodivergent individuals struggled to access the uniformed models of education where "one size fits all" for teaching and assessment of learning with no adjustments and environments that did not accommodate sensory or movement needs. This meant many children could not access school thus having significant impact, including **disempowerment** for them and their parents.

### 4.3.2 Being Impacted by School Ethos, Culture and Pressures they Face

Whilst the government was argued to be accountable for the education system and policies, parents contended that the government was also responsible for the pressures schools faced in terms of budget, finance, and legal obligations. *"The school have got this sort of law they have these responsibilities, things to maintain… including attendance, otherwise it looks bad on them" (Fahmida)*. Parents sympathised with the *"tremendous pressures"* schools encounter from how the government has positioned them, thus creating further consequences on their child's support and access to education. *"Schools obviously are skint, they have some difficult decisions to make… whether to fix the roof or hire a new TA, it becomes a political question, doesn't it" (Mark).*

However, it was contended that schools had elements of control and independence. This was displayed through the varied experiences in how schools responded to parents and children, applying the same attendance policies, under similar pressures from government.

Parents experienced *“emotional detachment”* from most school professionals, who inflexibly applied attendance and behavioural policies, thus abdicating responsibility onto parents, where parents were explicitly expected to *“drag him in in his pyjamas” (Anna)*. *Lucy* highlighted *“It's all on me to get them in... so you really feel so much pressure”*. This approach resulted in parents ***being attacked and blamed*** when they were unable to force their child into school.

The dominant approach that school is best, attendance a priority and that children are fine once in school (not recognising potential distress) meant that parents were often expected to physically handle distressed children against their wishes into school. Parents frequently experienced teachers *“luring them in under false pretences” (Grace)* or senior members of staff *“dragging my child from the car”(Libby)* to get children into school. However, some parents instead experienced compassion and understanding from schools; documenting *“absences as authorised due to mental or physical health needs” (Mark)*. It was highlighted that this was a rare luxury, and difficult to find.

Parents identified that *“not every school has the same culture”*, it was considered that their unique cultures were *“driven by an ethos” (Mark)*. Schools’ interpretations and response to SNA stemmed from this *“overarching sort of set of ethos” (Steve)* or lack of one, as well as their understanding of children’s presentations and circumstances. One parent highlighted *“Some schools are a bit more savvy to that and work to help the parent. I've had completely different experiences from one school to another” (Grace)*.

It was thought that the wider senior leadership teams and headteachers set the tone for the culture of the schools and for the professionals within their workplace which put constraints on “good” teachers or individuals. *“It's a kind of cultural issue, an organisational issue rather than individuals. It came from the top. It was hostile. It was mean” (Mark)*. However, dependent on leadership equally meant that teachers who were considered to need development were not encouraged. *“It's just particular teachers… there's no sort of leadership that's pushing them to be better… throughout the school, it's dependent on the teacher you get as to how good they are at supporting” (Steve).*

Only two parents reported an experience of a supportive headteacher driving a positive ethos, however they were still constrained by wider systemic pressures making them *“powerless” (Anna)* to meet the child’s needs. However, most parents had challenging relationships with headteachers and schools with many parents making formal complaints to governors. These were often not upheld leading parents to believe there was *“corrupt behaviour” (Grace)* present within the system.

Every parent described school professionals as lacking understanding and knowledge about neurodivergent presentations (Figure 6), with parents finding staff[25] putting *“insufficient”* support in place and *“googling what to do” (Grace)*. In the absence of knowledge, parents felt responsible for sharing knowledge by making “great effort” to educate, such as creating *“a book ‘all about me’ for my child’s teachers” (Fahmida)*. Overall, it was deemed the school’s development and drive to learn about neurodivergence depended on the leadership teams’ wider ethos and culture. *“They said we've got no legal requirement to understand autism, which I thought was quite an astounding statement because they do obviously have a legal requirement to understand the sorts of children who might be going to their school and how to help them” (Steve)*.

Figure 6 – Illustration by Missing the Mark (Eliza Fricker) depicting theme ”Lacking Knowledge”

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[25] Including: teachers, headteachers, governors, SENCOs, teaching assistants, substitute teachers, and lunch staff.

### 4.3.3 Being Impacted by What is Happening Within Professional Systems

Many parents were impacted by what was happening within professional systems including: assessment waiting lists, lack of consistency due to high staff turnover, referrals being passed from one service to another (due to various inclusion/exclusion criteria). As a result of high staff turnover, agreed plans were not always implemented or followed through. *“People come in and then they go and then people come in and they go, that's been difficult” (Lillian)*. This was further compounded by limited communication between professional systems resulting in delayed support, repeatedly sharing their story or unable to access support due to gaps in service provision.

Parents viewed the professional systems as *“disjointed”* within and between departments, *“Health don't talk to education, they don't talk to social services, they don't talk to health” (Mark)*. The lacking collective approach meant *“no one else is looking at this whole picture”* and it is parents who are positioned *“in the middle of it all… seeing the whole thing” (Lucy)*.

The availability and presence of services varied between local catchments and funding for provisions, it was experienced as incredibly difficult to navigate and access any support. One parent described it as *“This spider web of potential support systems, but you just don't know how to access them… and they don't speak to each other…” (Lucy)*.

All factors meant that children and parents were unable to access support which had implications for school provision, and parents were ***left holding everything***.

### 4.3.4 Experiencing Schools and Services as Gatekeepers for Support and Referrals

In many cases, services that complete assessments for neurodiversity, often require school input and agreement for a referral. *“Parents can't refer for a diagnosis… GPs will only refer if the school is supportive” (Steve)*. This became particularly challenging where school held different understanding of a child’s presentation to parents or held different knowledge of neurodivergent presentations. *“I think my child is autistic, but I ask the school to do a referral, and the school say no, he’s not autistic” (Fahmida)*. It meant that schools were experienced as *"gatekeepers"*, by *"managing access" (Mark)* to support, provision and diagnosis. It was contended that schools *"had a lot of power" (Maya)* whether referrals to neurodivergent assessments took place or not, regardless of a child or parent's plea for support.

## 4.4 Category Two: Receiving Ongoing Attacks and Blame

This category addresses the way parents reported experiencing interactions with schools and professionals. Parents shared that systems responded by attacking, ignoring and blaming them (Figure 7). It was described that the systems and professionals were afforded too much power by government so when they responded to parents, they were able to misuse power, make threats and take hostile actions. This was on top of being ***disempowered by the structures of the systems***. Parents shared that the interactions of disempowerment and attacks led parents to being "enthralled to the professionals", having no power or contributions to decisions, with choices of others forced upon them.

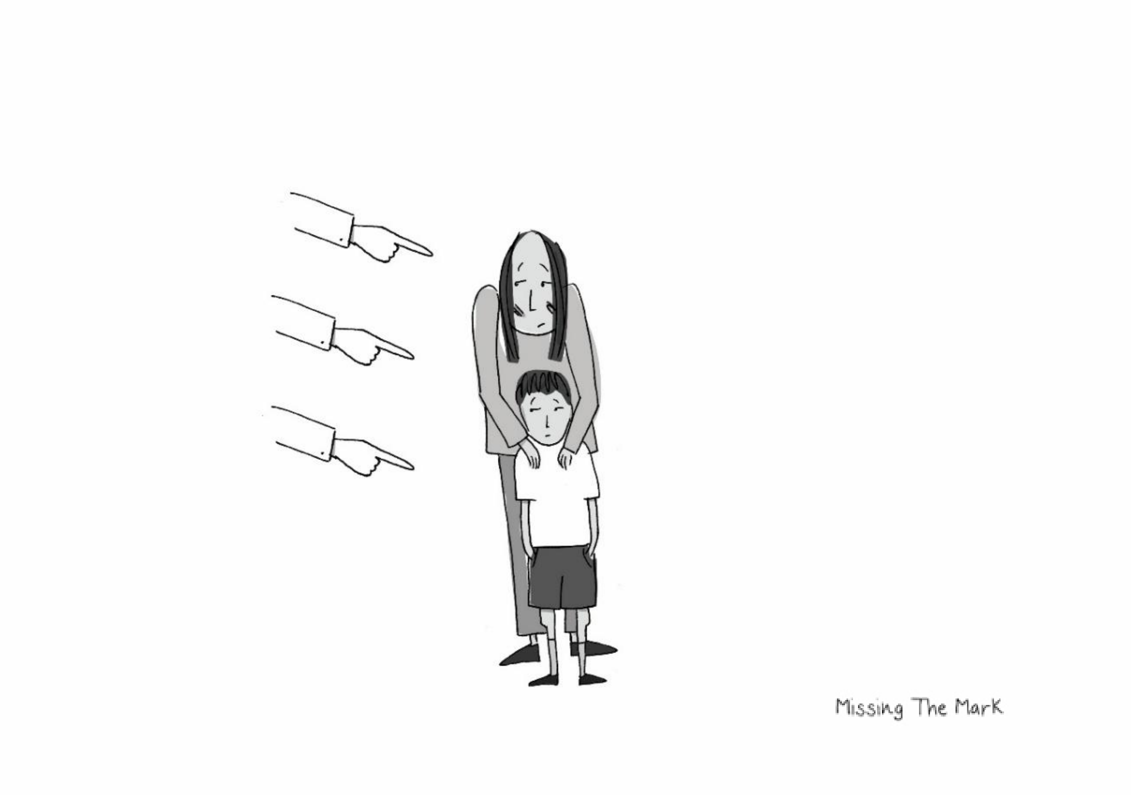

Figure 7 – Illustration by Missing the Mark (Eliza Fricker) depicting theme "Receiving ongoing Attacks and Blame"

### 4.4.1 Being Attacked

All parents disclosed scenarios where they were blamed and *"accused" (Grace)* by school and professionals for their child's presentation, needs or SNA, with some parents told that they need to attend parenting classes. Despite, parents sharing experiences of trying to get their child into school with their child attending under great levels of duress, schools would say parents were *"not trying hard enough" (Josie)*. It was highlighted that there was threats of *"fines" (Grace)* and *"social services" (Josie)* if their child was unable to attend.

The attacks came from lacking knowledge and awareness of neurodivergent presentations, *"instead of supporting… they blamed me" (Grace)*. Several parents shared that they were also reported by the school for *"fabricating"* difficulties and needs *(Libby)*, with some parents being investigated by police and social services. This was highlighted by *Anna* who shared *"The school then said we think it's the parents. Although we're having issues at school. We just don't think their autism issues. We think that there's a possibility he's being abused in the home and it came left field out of nowhere with no evidence"*.

It was outlined that some of professionals made *"very personal attacks" (Grace)*, these were said to parents in front of several professionals, and documented on systems, parents were also criticised to their child. *"We found a number of things in there that were really deeply concerning… really personal comments about my family, his personal dislike for us on record. It was the personal attack" (Anna)*. One parent reported that from the constant attacks it felt like… *"We're under siege all the time" (Libby)*. With another parent making sense of their experience with school by equating it with their experience of being in a domestic abusive relationship. *"I can draw so many parallels between that and domestic abuse" (Grace).*

If parents were able to push back on some attacks, like making complaints to school or professionals, it was observed that they were further attacked and blamed. *Steve* shared this: *"I actually got a letter saying that if I didn't stop making complaints, I'd be classified as a vexatious complainer. Even though they didn't actually deal with any of the complaints that I raised and they refused to do things like take it to the appeals panel"*. Parents felt like they were *"constantly justifying and explaining"* (*Anna)* themselves to professionals.

### 4.4.2 Being Ignored as a Parent

Among being attacked, parents described frequently being belittled and *"demeaned" (Anna)* to just "mum". Many shared that they were not spoken to like *"skilled parents" (Libby)* or even *"a person" (Anna),* dismissed in meetings with schools and professionals, *"with their voices not taken seriously" (Fahmina)* and reduced to *"Mum thinks and Mum says" (Anna)*. Although, parents understandably argued that they knew their child better and experienced more angles than school, parent's voices were often not centred in meetings and instead schools and professionals were considered the expert voices with more power. This is highlighted by *Maya*, *"If I come with an observation about my own child that I know better than anybody, people should listen because we know him. They just go, Mum says this and this. They put their version onto it, but their version is the one that's counted. It doesn't matter what I say, their version is the one that gets written down.* On several occasions school professional were argued to dismiss parents by saying *"well, he's fine when he's in school"*, *Grace* added *"They just didn't see it. They didn't want to see it. They didn't listen to me".*

By parents being ignored and dismissed, it meant schools and parents were unable to collaboratively work together supporting children in accessing school with needs being met. This is crucial as *Fahmida* raises *"They don't realise that parents of children with additional needs need to be able to tell you what things matter to their children because these things will ultimately choose whether or not they can access the curriculum… or go to school"*. Being dismissed further directly **impacted parent's own wellbeing** and self-esteem, *Anna* shared *"I don't think I've ever felt so inept and incompetent in my life like I'm speaking and no one's listening… And there's a child in this"*.

### 4.4.3 Being Enthralled to Professionals

Parents shared that they were initially "enthralled" when they *"believed and trusted" (Grace)* that schools and professionals were experts in comparison, assuming *"school know better" (H)* than their own knowledge of their child and needs, to which the schools took decisions *"out of your hands and implement" (H)* plans instead. *Petra* highlighted the *"damage"* frequently caused from these situations.

Overtime, parents voiced that the constant attacks, dismissing and blame frequently led them to being enslaved to the professionals. Many parents disclosed that they felt they had no choice or rights indicated by *Anna "You've got no rights here, no entitlements"*. This meant parents often felt they had to obey the professionals and *"accept the put downs"* otherwise they or their child would be punished as a consequence by *"impacting provisions"* or the *"speed" (Libby)* of actioning requirements.

*Mark* speaks to the experience of surrendering from commenting: *"We were still enthralled to the professionals…obviously, because we're naive new parents and in the presence of experts and professionals. We kind of deferred to them and felt responsible for it… It's either do as we ask or F off. And if you don't F off on your terms, we're gonna make it mightily unpleasant for you… without realising because we didn't know any better. We surrendered our own agency"*.

## 4.5 Category Three: Fighting the Systems

This category reports how parents were left to defend their child and themselves against the systems and professionals; this was considered by most parents as "***having to fight***" (Figure 8) in response to the ***disempowering harmful systems and ongoing attacks***. Parents were seen to ***fight the systems*** by advocating for their child's legal rights to education and health provision, which frequently included having to challenge and hold professionals and systems to account. Parents also drew upon their own inner strength and experiences to push for change for other individuals too with many individuals setting up their own support groups or organisations to consult local authorities and other systems. How parents responded to the systems and professionals depended heavily on their own positionality, knowledge, and life experiences. It was considered that parent positionality and skills also impacted how much the systems then listened and responded too.

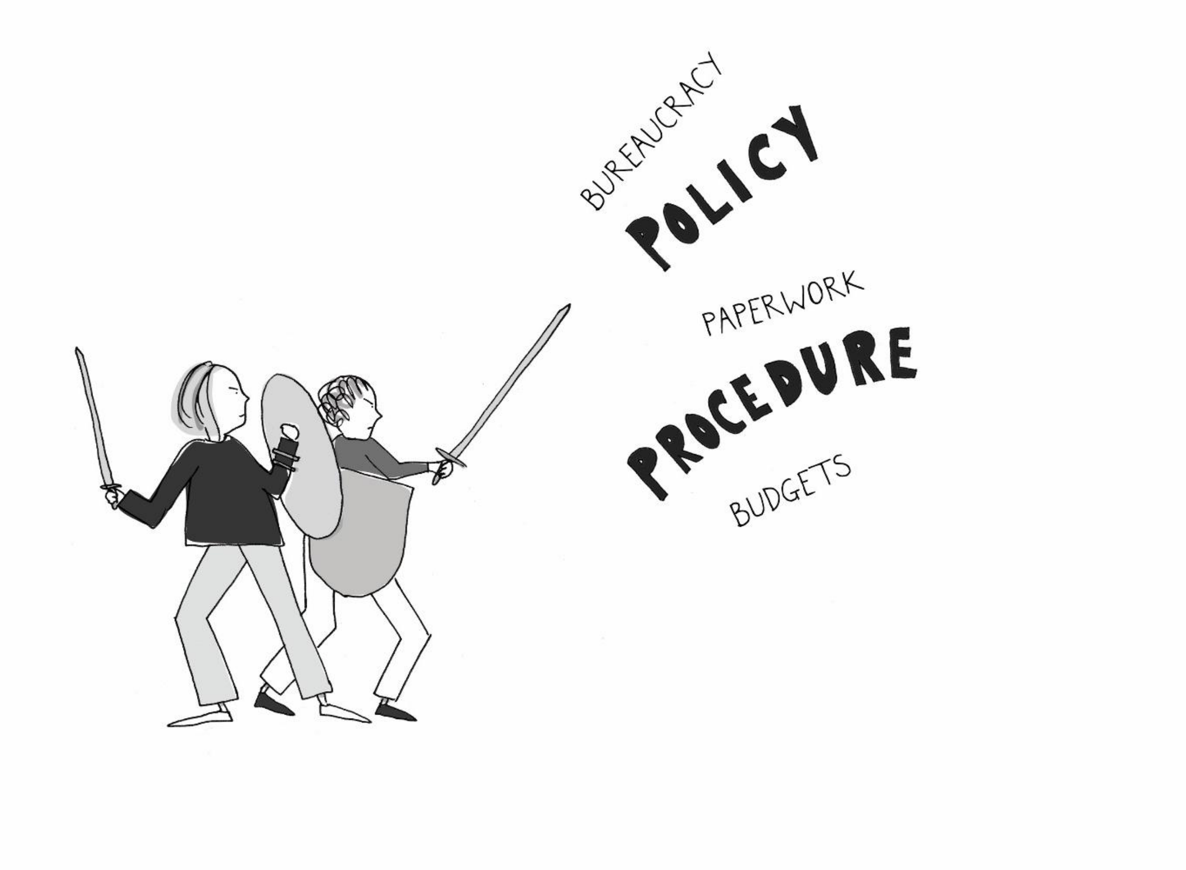

Figure 8 – Illustration by Missing the Mark (Eliza Fricker) depicting theme "Fighting the System"

### 4.5.1 Advocating and Fighting for Child's Rights to Education and Health Provisions

From the disempowering systems and responses from schools and professionals, parents described being left to advocate for their child's rights to both education and health provisions, *"It's all about a battle for education or service or therapy" (Libby)*. Parents described this as continuous *"uphill" (H)* battle, fighting multiple systems at the same time to try to get support in place for their children to begin to access provisions. This was described it as a *"constant daily fight"* against *"system that is set up to fail families" (Grace)*. Parents expressed how frustrated they felt as *"you shouldn't have to fight, you know" (Lillian)*.

Parents reported that advocating took place in the form of trying to educate professionals through sharing what they had learnt about neurodivergence and demonstrate the level of need, such as sensory sensitivities in classrooms, and why their child needed additional support (e.g. access ear defenders and safe space). It was seen as constantly *"pitching your argument"*, *"educate them" (H)* and *"say no, it's not, it's not actually what he needs" (Petra)*. Parents shared that they often spent every evening *"planning what to go back to school with the next day to get them to try and listen" (Maya)*. Other parents advocated for their child by raising concerns, making complaints and standing firm where their child's needs were not being met, "*all these agreements in place and they've not been put in place… causing my daughter to not be able to access education and coming home emotionally distressed (Steve)*, these often led to official complaints being made and attending tribunals.

Parents also described advocating for their child through fighting and challenging assumed and unhelpful narratives which often blocked their child from accessing certain provisions and care, such as seeking a diagnosis. *Fahmida* shared *"I started challenging people… He doesn't look autistic. And that I'll be like, what does it look to be autistic? "*. If professionals understood some neurodivergent presentations, they applied their knowledge rigidly not appreciating *"it is a spectrum and people are very different"*, leading professionals to have *"a very different idea of what autism was" (Maya)*. The onus was on parents to highlight *"autism doesn't look like this. And I said… with the greatest respect, you're a teacher and he's gone through a rather long and involved diagnostic process" (Anna)*.

Parents highlighted the amount of energy and toll that advocating and challenging took on them, ***impacting their wellbeing***. *Steve* disclosed *"I just don't have the energy… I was just already exhausted by it. So I ended up withdrawing the tribunal. We weren't going to get an apology willingly, so we could have forced an apology. But was it worth the effort to do that?"*.

### 4.5.2 Pushing for Change and Supporting Others

It was seen that parents also advocated for others pushing for a wider collective change for all neurodivergent children and families. This was seen by parents joining local authorities or schools to deliver feedback, training and service development. *Fahmida* shared *"I've had to focus my energies on other things like improving society..., I've been* *really advocating for changes and making some of these changes… We started this organisation… we work with the local authority on different issues. We work with the local NHS Commissioning team to look at how to improve services"*.

Pushing for change was also considered when raising complaints to appeal panels about schools and provisions, in hope that *"they might have learnt from it for other children in the future" (Steve)*, even when their child had stopped attending the school.

Despite having limited time for themselves as a result of fighting and being left to hold everything, parents frequently offered support and advice to other families and parents, including setting up *"support group in our local area"* because they knew how *"difficult"* and *"lonely"* *(Lillian)* these experiences were. This was frequently considered to be driven from a place of not wanting other families to encounter such isolating, depleting experiences that they themselves had encountered with limited support. *Anna* shared *"Now I spend an awful lot of time helping people find information because I know how difficult it was, especially when you're in crisis, you don't have time… Decided to write our story because I didn't want anyone to feel as alone as we did… I didn't want any other family to go through this in the future"*.

There was a sense of the parents regaining their voices and being empowered when pushing for wider change and connecting with others. *Lucy* added *"You're in the dark, very badly informed some of the information out there is woeful… it's really hard so I helped set up a parent support group and it's been a lifeline… really saved me because I find other parents in the same boat and everyone was like, Oh my God, I thought it was just me and I'm so glad to find other people. That has been the biggest lifeline, peer-to-peer support. It's really incredible"*.

### 4.5.3 Having Prior Knowledge, Skills, Positionality Impacting Experience of Fighting

Despite the horrific experiences outlined by the parents, all parents were mindful of their positionality and skills and how these interacted and influenced the overall experience of having to fight and respond to such powerful systems. Parents reflected that those who were new parents or those who lacked knowledge on neurodivergence or lacked knowledge on their child's and their own rights to education or alternative provisions were often in a tougher position and were more likely to be dismissed, enthralled to the professionals and internalised the systems response. *Josie* shared some difficulties she encountered, *"I was a first-time mam. I was young.... You have to go to school. Didn't really know much about autism. Didn't really know much about alternative education or anything like that and you get told the whole if they don't go to school, we will contact the police..., you'll get fined. So it's kind of fear mongering that you just must push them into school... I was clueless. Didn't really act much because I didn't know what I was doing"*. This was similar to when *Fahmida* raised many parents do not *"know their rights"*.

There was a lot of thought given to those who were a single parent and the struggles they may face, such as requiring employment to support their family while struggling to manage a child with SNA. This leaves them with limited choices and having to make difficult decisions when trying to fight. *Petra* considered this, stating *"We are in the position where we are able to do it, but there are people saying I'm thinking of home educating my child, I'm a single mom and work, how do you guys make it work? And you're like… it's gonna be really hard for you"*. Additionally, parents shared that if they were neurodivergent themselves, it meant they may be in a better place to support their child, whereas other neurodivergent parents highlighted that sometimes their neurodivergence meant they *"struggle getting my points across" (Josie)* to professionals, making it easy to "dismiss" them. Further difficulties were considered for those whose first language was not English, recognising the barrier this has when parents already needed to "learn the lingo" in order to be heard, or only being heard once they become a professional and worked within neurodivergent fields. *Fahmida* shared *"when I started speaking and because of my language, terminology and the way I spoke, the SENCO took me seriously".*

Some parents shared that they were supported by their wider family when fighting the systems like *"help me with the emails... she would help me with wording and complaints and how to approach people. I didn't have a clue" (Josie)*, but they continued to reflect on the barriers in family understanding and knowledge. Some spoke to being in somewhat of a better position whilst they experienced not having *"a voice when you're a parent"* but knowing *“where I had to go to get the voice” (Maya)* from certain professionals to support the fight.

Other parents reflected on their personal skills and qualities, like being *“outspoken” (Fahmida)*, plus work experiences and life experiences which supported them in fighting. *Fahmida* elaborated *“I was quite capable of explaining myself to people… I think all this advocating has really helped in terms of the way I approached the situation”.* Whereas *Steve*, reflected on his own characteristics disclosing *“I'm incredibly stubborn, which helped… I'm not going to get steamrolled over by a school saying ‘no it's not an issue’. If I see an issue, I'm going to be no, I can see there's an issue and I'll continue to fight that”*.

## 4.6 Category Four: Being Left to Hold Everything

As a result of the systems interacting together (***disempowering*** parents), and responding in ***attacking*** ways, it often met that parents were “***left to hold everything***” (Figure 9). This category speaks to how the parents are positioned to do professional system’s jobs, whilst trying to make sense of the situation and recover their child alone at the same time.

Figure 9 – Illustration by Missing the Mark (Eliza Fricker) depicting theme "Being Left to Hold Everything"

### 4.6.1 Doing Professional System's Jobs

From the impacts of what is happening within professional services, like high staff turnover, and being on waiting lists without support, it meant that parents had to step into professional's job roles to seek any provision. This was highlighted by parents having to *"elbow" (Mark)* into offices, gather paperwork to share this with multiple professionals as prior professionals did not transfer referrals. *Mark* highlighted *"We gathered together a bunch of paperwork and we sent it to the GP, we sent it to the community paediatrician and the local authority. We sent it everywhere… It required my partner and I to galvanise ourselves…"*. Another parent disclosed how they kept minutes of the meetings which they would then send out to the professionals.

Parents also described having to *"spend a lot of time"* in schools, acting as a 1-1 helper to support their child and their learning, because the school *"didn't have funding"*, which would mean their child *"wouldn't be able to access" (Grace)* school without parent's support. *Maya* shared the stress of *"sitting right next to him to try and keep him focused and to do it. But he doesn't want us in that role… as his teacher"*.

### 4.6.2 Trying to Make Sense of Situation "Learning as you Go"

Parents reflected on the process of *"trying to make sense of what was happening in your world" (Libby)* and *"figure out"* what was *"going on" (Maya)*, this was considered when they first noticed that their child was distressed from accessing school or nursery. Parents described how they then tried to understand what was causing this, by deciphering *"what was different?"* and *"bothering him" (Maya)*. *Petra* likened this to *"guesswork… going with hunches"*. Afterwards, depending on support from school they would try to seek a neurodivergence assessment. Throughout this whole process even after diagnoses parents explained that they still were trying to continually learn and make sense of how to best support their child, *Petra* described it as *"learning as you go"*, with *Libby* highlighting there is *"no road map for what to do"*.

Given the lack of knowledge in the systems around families, ***parents were left holding everything*** which forced parents to gain knowledge about presentations and anything that may support their child, through any means they could find, including *"endless social media groups" (Libby)*, attending more courses *"than you can throw a stick at"* and *"grabbing books" (Anna)*. *Anna* spoke to *"rallying around"* their child dedicating many *"late nights"*. From their new learnings, they would advocate and share this with school and other professionals involved with their child.

### 4.6.3 Recovering Child

Not only were parents juggling the systems, advocating, learning and doing professionals jobs they were also trying to support their child suffering the effects of traumatic school experiences. Parents explained the great impact on their child, including regressions in behaviour and loss in *"all that independence" (Lillian)*. From this, parents were constantly trying to regulate their child, re-establish a sense of safety, *"restore confidence, reignite curiosity" (Mark)*, and rebuilding their *"independence back up" (Lillian)*, all of which were often lost during their years of trying to access school, *“where she should have been safe” (Lillian)*.

Many parents highlighted that it takes months and years to recover, with *Maya* sharing *“It's only now that he's recovering from the time of primary and getting his little spark, you know, like smiling and laughing at stuff. His sleep is more stable now. So there's a lot of… and that's taking months to get him back”*. Parents spoke to constantly recovering their child from “lasting” impacts, *Steve* disclosed *“There are probably some emotional scars there from it... So in bed I'll need to go and sit with her for a few minutes just to reassure her that everything's ok”*.

## 4.7 Category Five: Living in Chaos and Uncertainty

This category describes parents sharing a sense of ***living in constant uncertainty and chaos*** *(Figure 10)*. From the continual uncertainty, need to respond and ***fight disempowering attacking*** systems, plus ***being left to hold everything*** with limited support, it meant that parents were unable to juggle demands they faced.

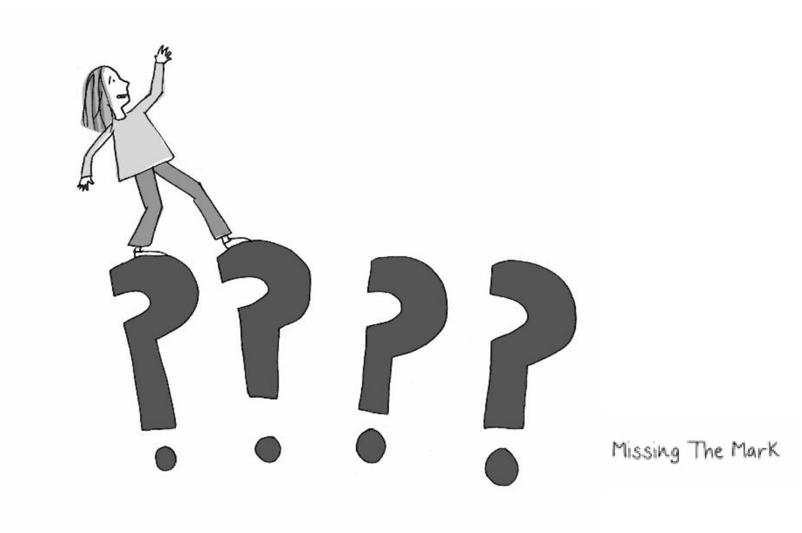

Figure 10 – Illustration by Missing the Mark (Eliza Fricker) depicting theme "Living in Chaos and Uncertainty"

### 4.7.1 Unknowing of What to Expect for the Day

Parents disclosed that they often did not know what to expect for the day, with each day being *"different and difficult" (Libby)*, full of uncertainty. *Grace* highlighted in each day *"we don't what's gonna happen, there is no regularity… no structure"*, like many parents *"We'll go see if she goes in… I drive 11 miles to the school. Get there. She won't go in and we try everything"*. This meant that their day was uncertain and relied on this, though parent's days were often disrupted by hearing back and needing to respond to various professionals, adding uncertainty to their days.

Parents described it as living in chaos and feeling *"out of control" (Lucy)*, thus ***impacting their mental health***, plans for the day and other demands which need attending to, like going to work. *Petra* highlighted how *"the unpredictability was really difficult"*. This experience is captured by *H* as *"It's kind of Russian roulette… it is quite tricky because with the inconsistency and uncertainty, it's really difficult to plan things and know what's going to happen. I find quite tricky"*.

### 4.7.2 Struggling to Juggle Everything

Parents explained that they struggled to manage and meet all the demands they faced, *Petra* described *"the Hokie cokie period… like in out in, out" being "tricky in terms of managing all the other aspects of life"*. The number of demands they faced was at a higher level compared to parents who were not in these situations. Parents doing "typical parenting roles", stepping into professional roles, spending time researching about neurodivergence to better advocate for their child, plus having to manage the rest of life and other wider responsibilities. *Grace* shared juggling demands *"is a logistical nightmare"* running her *"to the bone"*, *"paying for it later"* with no *"time to stop"*.

One of the particular areas that was difficult to juggle in the midst of these experiences was attending employment, which also was impacted by their employer. *Anna* summarised she was *"pressurised from the school to get on top of this and from my workplaces to get on top of this"*. *Petra* shared that she juggles working and home educating at the same time with *"limited success"*. Several parents explained that when their child was unable to access school and at home they were very *"emotional" (Steve)* and *"beside themselves" (Petra)*, which meant they needed supporting and comforting whilst parents trying to balance work demands. *Petra* added after supporting her child, *"I don't know whether I need a large coffee, a cry, punch a wall, like I've got my own emotions to process. And I've got a meeting at 9:30 you know… it was hard work"*.

Parents highlighted that whilst it was a massive challenge to try to juggle everything with one child, it was even harder juggling multiple children's needs especially if they were both neurodivergent and struggled to access school. *Fahmida* expressed feeling *"stretched between them"* trying to *"balance"* and *"juggle them all"*.

## 4.8 Category Six: Impacting Own Wellbeing

***Parent's wellbeing was greatly impacted*** *(Figure 11)* from being constantly ***attacked***, having to defend and ***fight*** against the ***disempowering systems***, whilst ***living in chaos and uncertainty***, and ***being left to "hold everything"*** with limited support. This category shares how parents' wellbeing was impacted from "being in the trenches", internalising the ***attacks*** and ***disempowerment*** from systems, and witnessing their child's distress, deterioration and regression. Their wellbeing was further impacted by their lacking space and support for themselves as well as a loss of opportunities, family experiences, finances and the stress attached to this.

Figure 11 – Illustration by Missing the Mark (Eliza Fricker) depicting theme "Impacting Own Wellbeing"

### 4.8.1 Being in the Trenches – Lasting Impact of Trauma Encountered

Multiple parents described that these overall experiences were a *"head f**k" (H)* and made them feel like they were constantly living in "*the trenches, on a hamster wheel feeling alone" (Lucy)*, experiencing a *"horror story" (Anna)* and "*f**k**g hell on Earth trying to save" (Libby)* their children. Parents routinely shared it was *"the hardest thing I have done" (H) (Anna)*, and encountered in life, this included parents who had a career in *"policing for 28 years*, *seeing the best and worst of human nature"*. *Lucy* compared her experiences with her twins being premature fighting to live, *"I walked into hospital every day not knowing if they were dead or alive. Like, that's how bad it was. And that was easier than this…"*.

All of these experiences were *"deeply traumatic" (Lillian)* for all parents and children, with many *"in complete survival mode, panicking, worried, lost, not feeling understood by anyone, holding me breath for years waiting for a breakthrough" (Josie)*. Many parents were still "in the trenches" when interviewed and shared that they understood how traumatic these experiences were and the impact of the experiences but did not have time to reflect and seek support for themselves as they had to continue the other fights at present. This left parents feeling there was *"no room for not being fine" which "takes its toll" (Lucy)*. *Grace* reflected *"I think I have post-traumatic stress disorder from my experiences, I find it very* *difficult to trust professionals. I haven't stopped to reflect on it. I can't stop. I'm like on a on a hamster wheel. But if I stop, it's all gonna be too much to actually deal with… there's no alternative. I will need some therapy to actually process and understand what we've been through".*

A minority of parents at the time of interview were no longer in such depths of trenches but were still deeply affected by these experiences. They highlighted the long-lasting emotional wounds that take them *"right back there"* despite it being many years later. Some parents had *"blocked their memories… like childbirth" (Petra),* or described it was a *"blur* ***of things went horribly wrong****" (Steve)* in which they didn't know *"how they managed" (Josie)*, this was considered a protection technique. If parents were able to feel in somewhat a better place, they emphasised how many years it took to recover parts of themselves and their lives though shared that *"It has a resurgence every while and it still takes me aback" (Libby)*. In the interviews *Anna* shared, *"I can very easily go back to that trauma, this doesn't go away easily, quickly… And it doesn't matter how strong you are or aren't. This is traumatic. There it is again. There's the tears. It hurts, it really hurts. It always catches me by surprise. Fine one minute and the next minute I really feel it again"*.

Living in the trenches had long lasting impacts on many parts of parents' wellbeing, *Steve* shared that he felt like he *"lost a year of life"*. Parents described feeling *"every emotion from overwhelmed, to exhausted, to angry and sad, but rarely happy" (Lucy)*, many shared they were *"close to not managing a lot of the time" (Libby)*. In addition to the trauma, it impacted their mental health and physical health, stating that *"our quality of life has deteriorated incredibly" (Libby)* and *"every school morning we wake up in a state of anxiety" (Mark), "It's like getting a kick in the chest from a horse… worrying about everything" (Lucy). Anna* shared *"It's the most unhealthy I have ever felt or been"*, with *H* sharing that *"life got small"*. This was further compounded by lacking space and support for themselves as well as ***losing their previous life and identity***.

### 4.8.2 Internalising System Response

Many parents' wellbeing was further impacted from the ongoing attacks and blame from the systems around them, particularly when parents started to internalise their responses. Some parents described that they *“began to believe I was just making things up, that I was not really a worthy person” (Libby)*, and found themselves listening to systems responses, believing they were not good parents, it was their fault, and they were impacting their child’s presentation and deterioration. Parents blamed themselves from wondering *“if I'd have done this, I'd have done that” (Lillian)* would it have been better.

Two of the parents shared that when some professionals gave validation and reinforced that it was the child’s *“needs have not been met, it's not anything you've done” (Lillian),* it supported them to stop internalising the system response further. *Josie* shared it was *“Purely validation. It's not just me. I'm not a crap mam, it's not something I've made-up in my head. It was just pure validation”*. However, this was rare as it relied on professionals having a wider knowledge and understanding of neurodivergence and the complexity of accessing schools.

### 4.8.3 Witnessing Impact on Child Accessing School

Parents’ wellbeing was also largely impacted by witnessing and experiencing their child deteriorating from the impacts of trying to access school, whilst being left to hold everything with either no or limited support. If children had gone to attend school, they were seen to *“get in the door and explode… she began to be quite violent” (Lillian)*. Parents described how *“horrible”* it was witnessing their children *“unable to sleep”, getting “stomach-aches”, “tics”* (*Maya*), *“losing weight, getting UTIs, pulling out their hair leaving bald patches” (Grace)* and becoming suicidal *“wanting to die” (Anna)* with the *“root cause of suffering being school” (Grace)*. In the midst of experiencing their child deteriorate, they were told *“They said that’s what autistics do… we wouldn’t get any kind of support” (Anna)*. *Petra* questioned *“Do The Tudors really matter that much?”* when there are *“literal physical costs”* for children to attend with their needs unmet.

### 4.8.4 Lacking Space and Support for Self

Parents often reported that they did not have space or time for themselves as they needed to be with their child *“24/7” (Lillian)* which meant they frequently did not participate in hobbies and did not even have space to regulate themselves. *H* raised that *"There wasn't the space to do things and be myself as much anymore"*. The lacking space for their own self stemmed from being left to hold everything, living in chaos and uncertainty, as well as needing to spend time learning about their child's presentation and advocating. The lack of space for themselves contributed to the impacts on their wellbeing. *Fahmida* shared *"Obviously, I have no time for myself. I'm having to deal with all of them and their difficulties"*.

In addition to lacking space for themselves, parents shared that there was *"no support for parents… it doesn't exist" (Lucy)*, which meant there were no provisions to access in helping them process and manage their current experiences and the impacts of their child being unable to access school due to their needs not being met. This frequently meant that parents felt alone and isolated and consequently were more likely to internalise the wider system's responses, impacting their wellbeing.

In the rare cases that parents had been able to finance or access support for themselves, they would often spend the session *"talking about my son" (Lucy)* and seeking support for them. Overall the majority of parents were unable to access support due to a lacking provision, time and finances "*being thrown into the children" (Grace)*. *Lucy* reflected *"You don't have the headspace to think I need help here because you're in the trenches and fighting. You don't have that time to give yourself the mental space to lift and walk away and talk about it and problem solve"*.

Whilst there was limited professional support, parents highlighted the impact of support they had experienced when they had a validating professional for their child on side. Parents emphasised that the best support had come from other parents with lived experience, it was described as *"powerful, to speak to people who've had similar experiences" (H)*, especially those who were able to signpost or explain some of their child's needs. *Josie* highlighted *"I just didn't know where I stood, there's nothing out there easily accessible to see. It's all hidden, it's only when you meet people in similar situations who have already been there and come out the other side where you find out that actually that would have saved me"*.

### 4.8.5 Losing Money and Family Experiences and Opportunities

Parents explained that their wellbeing was further *"hit hard"* from the loss of finances being unable to work, and the *"additional stress" (Lillian)* and worries this enhances. *Josie* disclosed *"That was the impact for me, not being able to go to work and earn a living, we didn't have much money"*. This resulted in their wellbeing further compounded by a loss of opportunities and family experiences, such as holidays that would support their own and their wider family's wellbeing.

Whilst the loss of opportunities was seen resultant from losing money through missing employment, it also stemmed from parents having to also fund their child's provision and assessments limiting any finances they did have. This was seen to be the case for *Libby* who shared *"We paid for educational psychologist, an OT, and a speech and language therapist, doing that on benefits is not an easy task. So we've lost things like family holidays as a result of having to fund those things"*. *Grace* added that they had funded provision for the school *"So we've been paying for that because we didn't have an EHCP, £200 a month for XX to go into school to train the new school staff on how to deliver this therapy that she needs integrated in school when she's there"*.

Parents further spoke to missing family experiences and time due to living in constant chaos, spending most time fighting, and being left to hold everything. *Grace* shared that she felt *"robbed of my time, that my children have been robbed of my time… I feel like their childhoods are slipping away whilst I'm fighting. I'm missing out on experiences and they're missing out on experiences"*.

## 4.9 Category Seven: Losing Previous Life and Identity

Parents frequently cited that they had ***lost their previous life and ultimately their identity*** (Figure 12). This category highlights that losing their previous life and identity was considered through a loss of friendships, socialisation, work, values, expectations and ways of living. These circumstances were considered forced through having to spend time defending and **fighting** against the ***attacking*** and ***disempowering systems***. Living in ***chaos***

***and uncertainty***, whilst being left to ***hold everything*** with limited support perpetuated the difficulties in maintaining a previous life.

Figure 12 – Illustration by Missing the Mark (Eliza Fricker) depicting theme "Losing Previous Lift and Identity"

### 4.9.1 Impacting Relationships, Missing Friendships – Feeling Removed from Society

Parents shared how isolating their journeys were, they spoke to feeling removed from society and *"the world" (Libby)*. Many noted the presence of "social stigma", and consequently were *"ostracised" (Anna)*, with "*people don't want to be part of our lives" (Fahmida)*. Parents *"pull back quite a lot" (H)* as a result of limited knowledge and understanding plus judgement from family members and other parents, they described being *"shut off" (H)*. *Maya* added that this included *"wider family as well, because not* *everybody understands… they just think oh you need to do more you need to push him more…when people don't understand what it's like to have a child that is a little bit different from what they know, it's really, really hard"*. *Lucy* and others shared *"I don't think anybody really knew how tough it was because no one got it. If you started to even start a conversation about we're struggling with school and going in very quickly turned into, oh, well, just got to go. Like, that's it".*

Some parents disclosed that their relationships with their partners were significantly impacted by the stress placed on both parents *"finding it difficult" (Fahmida)*, with limited time together, plus parents offering different types of support to the children, as well as approaching the experiences and responding to professionals in different styles. This causes tension between parents holding differing views, with some parents wanting to *"push further" (Steve)*. However, it was noted by all parents that their joint *"concern" (Steve)* for their children and responding as *"united" (Libby)* is what has kept parents together. *Libby* shared that understandably parents probably have *"quite fragile relationships because everything's been invested in the family and getting things that they need"*. *Lillian* highlighted *"It's been hard for both of us, coming to terms with sort of living separate lives sometimes. We don't have time together. We don't have that closeness because my position as a mum has taken over being the partner"*.

Moreover, many parents reflected that they had lost many friendships further due to not having time to meet with their friends or see them as frequently due to needing to support their child through their distress as well as fighting the wider onward battles. Friends were seen to be *"falling back" (H)*, with parents believing they were *"a rubbish friend right now" (Lillian)* because they do not have capacity to juggle friends alongside everything else. This is highlighted by *Libby "My life comes out as a really needy sort of mum, parent, friend, who hasn't really got that much to offer, and that's been true. A lot of the time because, the areas we are battling don't leave much at the end of the day to give to others"*.

Few parents expressed that they had established new relationships with other parents who were encountering similar experiences with their own children. Though, these friendships were still considered to be restricted as it was often spent trying to support each other and signpost rather than talk about other topics other friendships would. *Libby* shared

*"If it's another SEN parent, you just say I've had one of those days, that's all you need to say… they sort of yeah, gotcha… but everybody's spoons are empty. So people that do understand, they're completely drained and knackered by the whole system… even getting together to talk about anything always goes back to the same topics. But actually all you want is a normal friendship where you don't have to talk about that crap"*.

### 4.9.2 Losing Work and Professional Identity

The majority of parents had to stop working or reduce their hours to support their child's needs and partake in the wider fight against ***disempowering systems***, this was highlighted by *Mark* who shared the impacts have left him *"having to accept I'm not working and I'm much poorer"*. *Maya* enforced *"we've had to adjust our jobs, which is something you've got to do, but it's not idea because you plan on certain money"*.

Parents reported that by living in "states of uncertainty", not knowing whether their child would be able to access school until the day, and getting calls in the middle of the day to collect their child, impacted the amount of hours they could commit to. *Petra* shared that *"There'd be times when I'd take him in and he would physically attach himself to me and couldn't go in. I'd have to walk back from school with a child and I've got my work plans. I need to arrive at work, I've got a meeting at 9:30. I've got someone at 10 o'clock. I've got all that stuff and I'm thinking, how am I going to do this"*. *Anna* explained *"It didn't take long before the phone calls were coming for me at work as a professional mom. Come and get him. So that became very intrusive in work life. I ended up with an unhappy employer and an unhappy school. And I'm caught right in the middle of it"*.

Parents reflected that their ability to access work depended on how supportive their employer was to allow flexible hours and work. Parents shared that some of their employers understood they needed to get their child or that their mornings would start later if their child struggled to access school. *Petra* elaborated "*I am lucky I have control over my diary. I don't have a time to arrive at work or stay until. So work were very understanding that some days I wouldn't come in until lunchtime. But I'm working in the evening or other days I might need to leave at 2 o'clock because he can't cope and I need to pick him up"*. Whereas other parents spoke about unsympathetic employers making them choose between work and family. This was disclosed by *Mark* sharing a *“lack of sympathy I got from my employer”* meant *“I stopped to become XX principle full time carer”*. *Josie* added *"there was days that I couldn't go in… I was late because I couldn't get him into school… I left a job that I loved because she wasn't a very understanding boss”*.

Stopping work impacted parents in many ways, including parents’ finances meaning what they could afford to do changed. *H* reflected she had *“lost a bit of freedom”* from *“losing work”* and finances. Parents also shared by stopping work they lost their social network, work friends and their professional identity. Both *Lillian* and *Libby* raised the difficulties of losing *“financial income”*, but *Lillian* raised her identity had changed from *“Lillian, the midday supervisor, to just XX's mom now”*, and *Libby* shared other *“social implications of not having”* work including the loss of a *“support network".*

### 4.9.3 Reassessing Values, Expectations and Upheaving Entire Life due to Lack of Choice.

Parents were seen to reassess their values and expectations for life, with many parents sharing how their perspectives and thoughts on life had often been changed by the process. Parents spoke of *“losing touch with reality”* or life and *“getting a new one” (Libby)*, some viewed this as a positive whilst most experienced it as detrimental and isolating. This was highlighted by *H*, *“You got to look at yourself and make sure your values are aligned to what is important to your family… So I always liken maternity leave with your first kid to like a bit of a crushing of who you were and a rebuilding of something else. I felt a real breaking down of everything that I'd had. So it wasn't a nice process”*. *Fahmida* instead reflected *“I've had to change what I've done, what I'm doing… Even when other parents are talking get stressed out about it, I can talk them round now because I've changed my way of thinking in terms of it doesn't matter how you do in school, it matters what you, what your journey is like, where you go from there afterwards, what things you've learned, what's your valuable lessons that you've learned from life opposed to just school”*.

For most, the reassessment of values and expectations, led to an upheaval of their life in terms of having to move location for a new school catchment or different local authority, or upheaving the way they lived their life. *Josie* shared that they had to *“move* *house, mostly because of the school"*, with *Mark* similarly adding *"The most significant impact is that we moved so that XX could continue to attend a mainstream school. We moved from the only home she'd ever known surrounded by neighbours she knew"*. *Libby* instead reflected on how the losses changed their lives *"we had a whole lifestyle and career and everything that was before this happened… Opportunities… the opportunity to go back to my professional career. My husband had the opportunity in his business, all that changed our whole life ahead of us"*. *Anna* highlighted that *"Life now looks really different. We decided to try life differently, and moved into our motorhome, gave up our jobs, travelled around with XXX, teaching him about the world… I've never known freedom like it. I've never had so little and had so much"*.

# Chapter Five: Discussion

## 5.1 Overview

This chapter offers a summary of the findings, and considers these in relation to existing literature, research, and theoretical models. A critical review of the research will be shared with relevant implications for schools, policy makers and clinical practice. Finally, the chapter ends with conclusions and suggestions for future research.

## 5.2 Summary of Findings

Recent research has explored neurodivergent CYP's experiences of SNA, though there was a lack of literature that explored how parents experience SNA for their neurodivergent child. Therefore, this research aimed to explore: **What are primary caregiver's experiences of school accessibility for neurodivergent children?**

A tentative co-constructed model was created from interviews with twelve participants, and member-checked in a focus group. The theoretical model hoped to offer a potential understanding of the processes that underlie a parent's experiences of their neurodivergent child's SNA. Though every parent's journey is unique, the model's key processes appeared across all participants' experiences, shared in interviews. Most of the processes appeared to be relational with key stakeholders such as: government, school systems, mental health and other external professionals, families, friends and employers. These relational processes, like ***being disempowered or attacked***, highlighted the role of power and how this influenced the overall experience. However, there was also some internal processes like ***internalising system response*** or ***reassessing values, expectations and upheaving entire life***.

The model considers how many of the systems parents had contact with ***disempowered*** neurodivergent CYP and parents. From the setup of schools and systems around them, to how they responded to neurodivergent children and families with SNA, this was experienced as ***disempowering***. It was considered that the government had much responsibility for how these systems were setup, such as their funding and budget cuts etc.

Often systems and professionals were seen to ***attack and blame*** parents and neurodivergent children for their SNA. This ***disempowering*** and ***attacking*** forced parents into a position of defending by ***having to fight*** for their child's needs to be met, and access to education and health provision rights. As a result of the systems interactions, it frequently meant that parents were ***left to hold everything***. From acting in multiple positions it caused great disruptions to parent's lives and meant they ***lived in chaos and uncertainty*** as all situations were variable and everything could change across the day. These collective experiences had profound ***impacts on parent's wellbeing*** and led to a ***loss of previous life and identity*** due to their new positions conflicting with their prior positions and life. Many parents were seen to move into advocacy or voluntary support positions related to SNA and neurodivergence.

## 5.3 Relevance of Findings to Literature

For the purpose of exploring current literature and theories, this section will explicitly discuss and contrast these research findings with the broader category titles, though some specific sub-categories will also be mentioned[26].

### 5.3.1 Being Disempowered by Systems

This research found children and parents are disempowered by wider national education schooling systems driven by government, and shaped by individual schools. This disempowerment is further replicated by services for young people and their families, such as mental health and social care.

Parents experienced education systems as outdated, ineffective, economically-driven, *"fundamentally flawed"* and not meeting the needs of neurodivergent children, ultimately disempowering them and their families, and creating SNA. Maratos et al., (2023) also highlighted how schooling practices are dated and "rigid". This was further supported by the SLR findings that indicated a lack of supportive environments and responses led to SNA and

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[26] In line with CGT methodology, the literature review was delayed to develop a co-constructed theory as close to participant's accounts as possible and therefore trying to minimise external biases (Charmaz, 2014). However, once the SLR and other reading took place, the researcher started to notice similar connections and relationships to the concepts and processes identified by this current model.

deterioration in child's wellbeing. Fielding et al., (2025) further supported that mainstream schooling is currently not fit for purpose as it is unable to appropriately meet the needs of neurodivergent children, and linked this to SNA, indicating the disempowering nature of our current education system for neurodivergent children and their families.

Research has long advocated for discussions around the appropriateness of “traditional” pedagogical practices particularly for neurodivergent children where the majority are denied access to education due to the current schooling setup (Connolly et al., 2023; Lindsay et al., 2020). This current research also found parents advocating for educational reform. Like Connolly et al., (2023), parents felt education reform was needed for all children and if neurodivergent children’s needs were met than it would likely benefit neurotypical children too.

The UK Government called for change and shared that new SEND policies and local authorities were “failing” and providing inadequate support for children to access school (Azpitarte & Holt, 2022). However, research stresses that the government are accountable for their influence and recommendations on schools and local authorities, including attendance guidance, lacking educational reform, and wider pressures that schools face. (Hodkinson, 2025; Granoulhac, 2017; Griffiths et al., 2022). Likewise, this research also found parents place accountability with the government and those *“right at the top”* for the pressures school face and set-up of schooling. This research emphasised there were some professionals who were trying their best within educational systems but were stuck due to wider government impact. Therefore, this research and other existing literature highlights the government in a position of responsibility and accountable for individuals being disempowered through inaccessible schools, attendance and assessment driven policies, lack of SEN provision, specialist schools or alternative education (Vo & Webb, 2024; Fielding et al., 2025; Granoulhac, 2017).

Though the government play a role in disempowering neurodivergent children and families, parents highlighted that schools had a level of control, power and independence away from the government to decide how they responded to SNA. According to parents, the variability in school experience is shaped by the ethos, culture, pressures, and senior leadership of a school. Mincu (2022) also highlighted the power of the senior leadership teams within school arguing transformation cannot occur without effective school leadership, adding it is “naïve launching heartfelt calls” for teachers to change as they are responding to dynamics and contexts within schools. Parents in this research highlighted “organisational issues”, and teachers were seen as “powerless” working against the system.

Consistent with existing literature, this research found that school systems were experienced as punitive towards children (Brede et al., 2017) and parents (Mullally & Connolly, 2025), this led to the disempowerment of neurodivergent children and their families. Published literature, and the current research suggest, that the systems’ responses were underpinned by a lack of understanding and knowledge of neurodiversity within schools and professionals (Sproston et al., 2017; Nordin et al., 2024), often mirrored in wider society too (Cage et al., 2017). Anglim et al., (2018) found that teachers felt very apprehensive and lacked confidence when working with autistic individuals. It was thought they were uncertain how to manage a child’s behaviours when distressed, with several teachers describing “trial and error” (Anglim et al., 2018). Dimitrelloue et al., (2020) highlighted insufficient national training for inclusive practice. This current research shared similar findings, with teachers seen *“googling what to do”*, lacking confidence and not making appropriate or consistent adaptions (Anderson, 2020).

Finally neurodivergent children and families were also disempowered by external services like mental health and social care. This research echoed Vo and Webb, (2024) who highlighted that current evidence suggests parents have to navigate complex systems with limited guidance or information to try to access any support. Parents in this research stressed that provisions change depending on location, other research similarly found disparities in provisions calling it a “postcode lottery” (Azpitarte & Holt, 2022), with structural inequalities as a result.

This research further considered disempowerment took place through delayed diagnosis, disjointed services, limited communication, and delayed access to service provision. All of these factors have been raised by prior literature (Maciver et al., 2025; Vo & Webb, 2024; Martin-Denham, 2020), with many UK mental health services in states of “crisis” with increasing demand, funding stagnating and chronic staff shortages (Day, 2025). The delay in diagnosis was reported by parents to postpone accessing provisions from school and other external professionals. Though diagnosis is not officially required to access SEN support or EHCP, in practice diagnosis is needed to access provisions by supporting the process (O'Hagan, Bond, Hebron, 2024; Vo & Webb, 2024). Chapman (2023) raised that those awaiting diagnosis are more likely to be excluded from school. Interestingly, schools were observed to also be a block in referrals for further support or provision (Connolly et al., 2023), particularly if they did not support the parent, or recognise difficulties (Martin-Denham, 2021). This research noticed that due to some services' criteria, schools were in positions of power by needing their agreement for referrals to access diagnosis and support, meaning schools could act as gatekeepers.

Overall the current research findings are consistent with literature that children and families are frequently disempowered by systems and services. Bodycote (2022) summarises that the disempowerment came from systemic failures in lacking: effective guidance to access support, working partnerships between systems, child mental health awareness and support, inclusivity in schools, compliance with DfE guidance and legislation, accountability, knowledge and awareness of SEN, with differing interpretations of SNA.

### 5.3.2 Receiving Ongoing Attacks and Blame

Schools were often in a position of power, and weaponised this against parents within their relational dynamic, this was experienced as attacking parents. This ultimately created a dynamic where parents are "enthralled" to the professionals.

For many years research has been found children and parents blamed for SNA (Devenney & O'Toole, 2021), with parents signposted to parental courses (Martin-Denham, 2022; Gray et al., 2023) even when the cause is attributed to neurodivergent children's needs not being met (Mullally & Connolly, 2025). This research similarly found parents blamed for SNA and for their child's presentation, with some professionals believing parents were fabricating their child's needs or had "poor parenting".

After being blamed, this research heard that parents were consequently further attacked by threats of fines and being reported to social services. One parent shared that they were investigated by the police due to school reporting them, with the police concluding their child was safe at home and their presentation was likely due to their needs not being met within school. Other research has similarly found parents commonly threatened by the school system (Lissack & Boyle, 2022), though only a small percentage of parents reported being fined, having child services involved, or an attendance order issued (Mullally & Connolly, 2025). The same research also interviewed school professionals and 42.1% reported that they or a colleague had taken action against a parent (Mullally & Connolly, 2025), highlighting the frequency which school systems enforce punitive measures.

Parents, in the current research, described being ignored, unheard and dismissed in their interactions with systems. Published literature similarly found parents frequently ignored with concerns dismissed by school and other professional systems (Lissack & Boyle, 2022). Parents reported being dismissed by systems when sharing with them how they made sense of the situation, it was seen as unwanted, with professionals either normalising the behaviours or attributing symptoms to separation anxiety. Headley and Campbell (2013) previously commended teachers' accuracy in identifying anxiety in neurotypical students, however Adams et al., (2019) questioned their ability to translate this to neurodivergent students and recognise "autistic related behaviours". Parents often felt ignored and dismissed when trying to advocate for their child to access reasonable adjustments like utilising ear defenders in classrooms, or when requesting referrals to neurodivergent services which require school approval. Sproston et al., (2017) likewise found parents ignored when suggesting recommendations for their child. This research adds to literature, finding that the more parents tried to advocate, the more frequent and severely parents were blamed for their child's presentations. Clements and Aiello (2021) shared after challenging professionals, a growing number of parents were then investigated for fabricated illnesses.

The dismissing, ignoring and attacking from systems was found to position parents as "enthralled to the professionals". Parents often spoke to the professionals having more knowledge than them and therefore believing they know what to do. Mullally and Connolly (2025), also found parents reported being called into meetings; "made to feel small" and lectured by school professionals. Other parents in this research highlighted that they felt they had no choice but to go along with the systems from fear of negative consequences such as being reported to social services and losing their child. It was experienced as the systems abusing their power in some cases, though parents reflected that they understood the reasons why the systems need some authority to protect other children from child abuse. Mullally and Connolly (2025), likewise found parents to be very aware of the relational power imbalance with school.

### 5.3.3 Fighting Systems

Literature has highlighted parents are frequently positioned to “fight” the school systems and other professionals (Gray et al., 2023). This current research found parents forced into roles of advocating for their child, particularly when their child was not accessing other services. Brede et al., (2017) similarly commented that parents had to fight for their child’s needs to be recognised and to access support. In this current research, parents highlighted how their advocating role felt like an *“uphill battle”* for their child’s rights and needs to be recognised and met. Parents believed schools viewed their responses as “fighting”, whereas parents reflected that their response was from defending themselves and their child from the system. These findings are similar to other research where parents described trying to fight against an ableist, complex bureaucratic system (Neilson & Bond, 2023; Gray et al., 2023).

Not only were parents found to be “fighting” for their child, this research noted many advocated to systems for future improvements for other children. This was consistent with Singh et al., (2019) who found raising awareness, educating and supporting others as of upmost importance. The “Grassroots” theory of change model highlights that individuals impacted by a certain difficulty, join to act together to achieve social change (Stachowiak, 2013). This model could be connected to this current research finding where many parents often started support groups or worked with local authorities or schools as they did not want any child and family to encounter what they had. Parents shared through advocating they were able to support the redistribution of power away from the systems, creating a sense of empowerment for themselves, as found by Smith-Young et al., (2022) where parents felt empowered when they had mastered the skill of advocating. Even in the toughest of experiences, all parents were seen to draw upon their own strengths and skills in this process, especially when it meant coming together or supporting another family.

The parent’s positionality and skills were seen to impact their overall experience of fighting and in some cases how the systems received the parents’ responses. Whilst all parents were on horrific disempowering journeys, Mullally and Connolly (2025) highlighted that some parents were in more privileged positions than others, and hypothesised that parents in the most vulnerable positions with limited societal privilege were at heightened risks of the most harmful impacts. Parallel to this, the parents interviewed in this research also mentioned additional difficult layers to navigate for those positioned as single, a new parent, neurodivergent themselves, where English was not their first language, those who do understand of neurodivergence, and those with limited family support. Martin-Denham (2020) likewise found parents highlighted positionality, whereby not all parents are able to "fight their way through the red tape" due to lacking ability, knowledge and finances required for private provisions. In some cases, this current research found, when a parent had a job related to neurodivergent professions, or when they understood their child's and their own legal rights, they were more likely to have been heard compared to those who did not have these positionings. However, even for the parents in such positions, they experienced being unheard, blamed and had punitive actions taken against them.

In this research, parents reflected drawing upon certain skills they had learnt from other life experiences, careers, and also personality qualities that supported them in fighting and advocating for provision. This is consistent with previous literature whereby Taylor et al., (2019) found parents being supported in advocating by using their skills and knowledge as well as personality traits[27]. Research identifies the disparity and privilege of being able to draw upon such resources, giving some advantages when advocating and leaving others unable to effectively engage in such. Recognising this, many countries around the world have developed training sessions for parents to become empowered, through learning more about neurodivergence, the policies and law as well as effective advocacy (Citial, 2020; Burke et al., 2024).

### 5.3.4 Being Left to Hold Everything

This research found parents were "left to hold everything", particularly when parents were unable to access services, provisions or were disempowered by the systems. Similarly,

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[27] The professional skills included: networking, marketing, public speaking, leadership, argumentation, effective communication via phone calls and emails, knowledge of policies, terminology, community resources and funding.

Bodycote (2022) found parents proactively approaching and seeking to resolve SNA, though they highlighted that systems around parents are often not structured or prepared to support this process, due to many complex systemic barriers between and within systems. In this current research, parents were noted to take responsibility and step into some professionals' job roles, such as completing paperwork, making connections between services for them to offer more joined-up care. Parents were also seen to step into school roles where they volunteered as a 1-1 support in the classroom so their child could attend.

Given the lack of knowledge in most professional systems, this research found parents needed to learn about neurodivergent presentations so they could support their child and "step into" the professional's roles whilst sharing knowledge with these systems too. Bodycote (2022) shared that this process involved making observations, applying parental knowledge, and researching for advice or information. Likewise this research found parents trying their hardest to understand what was happening, and spending any time they had researching, including sacrificing sleeping.

In the midst of being left to hold everything, and frequent lack of support from professionals, parents tried to support their child alone. This research highlighted that parents were doing their best to try to support their child to recover from the trauma encountered as a result of SNA. This came through regulating their child, building a sense of safety and reestablishing their child's confidence. Lawrence (2025) found after children had attended school, their parents had to spend a few days "recovering" their child through low demands or environments which address sensory needs, it was seen that children needed time to decompress from the demands at school. The SLR findings were similar, with parents seen to respond to their child's decline in mental and physical health and an increase in behaviours that challenge. Martin-Denham (2020) heard how parents had often needed to quit employment to prioritise recovering their child, especially when there was limited external support.

### 5.3.5 Living in Chaos and Uncertainty

This research found parents living in "uncertainty", frequently not knowing what to expect as each day was so different, thus creating "chaos" compounded by having to juggle everything. The uncertainty experienced had significant impacts on their mental health. Blackwell (2024) similarly found parents reported frequent changes in school rules or provision, often without prior warning, meaning parents were unable to inform or prepare their child, creating additional distress for their child. Bodycote (2022) highlighted that unpredictability, uncertainty and chaos were common “features of home-life” based on their child’s day. The current research adds to existing literature by highlighting that the uncertainty and chaos is not only dependent on their children’s experiences of the day, but also when hearing updates or changes from schools, or external professionals. In this research a parent highlighted how their day had changed based on a response from a local MP and they had to stop what they had planned and go into advocating.

Parents also frequently shared how they struggled juggling the demands of employment alongside all of their other experiences connected with SNA, similar to Blackwell (2024), where parents had to curtail work unless they had a sympathetic employer who could support flexi-working. Parents similarly spoke to finding it difficult to meet the needs of all children while also finding time for themselves and their partners (Smith-Young et al., 2022; Mullally & Connolly, 2025). Parents finally reported how difficult it was to juggle all of the typical demands as well as responding and needing to fight the systems. Bodycote (2022) likewise found parents juggling and responding to many difficult dilemmas, including supporting their traumatised child, managing day-to-day family life, whilst having to comply with legal responsibilities related to their child and education, and being judged and evaluated on their parenting. All of these factors significantly impacted parents’ wellbeing and health.

### 5.3.6 Impacting own Wellbeing

Parent’s wellbeing and health were significantly impacted by a combination of factors, including disempowerment, fighting, being left to hold everything due to limited support, living in the midst of uncertainty, whilst juggling life’s demands as well as the experience of SNA. Current literature also finds the experience of SNA as detrimental; negatively impacting “every single aspect” of parent lives (Mullally & Connolly, 2025). The effects of SNA and unsupportive environments were also seen in the SLR to impact parents' wellbeing and health.

In the current research, parents highlighted the long-lasting trauma encountered from "being in the trenches". Living in the trenches was likened to "hell on earth" and living a "horror story", it was deeply traumatising for children and parents. Martin-Denham (2022) highlighted how heartbreaking these experiences were. In this current research, parents were found to speak to the harmful impacts on their mental health, wellbeing and physical health. This finding is consistent with others whereby research has suggested that over 50% of parents developed mental health conditions and were prescribed medication, as well as some parents developing physical health conditions (Gray et al., 2023; Mullally & Connolly, 2025; Martin-Denham, 2022).

From being disempowered by systems, with attacks and blame, this research saw many parents internalise the system's response and believe that they were not supporting their child, were not parenting right, causing their child to deteriorate, despite this not being the case. Internalising the system response deeply hurt parents and caused them to feel unworthy and not good enough, further impacting their wellbeing. Sadly, Mullally and Connolly (2025) shared a similar finding and named the experience as "professional gaslighting" with over 75% of parent experiencing this and manipulated into doubting their experience, understanding and perception. Mullally and Connolly (2025) added that their wellbeing was impacted by the internalising system responses as it made parents lose confidence in themselves and their parenting.

Parents' wellbeing was further impacted through watching their child deteriorate, become distressed and traumatised when trying to access school. This was similarly highlighted by Bodycote (2022) where a parent shared that the impacts of watching their child deteriorate was one of the hardest experiences they had faced in life, including their own experience of a life-threatening illness. Gray et al., (2023) likewise emphasised the impact on parents of witnessing their child deteriorate to the extent of becoming suicidal.

Mullally and Connolly (2025) found although some recovery post SNA occurred for parents (e.g. reduced daily anxiety and low mood ratings), overall anxiety remained high compared to before experiences of SNA, indicating a long term psychological impact. The long-lasting “wounds” were also found within this research whereby parents spoke that many years had passed and even though they were no longer within the trench, talking about SNA brought the experiences up as if they were reliving it again. One parent indicated that they believed they acquired PTSD from all experiences they had encountered.

Within this period, as parents were expected to attend and respond to all experiences attached with SNA, it was frequently reported that it meant they did not have any time to reflect or engage in any nourishing activities for their own self-care. Similarly, Mullally and Connolly (2025) reported the loss of leisure time and self-care to support their mental health, with Blackwell (2025) highlighting that parents responding to SNA are often “time-poor”. This current research also found that most parents were unable to seek professional support for themselves, due to financial and time constraints. In this research, one parent raised that they had no choice but to keep going to support their child, because parents would not get support until there was acknowledgement instead of a collective dismissing of the impact of SNA on parents from wider systems. In Bodycote’s (2022) research, one parent shared that they had stopped talking about their SNA experiences as it was too much to relive with no support or answers for them, leaving them no choice but to “keep going”. Therefore, the lacking support and access to space for themselves can be argued to further compound low mental wellbeing, should parents have access to time, space and support it would likely have improved their own wellbeing (Islam, 2024). Consistent with Mullally and Connolly (2025) work, parents in this research highlighted that the best support they accessed came from other parents with lived experience of SNA as they were seen to validate, empathise and offer practical support.

Parents’ wellbeing was further impacted by their lack of access to finances from often needing to curtail employment. This is consistent with Paulaskaite’s (2022) findings of losing income and with Edwards-Fapohunda and Adediji (2024) emphasising the additional worries and stressors attached with this. The research found as a consequence of being unable to access support or provisions, parents’ finances were also constrained from having to pay for private assessments and provisions to support their child’s access, Bodycote (2022) also noted a similar pattern. Not only did the loss of finance add worries and pressures to family life, but this research observed that families were impacted by no longer being able to access family holidays or experiences. It was reflected how these positive experiences and respite away from difficult situations were needed to support parents and families wellbeing and relationships. Some parents also added that they had lost family quality time and experiences from having such little time which was often spent advocating and being left to hold everything for their child. Barnes (2025) emphasised that advocating, trying to access provision, or filling in forms for their child can exhaust the limited time parents have. The lack of time and funds for family experiences and opportunities as well as parent’s own nourishment, compounds a lower wellbeing.

### 5.3.7 Losing Previous Life and Identity

Parents shared how isolated they felt during this journey juggling these experiences attached to SNA, and along their journey they had lost aspects of their previous life and identity. This current research found parents speaking to a sense of being removed from society due to the lack of awareness of neurodivergence, plus judgement received, which impacted their relationships with family and friends. Mullally and Connolly (2025) similarly commented on the isolation which systems enforce and the lack of societal understanding, they found many parents encountered “just about everyone” dismissing their experiences .

This research saw parents disclose the tremendous pressures placed on parents and their relationship with their partner from the experiences attached to SNA. The pressure was thought to stem from having limited time together, encountering enormous pressures and judgements from the systems, alongside having differing styles to responding to SNA and the systems. Mullally and Connolly (2025) contended they found significant impacts on relationships between partners, with both individuals having negative impacts on their mental health and careers, and a lack of time to connect. Bodycote (2022) noted that typically one parent held more responsibility for their child’s SNA by supporting them and their needs, attending meetings and advocating. Whilst some parents in this current research spoke to this, some parents reported both were involved. However, as in this research, Bodycote (2022) highlighted that some parents had conflicting approaches and opinions which sometimes added pressures to their relationship with each other.

Parents in this research also disclosed that their friendships were impacted due to not having time to meet due to components attached to SNA. Barnes (2025) reflected on the strain and time pressures parents face, alienating them from friends and family. Friendships were further considered to be impacted when they were experienced as lacking understanding, making judgements and offering unhelpful advice. This was similarly reported by Mullally and Connolly (2025), which added to parents’ experiences of isolation and losing part of their previous life and identity. This current research found new relationships and friendships established through connecting on experiences of SNA, though these friendships were still restricted as time would often be based on support or signposting rather than enjoying other aspects of friendships. This would make sense considering Mullally and Connolly (2025) shared other parents with lived experience are of beneficial support.

The majority of parents spoke to losing their previous life and part of their identity when stopping employment to support their child and respond to the experiences associated with SNA. Balachandran and Bhuvaneswari (2024) emphasised the complexities of balancing caregiving responsibilities with neurodivergent children and the conflict with work and career ambitions. Existing research and the SLR both highlight the different dilemma parents are positioned in with most being unable to work (Blackwell, 2024; Martin-Denham, 2022). Parents shared that they were unable to work based on the uncertainty present in their lives from SNA and therefore were often not sure what hours they could commit to and when. This was also found by Blackwell (2024), where parents were late to work after trying to support their child to access school, or received phone calls during the day to support the school in managing their child’s needs and distress. These factors made it very difficult for parents in employment, as demonstrated by this research also, parents’ ability to access work depended on the level of flexibility and support they had from their employer (Blackwell, 2024).

Stopping work not only impacted parents’ access to finances but also meant they lost their “professional” identity. This was significant in this research, with some individuals saying that they were just “XX’s mother” now and they had missed opportunities and connections that their employment supported them with. Bodycote (2022) and Blackwell (2024) highlighted that SNA frequently meant loss of stability, impacted future career and progression, impacted their professional reputation as well as significant financial impacts.

This often meant that parents' lost parts of their previous life, identity and part of their *"freedom"*.

Finally, this research found many parents forced into reassessing their values and expectations for life, following the loss of their previous life and aspects of their identity. Expectations were seen to change around supporting their child and plans for their child's life as well as the pressures placed on parents and their parenting, this was experienced as making an active decision to no longer conform with societal expectations. These expectations were considered to change based on parents reflecting on their own values whereby their child's happiness in life was more important than education etc. Parents focused on the "bigger picture" in life rather than just their child in school. Bodycote (2022) also found this experience present in parents' journeys and named this process rethinking priorities, whereby parents were seen to prioritise their relationship with their child over education or prioritise their child's opinions encouraging them to advocate their own needs.

From reassessing values and expectations, the current research found parents upheaving their life based on this or to access provisions within different catchment areas and local authorities. Existing literature highlights that many parents may be forced to upheave their current life in terms of deciding to home educate after traumatic experiences associated with SNA, quit employment to support their child or change schools (Paulaskaite, 2022; Martin-Denham, 2022). However, this research builds on this by finding that some parents have been forced to move to entirely new counties to access provisions. Whilst research has not explicitly reported this, the findings makes sense given provisions from local authority and mental health services change depending on catchment (Azpitarte & Holt, 2022). This research further builds on existing literature by adding parents upheave their entire life and way of living with for example, one parent shared they felt convicted to sell their house, give up luxuries and live in a campervan so that they travel and teach their child through this method after their experiences of SNA. Some parents shared how these changes had felt liberating, whilst others shared that these changes had devasting impacts on them.

## 5.4 Links to Psychological Theory and Concepts

These findings were considered through two psychological concepts and theories, the first, living in a "neurotypical world" and being neurodivergent with others constantly viewing situations from "neurotypical lenses", the second through the Bronfenbrenner's bioecological systems model (1979; 1998; 2005), please refer to Appendix Q.

## 5.5 Implications

This research has explored and identified the processes that frequently underpin parents' experience of having a neurodivergent child unable to access school, the research captured the devastating impacts on parents' lives and their wellbeing. From this, the research identifies many clinical implications and recommendations for mental health services, education sectors and wider policy-makers. In interviews, all parents were asked what they thought needed to be changed and their voices and recommendations are shared in Appendix R. Recognising the current understanding, support and provisions within the UK, recommendations have been separated into imminent and also longer term recommendations, for clinical practice (Table 15 and 16), education sectors (Table 17), and policy-makers (Table 18).

Table 16 - Implications for Clinical Services supporting Parents responding to SNA:

Parent's mental health and wellbeing was also seen to be severely impacted from being attacked by systems and internalising their responses, from witnessing their child become traumatised thus holding their child's distress, losing parts of their life and identity, plus trying to survive and support their child in the midst of this. Despite, the significant impacts on parents, there was no support from mental health services for parents to access themselves. From this the following recommendations can be made.

| Imminent Recommendations | Long-Term Recommendations |
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| Parents should be positioned as having expertise in understanding their own child, therefore their voices need to be respected and heard. Alongside the child's voices, parents' voices are key when considering formulating what may be happening | Adult mental health services should be encouraged to review their inclusion and exclusion criteria as much provision is based on experiencing a "mental health condition" to access support, though the parents responding to SNA are traumatised and have |

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| for the child as they often see wider pictures across several settings. | poor wellbeing. These services should advocate for commissioning to be able to offer these provisions to parents. |
| When services are working with young people, parents should be asked separately how they are managing these experiences and supporting their child. From these conversations services should be able to signpost parents to their own support, and other resources connected to supporting children in SNA. | For parent advocacy workshops to be offered, like other countries, whereby parents are taught skills and resources to support them in effectively advocating with confidence, understanding neurodivergent presentations and needed adaptions. These workshops could be ran by other parents with lived experience as they were found to be the best support. |
| Services should consider how they may be able to be accessed as a preventative measure with parents offered mental health support for themselves given when responding to SNA, parents are traumatised and have poor wellbeing. Trauma-informed care should be considered when working with these parents. | For mental health services to offer a “whole systems” approach recognising that parents, partners, and children are all impacted and therefore may be best supported through a “whole systems” approach together. For instance, this may look like parents attending a session together to explore how they can support each other in these times, and highlight their skills and resources they both have and can offer. |
| Mental Health Services should use strength-based approaches to empower parents to utilise their own power and resources they possess. | Mental Health Services should utilise experts with lived experience to consider future interventions, prevention and empowerment of parents. |
| For services to be aware of parents being overly blamed, attacked and dismissed and consider their relationship in this process by frequently recommending parenting courses with limited explanations | Neuroaffirming theories to be utilised. An example of this in clinical practice with parents could look like considering the social disability model (Woods, 2017) when creating and sharing formulations for young people. Thus centring the problem towards society enforcing a “neurotypical world” which causes great distress for neurodivergent children and families to live within. By utilising such theories it could support parents to stop internalising the blame that is present from systems and other professionals. For example, when supporting a family where a child is struggling to access school, consideration must be given to what adjustments need to be made to support access and accessibility |

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| | before placing expectations on families to do something different. Professionals should ask Is the environment the child is in safe enough and accessible enough to think about practical strategies on how to support them into the context? Has this been meaningfully explored with the young person and their family? We recognise that this is antithetical to the current processes where the focus is often on the family and parents to bring the child into school. |

Table 17 – Implications for Clinical Services supporting Neurodivergent Children.

Many parents shared their child was disempowered by mental health and neurodivergent services, which ultimately impacted on parents' wellbeing. It was highlighted that for their child the disjointed services, lack of overall support, long waiting lists, and missing communication added barriers to their journeys of being able to access school with their needs met. Further, if schools are required to be in agreement or to request neurodivergent assessments this frequently positioned children and their parents at the mercy of such systems. From this the following recommendations can be made;

| Imminent Recommendations | Long-Term Recommendations |
|---|---|
| Services to work in better collaboration and consider prevention with parents, school professionals, social care workers, and other external professionals involved if the family have consented to this. To jointly work with the young person at the centre of the care plans. | For services to consider how they can connect with school settings and offer education, training, consultation or formulation spaces for professionals when it is reported they are struggling to manage "complexity". |
| Services to offer formulation with children and families when presenting at a mental health service, in which SNA is considered through neurodivergent lens and can be used to share why young people may be presenting in such distress. It is important that services do not pathologize children and young people when their response is to neurotypical environments and systems like SNA. | For waiting times to be reviewed for neurodivergent assessments and provisions, and if additional funding is granted to consider how this may be used to support the current waiting times. |

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| Services to have clear, empathetic, validating communication with parents and to share realistic expectations around waiting times for assessments. | For services to review their inclusion and exclusion criteria, whilst a child's mental health deteriorating in response to SNA is not a "mental health disorder", there is still a significant amount of distress and trauma present that services should consider working with, especially as individuals can become suicidal in these contexts. |
| If children are on waiting lists, for services to signpost to resources, information on rights and support from known sectors in these times. | For services to review who can make referrals to them. In some cases many individuals have not been able to access support due to it being gatekept. Services should consider allowing referrals from children, young people and their families which can then be reviewed to see the appropriateness. |
| If individuals do not meet the criteria, it should be clearly communicated back to the families with further signposting of where they may be able to access support. | If it is noticed by services that there are "gaps" in provision due to various services inclusion and exclusion criteria, this should be noted and advocated for. |
| Neuroaffirming theories to be utilised. An example of using neuroaffirming theories in clinical practice with children and young people could look like having affirmation within therapeutic spaces. Supporting children and their families to understand theories such as double empathy theory when there is conflict or a difference of perspective on what is happening for the child and family, drawing on this theory could support services to think about what role they have in any miscommunication and what shift may be required of everyone involved to come to a shared understanding or position to support a child or young person. | For service to offer some support to the young person and their family, whilst highlighting that some SEN provisions should be able to be in place from schools before a diagnosis. |
| | Mental Health services should consult individuals with lived experiences to tailor interventions and assessments for young people, and make sure that the services and provisions offered are appropriate and not from neurotypical lenses. |

Table 18 – Implications for Educational Sectors:

Many parents advocated for Educational Reform as they were very aware how the education system is inaccessible for children to attend, especially with no provisions or reasonable adjustments in place. Many school professionals were lacking understanding of neurodiversity, which consequently meant many were unable to best support children or attend to their needs. Difficulties accessing school were further compounded by school's pressures, culture and ethos driven by senior leadership teams, who chose how they may respond to SNA and attendance policies. Parents often reported being threatened and blamed for their child's SNA, when parents offered recommendations or collaboration, school ignored, dismissed, or acted as gatekeepers. From this the following recommendations can be made;

| Imminent Recommendations | Long-Term Recommendations |
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| The research alongside other existing current literature stresses the urgency for discussions around the current educational and school systems accessibility for neurodivergent individuals to be at once reviewed. This includes reviewing the environment, provisions, curriculum, pedagogy practices, structures of the school day and methods of examining individuals. It is considered that an educational review is needed for all children both neurotypical and neurodivergent.<br>It is of utmost importance to review these practices and systems from neurodivergent lens to consider accessibility. Experts by experience should be sought for consultations on this process throughout. | For schools' systems, including teachers, assistants, senior leadership teams to invest in neurodivergent training to increase their knowledge, so that professionals feel confident to try to understand and respond to children and young people when in distress. The parents in this research highlighted how all professionals would benefit from this, including lunch-time staff who cover these periods and either support or trigger children in these times. |
| School and educational systems are asked to review SEN provisions and reasonable adjustments which may be possible to utilise without additional funding and to offer this to students when they are in the process of seeking diagnosis, EHCPs or other support provisions. If funding is needed to support students to back their families in advocating for this from the local authority. | Parents have raised that the training offered to schools needs to be created by neurodivergent individuals with lived experience, or those able to better advocate from a neurodivergent lens, as parents have reported harm from neurodivergent trainings in schools they have seen with misrepresentation and information. |
| For school senior leadership members to reflect on the schools' pressures, work cultures and their ethos and consider if their responses and priorities may be | Staff have access to more supervision spaces to reflect on working with particular student needs. Some of the parent wondered if there should now |

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| in line with this. This was similarly recommended by Sproston et al., (2017). | be a section on teaching training programmes about neurodiversity. Parents called for better continuous development plans for all staff within the school settings. |
| Given the broad nature and complexity of SNA, with journeys being different for all individuals, it is important that schools approach these circumstances with curiosity, and use compassionate and empathetic language with children and families to best work together in partnerships to support the child. | If schools are unable to meet a child's needs to be transparent and raise this to the local authority and parents to highlight the need of additional support, so that this can be reflected back to the wider government and department of education. |
| Parents have also called for more value and recognition to be given to teaching assistants. It was recommended that the teaching assistants who spend most time with their child may be able to better support advocating for their child's needs within the school system, and it was hoped that the teaching assistant's voices would be highly considered in these meetings. | Some parents reflected if there were more teachers nationally available, there would be more options to offer smaller classrooms which means the teacher would have more time and support to attend to each child and offer some more opportunities for individualised learning. |
| To use neuroaffirmative theories within school settings. One example could be to recognise the "neurotypical standards", expectations such as sitting still, not doodling etc, physical settings and the harm this causes neurodivergent children and young people increasing their need to mask. Neuroaffirming theories could include seeing all individuals strengths and acknowledging the variety in learning styles and learning needs, without labelling and penalising certain children. Additionally, theories such as monotropism could support schools in harnessing neurodivergent focus around specific learning. | |

Table 19 – Implications for Policymakers:

This research has highlighted many experiences of disempowerment within systems often resulting from policies, and decisions made within the wider governmental departments. The government and policymakers are seen to decide what the priorities are nationally, particularly highlighted with how the funding is distributed. The wording of policies often gives more power to professionals within the educational, mental health and social care systems rather than power to children and families voices, leading to further disempowerment. The wording of some policies also allows "grey areas" whereby limited accountability can take place within systems further adding barriers to individuals being able to access school. It is experienced that the policies can be harshly applied to parents enforcing responsibility, but that this is not equally mapped for services and systems involved and responsible with legal duties too. From this the following recommendations can be made;

| Imminent Recommendations | Long-Term Recommendations |
|---|---|
| This research alongside others has highlighted the urgency and crisis that is currently happening in the UK. Urgent meetings for educational reform and a review of the appropriateness of current school provisions is required, especially mainstream provision where most child are forced to attend. As raised in this study, the school system is no longer serving the majority of children and is inflicting such devasting impacts for many. This includes reviewing the environment, provisions, curriculum, pedagogy practices, structures of the school day and methods of examining individuals. | Policymakers and governmental individuals need to engage with several experts by experience and work in consultation with these individuals. This is crucial as much policy and legislation enforces a "neurotypical lens" that is not appropriate for neurodivergent individuals to be compared with. Policymakers and governmental individuals should be better aware of neurodiversity, and how ignorance can often lead to ableism taking place. |
| Governmental individuals within the department of education need to review SEN provisions available to mainstream schools, and the limited spaces within specialist schools and additional provisions. | Funding not only needs to be considered in school settings for SEN provision, but it is also recommended to review funding for mental health and neurodivergent services to support the current long waiting times for assessment, and also the limited aftercare. It is also hoped that funding would better support local authorities who encounter high staff turnovers, delaying provisions and EHCP responses. Gray et al., (2023) also call for government to support the provision of sufficient local authority professionals to support preventative measures. |

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| It is recommended that they review funding and highlight the current crisis occurring to obtain more funds to appropriately attend to this and be able to offer adequate SEN provisions. It has been suggested that there needs to be more specialist provisions within each county for equitable accessibility and provision within the UK | Policymakers should make considerations for alternative provision when children are unable to learn within current schooling structures and would benefit from more wider learning opportunities. |
| Policymakers need to urgently review the attendance policies and legislation and how these can be applied within the context of SNA. SNA is a complex experience dependent on multiple factors with many systems and professionals equally liable and responsible, yet currently this policy is often weaponised and used to attack parents and children. There should be a consideration or note in place to protect parents responding to SNA, and to equally hold systems accountable for what they are doing to support the child and families in the context of SNA. | Neuroaffirming theories to be utilised. Policy-makers could better understand social-disability model and how many systems as well as a society have created several barriers for many individuals whilst penalising them for being unable to cope within a neurotypical setting and world. If policy-makers had an increased understanding and insight it would support removing some of the unnecessary barriers that are currently present and stop blaming and fining parents for a system that is not set up to support neurodivergent pupils. |
| Parents highlighted that there should be accountability and repercussions for the system as there is parents, when child's needs have been dismissed and avoidable harm has taken place. One way that parents thought policymakers and the department of education could support accountability was to consider schools in line with their ethos and values reported. | |

## 5.6 Evaluation of Research

This research offers numerous strengths including offering a co-constructed model of an understanding of parents' experiences and impacts of SNA, which supports filling gaps in literature as well as supporting existing literature. However, there are also some limitations present which the researcher acknowledges, including their influence over the research, such as the impact of an insider-outsider perspective and having a critical realist epistemological stance. The quality of this current research was assessed from utilising the CASP tool (CASP, 2024), see Table 19.

Table 20 – Quality Assessment of current research using the CASP (2024) tool

| Title | Assessment (Yes, No, Cannot Tell) | Evidence |
|---|---|---|
| 1. Was there a clear statement of the aims of the research? | Yes | The aim of this research was to explore primary caregiver's experiences of having neurodivergent children unable to access school, as well as the processes that underlie this and the impacts these experiences have on parents and primary caregivers. In Chapter 2, there is a clear statement of the research's aims. |
| 2. Is a qualitative methodology appropriate? | Yes | A qualitative methodology was chosen as it aligned with the exploratory nature of the research, whilst maintaining rigor. Applying a qualitative methodology was valuable for exploring a new topic area, which had limited research, and aimed to generate theory. Qualitative research offered detailed data exploring parents understanding of SNA, neurodivergence, and phenomena that surround these experiences. For further evidence of appropriateness of utilising qualitative methodology, see Chapter 3. |
| 3. Was the research design appropriate to address the aims of the research? | Yes | The research design was considered appropriate as qualitative research offers rich detailed data, thus allowing for parent's experiences to "deeply" be explored and considered. In current literature, parent's experiences and their impacts have started to be further explored, though many gaps still remain with many questions. It was appropriate to use Constructivist Grounded Theory (CGT) as it was able to attend to the researcher's epistemology, the researcher's insider-outsider positioning whereby it is seen that the researcher is "inseparable" from constructing the reality of the research. CGT also seeks to study the "how" and "why" participant's construct meanings and actions in situations which was aligned with the aims of this current research, and could support some of the gaps in existing literature if some "how and whys" were answered. CGT offered to explore the structural aspects of parent's lives as well as the meaning-making which occurs. See Chapter 3 for more information. |

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| 4. Was the recruitment strategy appropriate to the aims of the research? | Yes | Participants were recruited through various social media platforms with hopes that this would allow wider participation from around the UK and not just from physical locations nearby connected to the research and researcher. Adverts were sent to various Autism and ADHD charities and advocates, as well as several Special Educational Needs and Disabilities Information, Advice and Support Services (SENDIASS). It was hoped that these charities would be able to support those who do not participate in social media to still be involved in the research. After these methods were used, the research then relied heavily on “word of mouth”. Purposive sampling was initially utilised with hopes to produce a sample that reasonably represented the population. After initial phases of recruitment had been completed, the research then used theoretical sampling (in line with the CGT methodology). This resulted with a total sample size of 12, which was considered to have met theoretical saturation. Chapter 3 outlines more about recruitment and highlights decisions made with rationales. |
| 5. Was the data collected in a way that addressed the research issue? | Yes | The data was collected via the use of semi-structured interviews. The semi-structured interviews took place through telephone calls or video platforms (Microsoft Teams). By offering both of these, it meant that participants could chose which would make them feel most comfortable, thus supporting an open space for them to share their experiences. The researcher offered various interview times to best support individuals understanding that many may be needing to support their child throughout most of the day. The data collected was reviewed in line with the CGT processes to ensure that it was addressing the research question, and could allow for theoretical saturation with a co-constructed model at the end. The interview schedule was adjusted in line with this process to support data collection and answering the research aims. See Chapter 3 for more information about data collection, including thoughts around interviewing styles and the development of the schedule. |
| 6. Has the relationship between researcher and participants been adequately considered? | Yes | The relationship between the researcher and participants was considered throughout the research. CGT also highlights the importance of engaging in such reflections as the data is considered a “co-construction” between the researcher and participants. Therefore, the researcher’s insider-outsider stance, their epistemological stance is considered and shared with |

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| | | the readers in Chapter 1. Reflexivity offers scrutiny to the research, the decisions and interpretations, it examines the researcher's interests, positions, assumptions and how these interlink with the research process. As means to consider the researchers relationships to the participants, they engaged in a reflexive journal, they utilised memo-writing, as well as sharing work and reflecting with other colleagues as well as their supervisory team. Reflecting on their relationship with participants meant that the researcher was better equipped to consider their interpretations and attend to any bias. The researcher also sought advice from expert by experience consultants. Please refer to Chapter 1 and Chapter 3 for more information pertaining to this. |
| 7. Have ethical issues been taken into consideration? | Yes | This research sought ethical approval from The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority on 26/04/2024. The research also adheres with the BPS Code of Conduct, Ethical Principles and Guidelines (British Psychological Society, 2018). Several ethical considerations were made including: informed consent, confidentiality, potential harm and distress and use of tokens of appreciation. Ethical considerations were also made around making individuals feel as comfortable as possible, including language used and responses, arranging interviews online or telephone, arranging interviews at various times of days and evenings that best suited participants, allowing time for debriefs and breaks throughout if needed. Particular thought was given around anonymity for both parents and their children mentioned. Ethical considerations are noted in Chapter 3. |
| 8. Was the data analysis sufficiently rigorous? | Yes | The data collection and analysis are considered to be rigorous. During the data collection and analysis the researcher engaged in reflexive journalling, memo-writing and making comparisons within the data. From making comparisons it meant that the researcher could identify similarities and also differences, when differences were noticed it allowed the researcher to explore this with participants to seek to gain understandings of why this may be. The data analysis and coding was completed strictly applying the CGT procedures (Charmaz, 2014). Low (2019) contends that research can be robust and coherent attending to the "how and why" questions, using theoretical sampling, generating a conceptual model which accounts for |

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| | | sufficient data. Under this definition, this current research can be argued as robust as it meets all of these. To add further reliability and credibility, all participants were invited for member-checking, in the form of a focus group, to explore whether the constructed end model and categories resonated with them and in hope to seek further opinions. See Chapter 3 for further outlines of the data collection and analysis processes. |
| 9. Is there a clear statement of findings? | Yes | There is a summary of findings at the start of Chapter 5, and there is also an overview of the model with findings of categories in Chapter 4. |
| 10. How valuable is the research? | Yes / They are valuable | This research is considered to be valuable. There is limited literature currently published exploring parent's experiences and the impacts on them. It is important for this area to be explored as parents are key stakeholders when responding to SNA, especially as they are seen to carry and attend to many roles. This research is one of the first to offer a co-constructed conceptual model sharing parent's experiences and the impacts. With such model, many recommendations and implications can be raised to better support parents, which will also indirectly support children in their experiences of SNA and their own distress. This current research also offers support to some of the existing literature whilst making connections and extending upon their findings too. |

### 5.6.1 Strengths

This research can be argued to be valuable with several strengths. At present there is limited literature exploring parent's experiences and impacts of SNA with neurodivergent children. This research offers support to the current findings in existing literature that specifically explore impacts on parents (Mullally & Connolly, 2025; Blackwell, 2024; Bodycote, 2022). This current research extends upon these findings by attending to the "how" and "why" of parents' experiences including their meaning-making and responses. This research additionally offers a conceptual model of an understanding of parent's experiences, with several recommendations and implications for services and policymakers. When assessing quality and reliability using the CASP tool (CASP, 2024), it is considered that this research meets all criteria, the strengths in relation to this are outlined in Table 19. This research spent much time considering the rigor, validity, and reliability of the research and making decisions where possible to increase this, such as engaging in reflexive journalling or inviting participants for feedback on the conceptual model etc.

### 5.6.2 Limitations

Though there are strengths and value in the research, the researcher is aware of some limitations. The research had hoped for more of a diverse sample representative of parents and other primary caregivers whose children are currently unable to access school. Despite the researcher utilising purposive sampling and not responding to participants on a "first-come-first-serve" basis, the diversity of the sample is still limited. The researcher contacted individuals with various differing intersectionalities, experiences and positions, who completed the interest forms, but unfortunately did not get responses. The researcher wondered if this finding in itself highlights how power, privilege, and resources may play out in individuals being able to take part in research, especially as many parents raised what it is like "being in the trenches". The lacking diverse samples is a common difficulty within SNA research as also raised by Connolly et al., (2023). This research would have valued hearing more from: fathers, other primary caregivers outside of immediate parents, non-binary parents, those from non- White: English, Scottish, Northern Irish or British backgrounds, those from Wales, and those with children who have self-identified diagnoses. There was a bit more diversity present in the parent's child's characteristics and positions. Though the research was only able to recruit biological and adoptive parents, it was important to keep the original title of primary caregivers' experience as this research did seek to recruit and hear from these individuals. It is important for this title to remain so that other researchers can be aware of the difficulties recruiting this particular sample.

A further limitation would be that this research was completed in line with the researcher's professional academia requirements and therefore had time restrictions. If there was no time restriction, the research would have hoped to have utilised a Participatory Action Research (PAR) approach throughout including seeking research topics and questions from impacted communities and experts be experience. For this approach to be applied meaningfully the researcher believed more time was required.

A final limitation could be argued that the researcher was considered a "novice" to applying the CGT methodology and analysis. This has been raised by several researchers offering challenges to applying the CGT approaches (Bobbink et al., 2024). However, the researcher was mindful of such when starting to utilise this approach, and fought to ensure rigor. In order to account for the challenges attached to being a novice, the researcher sought advice from colleagues who have previously used CGT, as well as bring their reflections, analysis, coding to their supervisory team who have also supervised CGT research prior. The researcher was supported by these individuals as well as from engaging in their reflexive journalling and reading further literature to support using such approach.

## 5.7 Suggestions for Further Research

As highlighted throughout, CGT recognises how research evolves and moves with different researchers, contexts, systemic changes, as well as at different time points (Charmaz, 2014). Therefore, this research advocates for further research to take place given the impact of the contextual variables throughout all systems surrounding parents and their children. In the UK, there have been recent discussions around education and attendance policies, particularly after COVID, with a change in government party, all are known to impact experiences (Maratos et al., 2023) and therefore further research is recommended to continue to seek parent's experiences and impacts of any changes. Consistent with Lissack and Boyle's (2022) recommendation, future research should particularly focus on the implementation of recent guidance from governmental bodies to ascertain whether such implementations are happening and the facilitators and barriers to this, as well as gathering feedback of such implementations.

Future research is urgently needed to explore under-researched demographics to ensure their voices are heard and for their impacts to be reviewed. One wonders about these individuals' circumstances and experiences, given the devastation for those who may be considered in more "privileged" positions. It is important for this research therefore to take place so further recommendations can be made to ensure all parents are able to access support in the context of SNA.

Parents were observed in this research to "dig deep within" to get through these experiences and best support their child in distress whilst attending to the rest of the system's responses. Parents were reflected to possess such skills and characteristics that they utilised to support them in responding to these experiences. It would be recommended that future research explores these parents' strengths, skills and valuable tools that support them. If this experience was to be better understood, these skills, strengths and "gems" could be shared with other parents and considered in mental health services, such as using strengths-based approaches to empower parents in their own resources that they already possess.

## 5.8 Conclusion

In the UK, many neurodivergent individuals are unable to access school with detrimental impacts on them as well as their parents (Connolly et al., 2023; Mullally & Connolly, 2025). This research offers an understanding of parent's experiences of SNA in the context of neurodivergence, and the processes that underpin such experiences. The research highlights many of the life-changing impacts these experiences have on parents, as well as the limited support available. The current research supports and builds upon existing literature whilst continuing to highlight the need for further research. These findings offer important implications and recommendations for those in the following sectors: mental health, neurodivergent assessment services, social care, education as well as policymakers and governmental figures. For concluding reflections see Appendix S.

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# Appendix

## 7.1 Appendix A – Researcher's Relationship to the Research

Despite Sunshine and the family's great effort, Sunshine was not able to attend school safely for numerous years. During this time, Sunshine and my family were not supported by the school, despite having various assessments outlining their needs and an EHCP of reasonable adjustments that were required for them to access school. It meant that one of Sunshine's parents had to be on the school site each time Sunshine was, and was seen as Sunshine's 1-1 support.

Fortunately, Sunshine was supported by a few kind professionals over the years, including a headteacher from a different school, who slowly introduced them back into a school environment, utilising a trauma-informed approach. The headteacher focused on and prioritised getting to know Sunshine and what they enjoyed and were passionate about, this put Sunshine at ease. The headteacher also understood the need of accessing a safe space in tricky moments, which allowed Sunshine to regulate themselves before returning to lessons.

Years later, Sunshine was able to attend mainstream school full-time again and started secondary school. Despite Sunshine's progress, the impact of their schooling trauma persists and can resurface from their experiences over a decade ago. Though Sunshine currently accesses school, not all professionals and teachers understand Sunshine's needs and therefore do not meet them and sometimes make unhelpful judgements.

The impacts from a decade ago on family members are also still present, with one parent experiencing panic attacks and flashbacks when school calls, due to their trauma initially encountered. During the family's experiences, there was no support for them, no signposting or procedures which exacerbated the journey. It was seen that the parents "tagged teamed", one with knowledge from working within schools and understanding Sunshine's rights, but too distressed to attend meetings, and the second attending meetings to advocate for Sunshine.

As a family unit we were led to believe that this experience was rare, though we have sadly learnt just how frequent and common these experiences are for families, with many children not able to access any education or school as a result. We acknowledge that we were lucky to have experienced some kind professionals who were able to offer support, and understand this is a rare luxury. These experiences made me more aware and curious to learn young people’s and families’ journeys and the impacts, as well as processes and nuances that underlie these. It was hoped that if more was understood in this area, more change would be able to take place.

## 7.2 Appendix B – CASP Table

| Research Title | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? |
|---|---|---|---|---|---|---|---|---|---|---|
| Autistic girls and school exclusion: Perspectives of students and their parents | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes - The research highlights the contributions of inappropriate school environment, tensions in school relationships and problems with staff responses with school exclusions for autistic females in secondary schools |
| Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes - The research highlights the experiences pre-exclusion for the young person and also key findings that aid re-integration into education |
| School Attendance Problems Among Children with Neurodevelopmental Conditions One year Following the Start of the COVID-19 Pandemic | Yes | Yes | Yes | Yes | Yes | No | Unclear | Yes | Yes | Yes - The research highlighted the importance of the teacher-parent relationship for school attendance and lower likelihood of being excluded from schools, it builds on previous qualitative literature findings by using statistical analysis. It also continued to build the picture of those not attending school by exploring facilitators and barriers. |

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|---|---|---|---|---|---|---|---|---|---|
| Elective home education of children with neurodevelopmental conditions before and after the COVID-19 pandemic started | Yes | Yes | Yes | Yes | Yes | No | Unclear | Yes | Yes | Yes- The research added to previous literature and was the first study to explore EHE specifically in children with neurodevelopmental conditions in a sample much larger than previous studies. It highlighted the barriers and facilitators of elective home education as well as reasons for de-registering school. |
| Marginalisation, autism and school exclusion: caregivers' perspectives | Yes | Yes | Yes | Unclear | Yes | Yes | Yes | Yes | Yes | Yes - Due to a small sample size there is a deep understanding and analysis of those individuals' experiences who did take part, and the impact it had on them. The research offers IPA themes but also visual graphs to represent the journeys the individuals have experienced. Research offers multiple recommendations and speaks to the current Uk context deeply. |
| "I felt shamed and blamed": an exploration of the parental lived experience of school distress | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | Yes - This research builds and elaborates on previous literature in this area, with a large sample size with a control group. It also offers links with other research offering potential hypothesis of why those may be responding in the way they do. For instance, it has long been research that parental mental health links with child attendance, but this piece of research goes to offer a direction of that relationship, and hazards warning for research to consider directions when reporting correlations. It also gives much thought to language used and holding |

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| | | | | | | | | | | various parts of the system accountable. |
| Parent/carer views on support for children's school non- attendance: ‘How can they support you when they are the ones who report you?’ | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes - The research builds on previous literature and the complexity around school non-attendance. The research also highlights implications for policies and practice on different system levels. |
| ‘After a long period of being in hibernation – These little green shoots were growing’. Lived experiences of effective support for autistic young people who have experienced extended school nonattendance | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes - The research build on previous literature, it considered a multi-layered approach and relationships between various individuals in the system. It highlights the importance of participation inquiry and the power within research. |
| School distress and the school attendance crisis: a story dominated by neurodivergence and unmet need | Yes | Yes | Yes | Yes | Yes | No | Yes | Unclear | Yes | Yes - The research has a large sample and builds on previous research in this area, by breaking down characteristics and also has a control group of no school distress and those who have only ever been home educated. |
| The impact of school challenges on parental employment among families with children on the autism spectrum | Yes | Yes | Yes | Yes | Yes | No | Yes | Unclear | Yes | Yes - The research built upon the literature within this area and the impact on parents’ employment specifically. It uses a system approach to consider the school system as well as employers as a system and highlights implications in both. |

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|---|---|---|---|---|---|---|---|---|---|---|
| Autistic girls and emotionally based school avoidance: supportive factors for successful re engagement in mainstream high school | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes - Valuable, it adds to the literature when exploring supportive approaches to reintegrate into school it explores a multiple stakeholder perspective to triangulate data. |
| “He’s shouting so loud but nobody’s hearing him”: A multi-informant study of autistic pupils’ experiences of school non-attendance and exclusion | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes - The research adds to previous literature, and uses a multi-stakeholder position as a way to consider the complexity of this area and to use a systems approach. As a result of this wide lens it was able to see relationships between the systems in multiple layers. It also explores impacts from as wide as the government |
| Making the spoons last longer: Parents' views on flexi schooling with their child with special educational needs | Yes | Yes | Yes | Yes | Yes | No | Unclear | Yes | No | Yes - Adds to previous literature on why individuals may choose flexi-schooling as well as advantages of this set up. Also speaks to if schools set up were more flexible and better able to meet needs then flexi-schooling options may not be needed as much |

## 7.3 Appendix C – CASP Reflections

All thirteen studies included in the research had clear aims, research designs, appropriate methodologies, and collected data that addressed the research aims thus building literature in an under-researched area. Therefore, many studies possessed a moderate to high quality rating on the CASP checklist as they were able to meet the majority of the criteria. Those that were considered to be of higher quality ratings on the CASP checklist compared to others included: studies that deliberated on the relationship between the researcher and participants, those which displayed consideration for increasing the reliability of the analysis (for example, including a second rater to cross-reference with when coding data), as well as those which demonstrated reflexivity like Neilson and Bond (2023). The studies that were thought to be lower in the quality ratings when compared, were those that lacked descriptions on attempts to ensure the reliability of the research findings such as comparing findings with a second rater or use of reflexive spaces, or when ethical considerations were not explicit, or when the impact of the relationship with participants was not reflected on.

All studies clearly documented their aims and research designs. The studies' qualitative or mixed-methods methodologies varied from participatory inquiry (Neilson & Bond, 2023) to exploratory case designs (O'Hagan et al., 2024). All were reviewed as appropriate designs according to the CASP checklist. There appeared to be two main approaches to collecting data with six studies utilising questionnaires (Mullally & Connolly, 2025; Lawrence, 2025; Connolly et al., 2023; Paulauskaite, 2022; Lissack & Boyle, 2022; Totiska et al., 2023) and seven studies using semi-structured interviews (Blackwell, 2024; Gray et al., 2023; O'Hagan et al., 2024; Sproston et al., 2017; Neilson & Bond, 2023; Martin-Denham, 2022; Brede et al., 2017). All studies were argued to have collected their data in a way that addressed the research questions, aims and topic area.

Sampling techniques included purposive sampling (Martin-Denham, 2022) and convenience sampling (Totiska et al., 2023). All studies were deemed to have appropriate and clear recruitment strategies except Martin-Denham (2022) where their strategy appeared unclear to the reader. When appraising O'Hagan et al's., (2024) study, additional reflection was given where recruitment was decided by professionals working with young people; initially, there were questions regarding the appropriateness and whether there would be bias in who participated with this recruitment strategy. Given the context and sample, it is likely that individuals who were able to engage with research with minimal distress talking about experiences were likely chosen and therefore these studies were marked as appropriate recruitment, however this was marked as a slight limitation when reviewing the article. The remaining studies recruited through schools and specialist provisions, or they used various platforms like social media or third sector charities and organisations. Whilst overall recruitment was appropriate, studies were still critiqued where it was felt that opportunities had been missed in recruitment for instance, Sproston et al., (2017) only recruited individuals excluded from school through specialist provision or charities, rather than further attempting to utilise social media to gather experiences of children excluded and unable to access specialist provision. Sample sizes ranged from 3 – 1121 parent participants, not all parent demographics were reported given that they were not the target sample for the majority of studies. However, in those that were able to offer demographics it was noted that the samples predominantly included mothers and those of white ethnicities. Some of the studies reflected on the lack of diversity within their own review of their research, like Connolly et al., (2023). From this, the SLR confirmed that many voices continue to be underrepresented in this research area and are yet to be heard.

Ten studies clearly reflected on the ethics of the research, for instance where they reflected on building rapport with participants to establish safety, and made extensive efforts to ensure this, like Brede et al., (2017). Whilst Totiska et al., (2023), Paulauskaite (2022) and Lawrence (2025) all mentioned that ethical approval was sought and ethical considerations were made, it remained unclear what these were as they were not further elaborated on. As per the CASP checklist, the relationship between the research and participants is reviewed, only seven studies were found to adequately describe this. It was noted that Mullally & Connolly (2025), Connolly et al., (2023), Lawrence (2025), Totiska et al., (2023), and Paulauskaite (2022) did not describe this within their published studies. Interestingly, all of these studies utilised questionnaires as their data collection compared to others which used semi-structured interviews. This is important to consider as in interviews researchers can be argued to have more influence on the data and its’ quality based on their relationship with participants (Schmid et al., 2024), therefore those using questionnaires in comparison may not be expected to consider the relationships at such detail. This may offer an explanation for various studies which did not explicitly speak to this in the journal articles. Still, those employing questionnaires as their research methodology, possess much value as they were able to recruit larger samples consequently increasing the ability to make broader generalisations. Finally, it was noted that Blackwell (2024) did not report reflecting on the relationship between researcher and participants; despite using a semi-structured interview and a thematic analysis whereby it is important to engage in reflexivity.

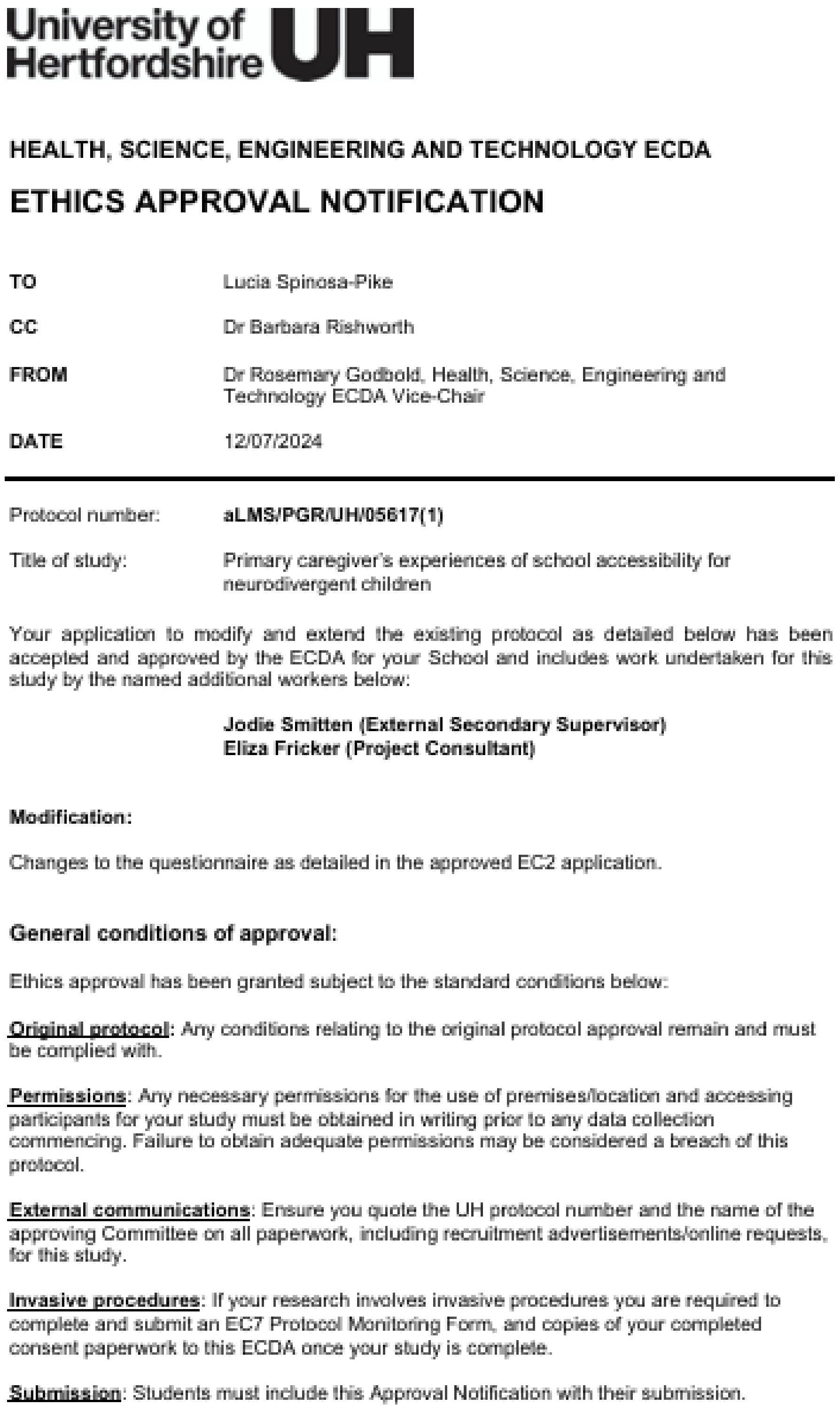
Eleven studies were argued to have a sufficiently rigorous data analysis. Examples where data analysis was argued to be rigorous was when studies used multiple reviewers or reflective spaces to cross-reference findings like, Totiska et al., (2023) or member-checking like, Neilson and Bond, (2023) or O'Hagan et al., (2024) or where clear data analysis was outlined like, Mullally and Connolly (2025). In contrast, it was unclear how rigorous Blackwell (2024) and Connolly et al's., (2023) data analysis was. In Blackwell (2024) there was no mention of how reliability was considered in their data analysis and coding processes, thereby it is unclear of how rigorous their data is. In Connolly et al's., (2023) study, whilst there was an outline of their data analysis it was unclear what specific exploratory tests were used. Further, in the results section, there are reporting of tests that were not found in the data analysis section or even described as a follow up test or further exploration test. Therefore, it was decided that it would be ranked as unclear as to whether the data analysis was rigorous or not. All studies had clear findings outlined apart from Lawrence (2025) where it was considered that improvements could be made.

## 7.4 Appendix D - History and Development of CGT

CGT is a contemporary revision of Grounded Theory (GT) that was developed by Glaser and Strauss (1967) (Charmaz, 2017). Glaser and Strauss contended researchers needed a method to move from data to theory for new theories to emerge; and that they would be developed grounded in data gathered rather than relying on pre-existing theories (Willig, 2008). Therefore, GT uses inductive strategies to develop theory through close-up contact with the empirical world (Lauridsen & Higginbottom, 2014). This aligns with the research aims to explore and generate a theory which connects parents' experiences of school accessibility for neurodivergent children. There currently lacks data and theories, highlighting a need for one "grounded in data" which may suggest appropriate resources and better inform policy, guidance, as well as educational and clinical practice within the community.

Over time, Glaser and Strauss developed separate schools of thought as they held differing ontological and epistemological positions (Charmaz, 2006; Lauridsen & Higginbottom, 2014). This led to Glaserian GT, which is argued to have more positivist underpinnings (Charmaz, 2000); and Straussian GT which was co-developed with Corbin, and aimed to move away from post-positivism (Rieger, 2019). Various other individuals have further approached GT with other ontological and epistemological lenses, leading to a second generation, like CGT (Lauridsen & Higginbottom, 2014). CGT is argued to have built on classic Glaserian GT but has repositioned to move towards constructivist stances towards data analysis and away from previous positivist underpinnings (Rieger, 2019).

## 7.5 Appendix E – Ethics



University of Hertfordshire UH

**HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA**

**ETHICS APPROVAL NOTIFICATION**

| | |
|---|---|
| **TO** | Lucia Spinosa-Pike |
| **CC** | Dr Barbara Rishworth |
| **FROM** | Dr Rosemary Godbold, Health, Science, Engineering and Technology ECDA Vice-Chair |
| **DATE** | 12/07/2024 |

| | |
|---|---|
| Protocol number: | **aLMS/PGR/UH/05617(1)** |
| Title of study: | Primary caregiver's experiences of school accessibility for neurodivergent children |

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

**Jodie Smitten (External Secondary Supervisor)**
**Eliza Fricker (Project Consultant)**

**Modification:**

Changes to the questionnaire as detailed in the approved EC2 application.

**General conditions of approval:**

Ethics approval has been granted subject to the standard conditions below:

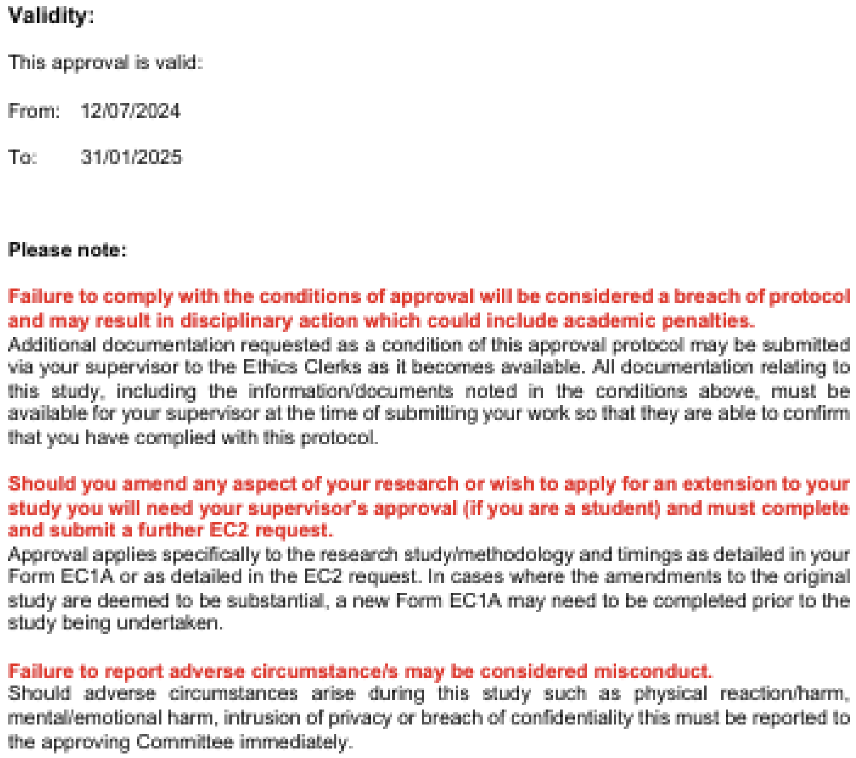
**Original protocol**: Any conditions relating to the original protocol approval remain and must be complied with.

**Permissions**: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications**: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures**: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission**: Students must include this Approval Notification with their submission.



**Validity:**

This approval is valid:

From: 12/07/2024

To: 31/01/2025

**Please note:**

**Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.**
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

**Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.**
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

**Failure to report adverse circumstance/s may be considered misconduct.**
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

## 7.6 Appendix F – Advert Poster

# PARTICIPANTS NEEDED

## Primary caregiver's experiences of school accessibility for neurodivergent children.

The purpose of this piece of research is to understand primary caregiver's experiences of school accessibility for neurodivergent children, the impact these experiences have had, any facilitators and barriers to their child accessing school, as well as if/how they have been supported by services, schools, or guidance through these times

### Who can Apply?

You must be a primary caregiver to a neurodivergent child who is currently not able to access UK mainstream schools full time predominantly due to their needs not being met.

### Interested in Participating?

Click the link below

https://herts.eu.qualtrics.com/jfe/form/SV_3CxSJu0fwsFI1tl

### Any Questions?

Contact Researcher:
Lucia Spinosa-Pike
Ls22abu@herts.ac.uk

University of Hertfordshire UH Ethics Committee

This is an official notification by a student of the University of Hertfordshire in respect of a study involving human participants.

Title of study: Primary caregiver's experiences of school accessibility for neurodivergent children

Protocol Number: aLMS/PGR/UH/05617(1)

Approving Committee:
Health, Science, Engineering and Technology ECDA.

If you have any queries concerning this document, please contact me Lucia Spinosa-Pike (ls22abu@herts.ac.uk)

## 7.7 Appendix G – Participant Information Sheet

**UNIVERSITY OF HERTFORDSHIRE**

**ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS**

**(‘ETHICS COMMITTEE’)**

**FORM EC6: PARTICIPANT INFORMATION SHEET**

### 1 Title of study

Primary caregiver’s experiences of school accessibility for neurodivergent children

### 2 Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. This study is part of the researchers Doctorate in Clinical Psychology and academic qualification. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University’s regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

## 3 What is the purpose of this study?

The purpose of this piece of research is to understand primary caregivers' experiences of neurodivergent children's difficulties accessing school, the impact these experiences have had, any facilitators and barriers to their child accessing school, as well as if/how they have been supported by services, schools, or guidance through these times.

## 4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any signposting for further support.

## 5 Are there any age or other restrictions that may prevent me from participating?

You must be a primary caregiver to a neurodivergent child who is currently not able to access UK mainstream schools fulltime predominantly due to their needs not being met.

## 6 How long will my part in the study take?

If you decide to take part in this study, you will be involved in it for the time it takes to complete the initial questionnaire, which will be approximately 20 minutes. At the bottom of this questionnaire, you can choose whether you would be willing to engage in an interview, this will approximately take one hour. We may also invite you back to discuss the findings however this will be your choice.

7 **What will happen to me if I take part?**

The first thing to happen will be to complete a set of demographic information questionnaires. At the bottom of the questionnaire, you can select whether you would be willing to take part in a semi-structured interview. If you opt for this and are contacted by me to take part in the interview, you may then be invited to attend a remote interview via telephone or “Microsoft Teams” or face to face. This means that there will be some questions we will ask, however you will be able to discuss whatever you feel is important to you. As this research aims for an accurate representation of the population, purposive sampling will be used. This unfortunately means that we are not able to offer every individual an interview, however you will be updated if this is the case and will be offered information on a dissemination conference.

In total, we expect the study could roughly take around 1 hour and 20 minutes to complete. You would be able to have a break at any point in time and are encouraged to do so if you felt one was needed.

8 **What are the possible disadvantages, risks or side effects of taking part?**

(Note: Please also note that circumstances may arise that could result in the need for you to withdraw from the study; should such circumstances occur, the investigator will discuss the matter with you.)

Some of the questionnaires and interview questions may ask about sensitive or upsetting topics. You do not have to answer any questions that you do not wish to answer. Support will be available from the researcher should you be upset by any of the topics. You will be provided with a list of national support services with contact details in case you would like to access them.

### 9 What are the possible benefits of taking part?

We hope that there are several benefits to taking part in this piece of research. As there is currently a lack of literature published in this area, we hope that this current research will lead to a better understanding of primary care giver's experiences of how schools respond to neurodivergent children's access needs. We also hope that you find the interview space useful and an open safe space to reflect on your own experiences. It is hoped that this can build on research in this area which can in time support change within schooling systems to better support children's access and also primary care givers in the wider community.

### 10 How will my taking part in this study be kept confidential?

All data from this current research will be handled under the Data Protection Act (1998). The researchers will follow ethical and legal guidelines. The information gained from this study will be handled in confidence and treated anonymously. If any evidence of abuse, criminality or neglect comes to the attention of the researchers, we are duty bound to report this to the appropriate services. If a participant poses a risk to themselves or others, we are duty bound to report this to relevant services. Similarly, if it comes to attention of the researchers that a child or family are at risk, we are also duty bound to report this to the appropriate services.

The data collected in this study will be anonymised and coded. The interviews will be recorded on an encrypted device and stored on a password protected file on an encrypted drive, and once transcribed, these recording will be deleted. All electronic data will be password protected and stored on a single encrypted drive which also password protected. Only the researchers involved in this study will have access to the data.

### 11 Audio-visual material

Recordings will be made of the interview in order for transcriptions to be used in the data analysis.

## 12 What will happen to the data collected within this study?

- The data collected will be stored electronically, in a password-protected environment, until the research has been disseminated, after which time it will be destroyed under secure conditions;
- The data will be anonymised prior to storage.
- The data will be written in a published journal, shown in conferences and talks. The identities will not be revealed at any point in this process. The data will be grouped together via themes reported by participants and displayed as such. Quotations may be pulled and used to give examples, if you would not like your quotes to be used in dissemination you will have the opportunity at the end of the interview to share this with me, where consent will be sought again.

## 13 Will the data be required for use in further studies?

- The data will not be required for further studies. The data collected will be destroyed on completion of qualification and publication of work.

## 14 Who has reviewed this study?

This study has been reviewed by:

*<Please delete whichever does not apply:>*

- The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is <*enter*>

## 15 Factors that might put others at risk

Please note that if, during the study, any unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

## 16 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by email: ls22abu@herts.ac.uk.

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:**

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Principal researcher: Lucia Spinosa Pike (Trainee Clinical Psychologist)

Supervisor: Dr Barbara Rishworth

b.rishworth@herts.ac.uk

**Thank you very much for reading this information and giving consideration to taking part in this study.**

## 7.8 Appendix H – Consent Form

University of Hertfordshire UH Ethics Committee

**Project Title: Primary caregiver's experiences of school accessibility for neurodivergent children.**

**UNIVERSITY OF HERTFORDSHIRE**

**ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS**

**('ETHICS COMMITTEE')**

**FORM EC3**

**CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS**

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……………………………………………………………………………………………………………………

of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address]*

……………………………………………………………………………………………………………………

hereby freely agree to take part in the study entitled *[insert name of study here]*

……………………………………………………………………………………………………………………

(UH Protocol number ……………………………………….)

**1** I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

**2** I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

**3** In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

**4** I have been given information about the risks of potential harm or adverse effects. I have been told about the aftercare and support that could be offered to me in the event of this happening. In signing this consent form I accept that support might be sought for me, should circumstances require this.

**5** I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

**6** I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

**7** I have been told that I may at some time in the future be contacted again in connection with this or another study.

Signature of participant…………………………………….….Date………………………..

Signature of (principal) investigator……………………………………………………Date………………………..

Name of (principal) investigator *[in BLOCK CAPITALS please]*

*LUCIA SPINOSA-PIKE*

## 7.9 Appendix I – Debrief Sheet

**Thank you!**

Thank you for your participation and contribution in this piece of research.

The Human Rights Act (1998) states “no person shall be denied a right to education”. However, research highlights the substantial number of neurodivergent individuals who are not able to access education based on their experience and not having their needs met (Connolly, Constable, & Mullally, 2023). This leaves an impact on the young individual not being able to access school as well as the parents who are left to manage the situation often with limited advice and guidance.

The purpose of this piece of research is to understand parents’ experiences of neurodivergent children’s difficulties accessing school, the impact these experiences have had, any facilitators and barriers to their child accessing school, as well as if/how they have been supported by services, schools, or guidance through these times.

We hope that this study will be able to contribute to the important topic of neurodivergent children’s access needs to utilise mainstream schools as well as parent’s wellbeing and support in such times.

You have the right to withdraw your data and contributions from this study, up to two weeks after your interview has been competed due to data analysis purposes. Please contact the main researcher, Lucia if this is something you wish to do. Please let Lucia know if you would like to be kept up to date with the progress of the study and any publications or conferences which may result. Lucia’s Email: Ls22abu@herts.ac.uk

**Services for You**

There are several sources of support which may already be familiar to you. If taking part of this research and talking about your experiences has left you understandably feeling distressed, you may want to access some of the following services:

**Your GP:** Your GP will be able to signpost you to specialist services in your local area which they may be able to refer you to.

**The Samaritans:** The Samaritans offer a helpline which is open 24/7 for anyone in need. It is staffed by trained volunteers who will listen to you empathetically. **08457 90 90 90.**

**Parent Talk:** They offer free information, advice and support to parents and carers of children aged 0-19, or up to 25 where a young person has special educational needs. Its confidential 1:1 live chat service connects parents and carers directly to an experienced parenting coach for judgement-free practical advice and emotional support.
https://parents.actionforchildren.org.uk/

University of Hertfordshire UH Ethics Committee

This is an official notification by a <delete as appropriate: member of staff/student> of the University of Hertfordshire in respect of a study involving human participants.

**Title of study**: **Primary caregiver's experiences of school accessibility for neurodivergent children**

**Protocol Number**: Alms/pgr/uh/05617

**Approving Committee**:
Health, Science, Engineering and Technology ECDA.

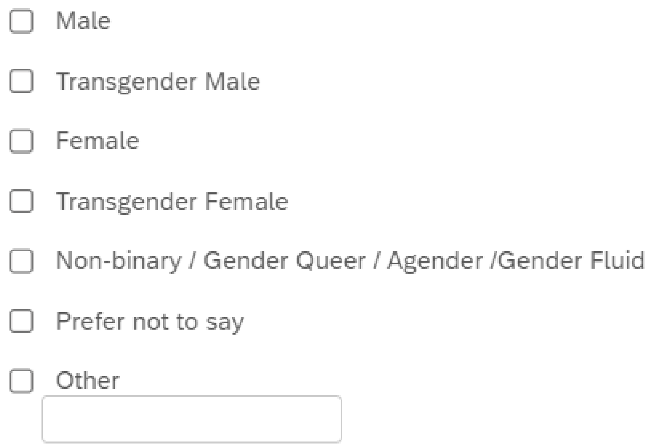
If you have any queries concerning this document, please contact me: Lucia Spinosa-Pike (ls22abu@herts.ac.uk)

## 7.10 Appendix J – Demographics Questionnaire

Online Questionnaire

How old are you?

To which gender identity do you most identify?



☐ Male

☐ Transgender Male

☐ Female

☐ Transgender Female

☐ Non-binary / Gender Queer / Agender /Gender Fluid

☐ Prefer not to say

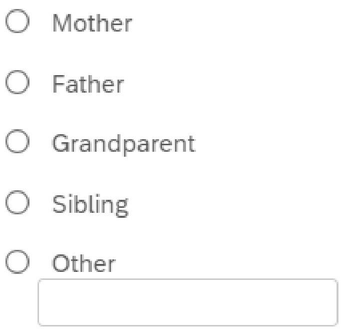
☐ Other

What is your ethnicity?

To understand who approached us in relation to this research and what area they are from, we are asking for the first part of the postcode. What is the first part of your postcode?

How many children do you have that currently have (or have previously had) difficulties accessing school and have a neurodiversity?

As a primary caregiver, what is your relationship to the child/children?



○ Mother

○ Father

○ Grandparent

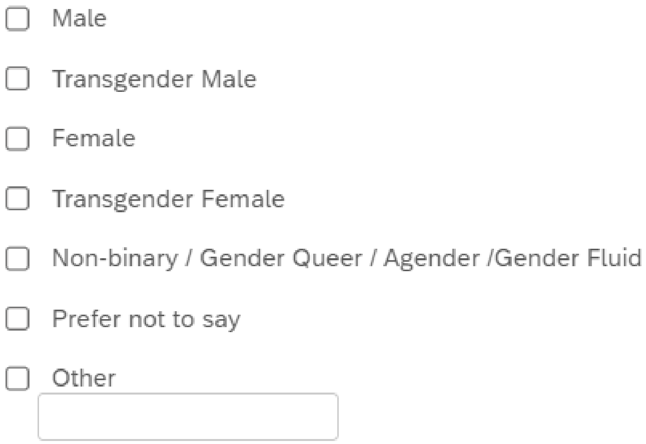
○ Sibling

○ Other

Do they live at the same address as you?

How old are they (the child/children)?

To which gender identity do they (the child) most identify? If you are answering this questionnaire on behalf of more than one child please tick multiple boxes.



☐ Male

☐ Transgender Male

☐ Female

☐ Transgender Female

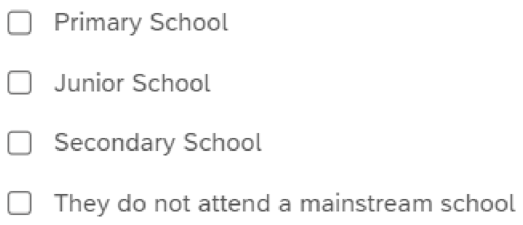
☐ Non-binary / Gender Queer / Agender /Gender Fluid

☐ Prefer not to say

☐ Other

What is their (the child's) ethnicity?

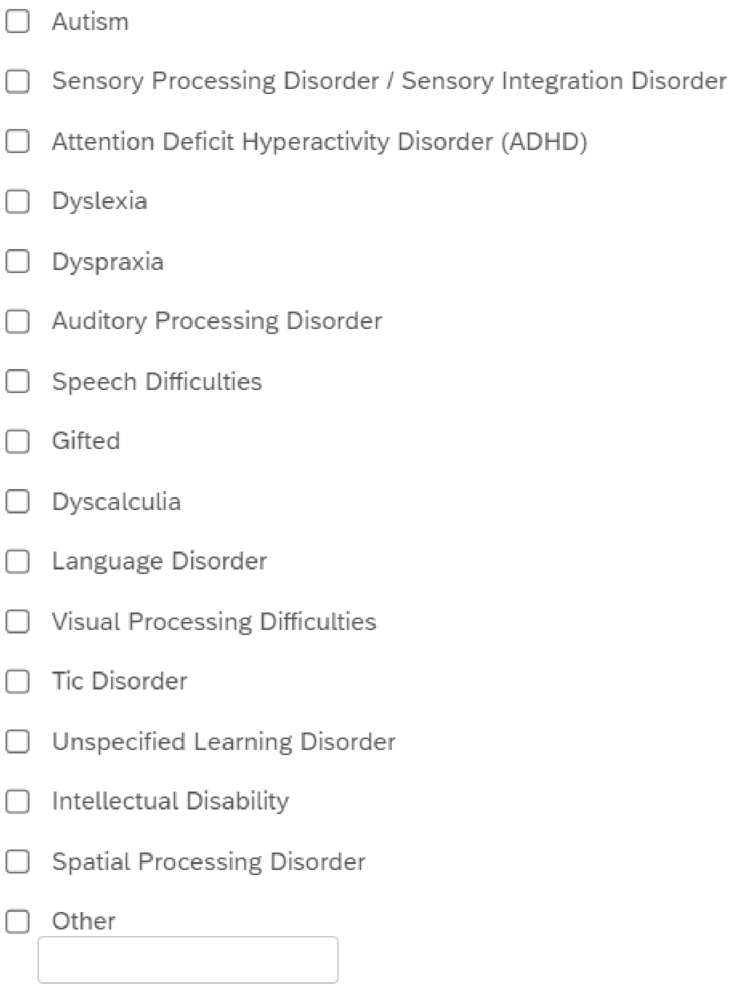
What school are they in? If you are answering this questionnaire on behalf of more than one child please tick multiple boxes.



☐ Primary School
☐ Junior School
☐ Secondary School
☐ They do not attend a mainstream school

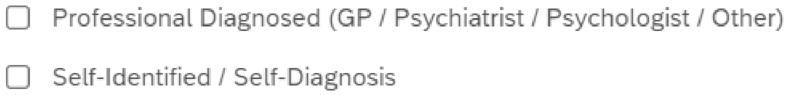
Are they (the child) neurodivergent? (This includes self-identification, self-diagnosis as well as professional diagnosis). If you are answering this questionnaire on behalf of more than one child please tick multiple boxes.

What neurodivergence do they (the child) have? If you are answering this questionnaire on behalf of more than one child please tick multiple boxes.



☐ Autism
☐ Sensory Processing Disorder / Sensory Integration Disorder
☐ Attention Deficit Hyperactivity Disorder (ADHD)
☐ Dyslexia
☐ Dyspraxia
☐ Auditory Processing Disorder
☐ Speech Difficulties
☐ Gifted
☐ Dyscalculia
☐ Language Disorder
☐ Visual Processing Difficulties
☐ Tic Disorder
☐ Unspecified Learning Disorder
☐ Intellectual Disability
☐ Spatial Processing Disorder
☐ Other

How is the neurodivergence diagnosed?



☐ Professional Diagnosed (GP / Psychiatrist / Psychologist / Other)
☐ Self-Identified / Self-Diagnosis

Would you be interested in attending an interview about your experiences?

Please leave your email address that would you like to be contacted on to organise an interview.

Thank you for taking the time to complete this questionnaire.

As previously mentioned in the information sheet, we are unfortunately not able to interview all parents due to demand. If you are selected for an interview you will be contacted over the upcoming months. If you are not invited to the interview you will be contacted to explain this.

As a gesture of thanks for taking part in this study, we are offering the chance to be added to a draw, where two random names will be drawn to win a £20 voucher. Would you like to be included in this draw? If you would please insert your email address below.

## 7.11 Appendix K – Interview Schedule

On average how many days of the week do they utilise mainstream schools? On the days where they access school how many hours do they attend? How long have they been accessing school in this way?

- If it is okay, I would like you to think back to when they (insert child's name first) stopped accessing school. Could you tell me how X came to stop accessing school. What was that experience like for you and them? What made it difficult for child's name to access school?

  Prompts:
    - Thoughts – Could you tell me what you thought when it first happened?
    - Feelings – How did you feel.
    - Actions – How did you respond when it first happened?

- *What has been the impact? Prompts: Impact for child, for parent, for wider family.*

  *Prompts:*
    - On your/child Wellbeing and Mental Health
    - Work/Financial
    - Relationship with Child
    - Relationship with school
    - Relationship with services.
    - Relationship with community and network
    - Personal Relationships

- *What has been your relationship to this?*

- *How have you managed the impact of this?*
- *What strengths, resources and skills have you relied on?*

- During the overall period that your child has not been able to access school. How have others responded? How did the school respond? Was anyone else/ service involved? Prompt: Have they offered support or guidance?

- Has there been anything that has been useful or has been supportive on the days your child has accessed school? What has been unhelpful on the days your child has accessed school.

- What other support have you accessed for child's name?

- Have you accessed any support for yourself?

- What do you think needs to change?

- After having these experiences, what advice would you give to someone whose child has just stopped being able to access school?

- Is there anything else you think I should know to understand school accessibility for neurodivergent children better?

- Is there something you might not have thought about before that has occurred to you during this interview?

## 7.12 Appendix L – Initial Coding

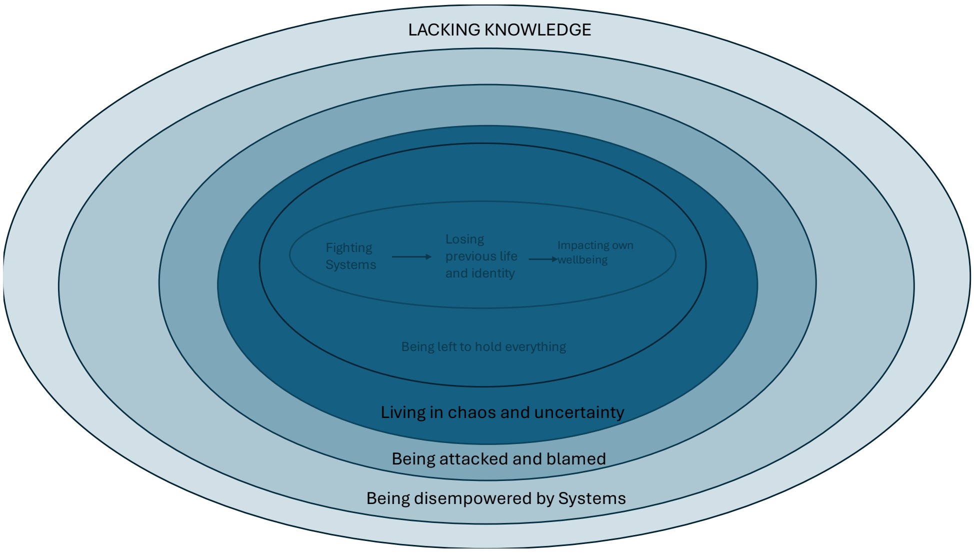
| **Interview** | Line by Line Coding |
|---|---|
| **Participant**<br>I was angry because there was just we weren't getting, you know, they were saying telling me one thing, but I could see another thing. And then they finally listened and it was relief. But also since then, it's just been a fight. And it's frustrating because you shouldn't have to fight, you know. Teachers and stuff. They should believe the parent when they say you know something's not right, you know, she’s doing this.<br>Um we were actually blamed with our parenting. With our not having parental boundaries, we were sent on courses so that sort of felt like, oh, you're the problem. It's your fault. This is not happening. So obviously we were fighting that as well. We were fighting, obviously, that we didn't have the confidence to be a parent. So yeah, there was a lot of stress and it was quite it's. It was traumatic not only for us, but for XX as well. | Feeling Angry<br>Not getting…<br>Inconsistency in knowledges<br>Listened by others, felt relief.<br>Having to fight, feeling frustrated.<br>Fighting teachers<br>Teachers not believing parents.<br>Thinking something is not right<br>Blaming parenting<br>Blaming lack of parental boundaries<br>Attending courses<br>Thinking it’s my fault.<br>Fighting narrative of fault?<br>Fighting lack in confidence<br>Feeling stress<br>Feeling traumatic for parents and X |
| **Researcher**<br>Yeah. And when you say fight, could you tell me a bit more about that? | |
| **Participant**<br>Um so obviously you'd be fighting with the school. Um, you'd also be fighting with, like, um the neurodevelopment team 'cause obviously you put in the assessment and | Fighting school<br>Fighting neurodevelopment team |

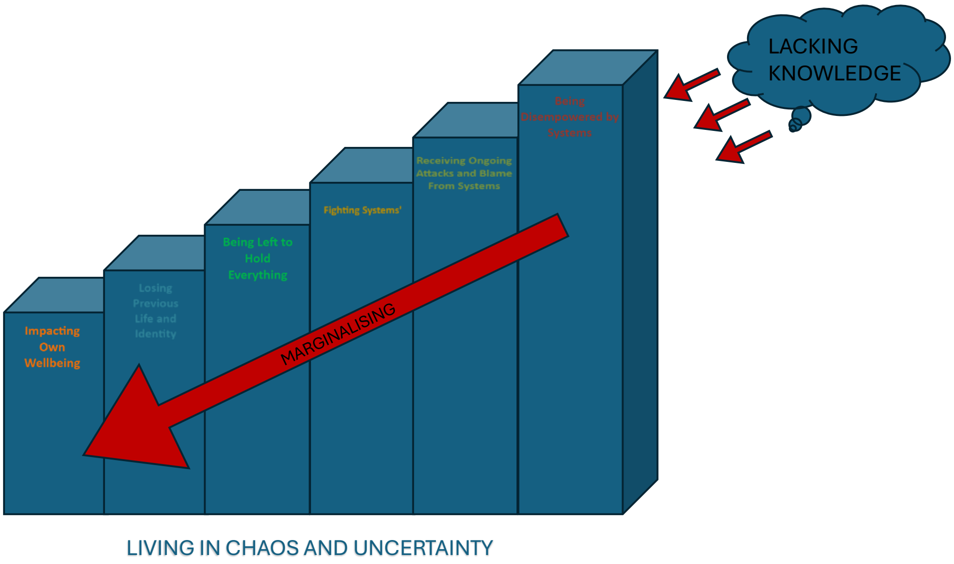
| | |
|---|---|
| then you don't hear from them. So, like, it's sending up an e-mail, as you know, you know, are we there yet? Are we? Are we reached the top of the list yet? No. You've got another 7-8 months left and it's like, but we need something now. Oh, there's nothing for you now. And then you fighting with CAMHS, you know, you you can see your daughter deteriorate your daughter or son. You can see them deteriorating and you're like I need help now and then like, Oh, no, you've got to wait on the list for another six months and try this person. And you sent to that person. Oh, yeah you've got a six week week for that and meanwhile, obviously, you're the parent at home thinking you know, Oh, it's probably your fault because you're not doing the boundaries and you're not doing the routine because that's what school said. And then um you've got your child, just, you know, she wasn't happy. She was really sad she couldn't sleep. She couldn't eat. So, like, you've got that. And it was just really, really stressful to deal with. | Not hearing back from service<br>Emailing service to follow up on support.<br>Waiting on list for months<br>Needing support now<br>No support ready now<br>Fighting CAMHS<br>Watching child deteriorate<br>Watching deterioration; needing help now<br>Having to wait.<br>Signposting to other places/people<br>Waiting for places signposted to.<br>Same timing thinking parental blame “it’s my fault”. Blaming lack of parental boundaries<br>Blaming not doing routine school said.<br>Managing daughter’s sadness, lack of sleep<br>Not being able to eat.<br>Feeling stress. |

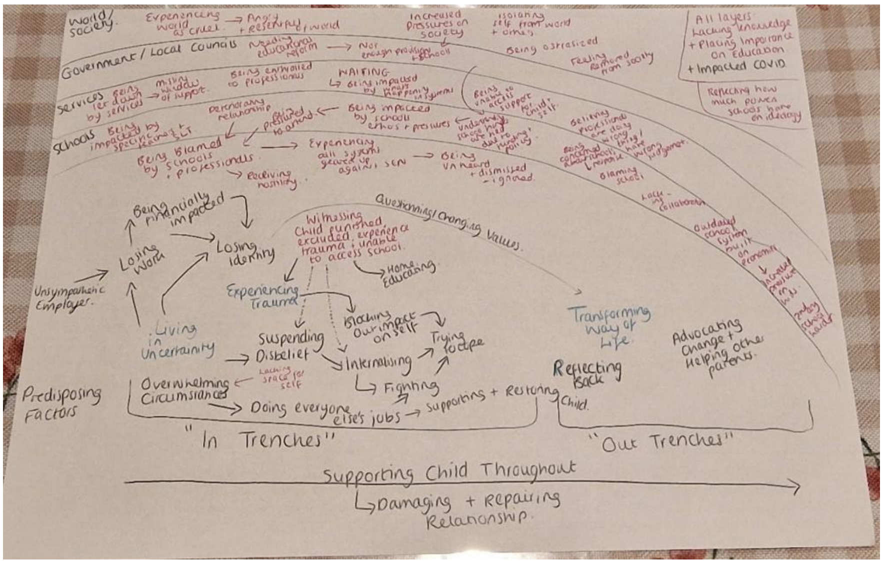
## 7.13 Appendix M – Focused Coding

| Focused Code | Line by Line Code | Corresponding Coded Text |
|---|---|---|
| Losing Finances | Worrying about future finances and implications | “We’d suddenly become parents without any income, parents without any proper means of reimbursing ourselves in the future, because A – our age, and B – the potential’s just gone now. So that’s quite a startling sort of thing to think.” |
|  | Having to pay and fund provisions | “she needs specialist speech and language therapy. So we’ve been paying for that since because we didn’t have an EHCP, £200 a month for her to go into school to train the new school staff on how to deliver this therapy that she needs integrated into a days in school when she’s there.” |
|  | Losing Freedom | “I kind of lost my work and that sort of thing and lost a bit of freedom with that really like, financial, you know” |
| Trying to find and access support | Using social media sites for information, support | “I would look probably like most people do at endless social media groups that might have support mechanisms and different families going through similar things. You try and find some resemblance of order in the world where<br>somebody have made sense of it”. |
|  | Seeking support group | “So I sought a support group for the autism”. |
|  | Being passed between services and professionals when seeking support | “So it's you start with, you know, the teacher, then it's the head of year and maybe it's the headmaster. And then you talk to the SENCO and then they refer education welfare services as well as autism intervention services, who then will tell you to contact CAMHs and if you're in the waitlist for CAMHs you can't access the family support hub. So then you go to the back of a waiting list. And I have this and I think there's” |
|  | Chasing Support | “constantly on the phone to children and young person services begging them when is his assessment like or is there anything else I can access in the meantime? Just chase them constantly and always. I just felt like I held me breath for years” |

## 7.14 Appendix N – Model Iterations







## 7.15 Appendix O - Memo-Writing (Extracts)

**Relationship between School Systems and Parents:**

The relationship with schools appears to be key for understanding the level of provision, support and compassion families receive, it is integral to parents' experiences. Whilst, all schools have the similar pressures to enforce attendance policies, cover national curriculums, and complete examinations, there is a difference continuously highlighted by parents. Schools that were considered unsupportive and not helpful was those that blamed parents, penalised children, gatekept and enforced strict attendance policies. Those that were considered more supportive still were not able to meet children's needs though, they approached parents with more compassion, collaboration and willingness to try.

What I am learning from parents is that there is a lot of weight depending on the headteachers, governors and those in senior leaderships and how they want to approach SNA and understand neurodivergence. A parent shared that the headteacher allows all absences to be marked as authorised reducing pressure with hopes to slowly re-introduce the child back into schools with no timeframe or expectations, where at a previous school they informed parents that they would not do this. It makes me wonder if there are other factors at play compared to just the senior leadership teams. I have noticed a few parents linking this to organisational hierarchy and this is not a connection I have had previously. This need to be given significance and consideration when considering categories and the wider model.

**Creating Reassessing Values and Upheaving Entire Life Subcategory:**

This needs to be its own subcategory as it felt a part of a core parent's identity, with significant changes to their lives consequently. First I noticed in the beginning of interviews that many parents were "forced" into moving houses, moving schools or to entirely new areas in other catchments for different provisions. These interviews shared how these changes were in one sense out of their control as they felt stuck and needed to try something new, and new necessarily wasn't better.

But when comparing with interview 4, 9, 11 and 12, I noticed similarities in the forced reassessing of values, and what is most important in there lives, but differences from the other interviews. These differences were connected with new found identities and some sense of almost “freedom”, no longer comparing themselves with “societal expectations” of life and creating their own narratives and ways of living. One parent shared they have nothing but yet so much and that really stuck with me. Some of the parents in some ways appreciated parts of the new identity such as advocating and making changes for all, though this does not remove the trauma and costs that they faced. It makes me wonder when capturing this subcategory to ensure that both sides of this are represented. I wondered if the length of time in the trenches total, or length of time out of the trenches interlinked with this and differences of views and experiences, but it appears this is not the case.

## 7.16 Appendix P – Reflective Journal

### Reflective Diary Extracts

Extract One:

Despite the first three interviews with parents and talking about some of the impacts on themselves, I noticed that much of the conversations veers towards their child and what they experienced rather than what happened for themselves. I am curious why this is? Is it that they want to highlight their child's experience for change to happen here? Is it that their child is considered such priority that this is where their focus is? Is it that they may feel expected to speak to their child's experience? Is it too traumatic to reflect on their own experience and it is blocked out? From being blamed and dismissed have parents dismissed the importance of their own emotions and feelings? It is making me wonder how I may be able to better access this with parents, even though I have explicitly asked several times what this meant for them, how they felt and responded, it seems tricky to get to the "feelings". I need to address this for future interviews to ensure that I am able to accurately reflect parent's whole experiences rather than "parts", I will bring this to supervision.

Extract Two:

In the last two interviews, I have been questioning whether I have been able to meet theoretical saturation. I have reviewed the definitions of this and I want to complete one more interview to test this concept and see whether theoretical saturation according to Charmaz has been met. I will see if any new categories, concepts or insights occur.

Extract Three:

I felt so nervous today attending the focus group with the parents, I really wanted to get the model accurate to what the parents had shared with me. I have been reflecting on the pressures in building this model and categories, because parents have been dismissed with their feelings minimised, I really wanted this model to not replicate these experiences. Though, I put so many weeks and hours into the model, categories and building, I was surprised that the parents felt this model reflected their experiences. It was interesting to see the various responses to the model, with some parents in agreement, and others being able to make sense of their experiences by visually seeing the model. One person shared that this model made them consider the power the schools, services and systems hold, and reflected that they now seeing how this was almost like an abusive relationship, to which another parent shared how had previously drawn parallels with their lived experiences of both. Even in this space, with such saddening models being shown, I saw parents supporting each other, offering such compassion and advocacy. I really saw the beauty and power in the parent's voices and them being together, I could really understand how being together was such as effective support. I have truly been touched by each of these individuals and really see the strengths each person possesses.

## 7.17 Appendix Q – Links to Psychological Theory and Concepts

Pelicano and den Houting (2022) argue that the present physical and social environments were created and designed to meet the need of those who fall within “typical” range of neurodevelopment. Yet these environments are regarded as “sub-optimal” and hostile for many neurodivergent people (Pelicano & den Houting, 2022). Happe and Frith (2020) added that autism is regarded a type of neurodivergence, and within the context and demands of the neurotypical world, it constitutes a disability. Such literature makes one consider the set-up of mainstream schools, whereby the environments are typically, loud, chaotic, requiring several transitions throughout the day, and with many expectations and social rules to attend to (Fielding et al., 2025; Lawrence, 2025). Such environments are not accessible for many individuals who are neurodivergent (Connolly et al., 2023). Pelicano and den Houting, (2022) add that such contexts designed for neurotypical individuals, incorrectly portrays neurodivergent individuals less able than “peers”.

Day (2025) accentuates that stresses of living in neurotypical worlds make neurodivergent people more susceptible to experience trauma. This is further supported by Grove et al., (2023) where neurodivergent individuals reported living and having to navigate in a neurotypical world “that’s not about us” as “overwhelming”, with additional pressures on these individuals to meet expectations and fit in. Grove et al., (2023) found that individuals regularly masked to “fit in” with the neurotypical world and demands at a tremendous costs. These findings are related to those in this study whereby many children were seen to struggle to access such neurotypical setups of mainstream school. If children were attending school with no reasonable adjustments, they were often seen to have regressed behaviours, and deterioration in their mental wellbeing and physical health. When parents were “trying to make sense” of what they were noticing, many came to this realisation of their child’s presentation being a result of the neurotypical environment around them with limited support, and when they were seen to reassess their expectations and values, it came from this knowledge.

Pelicano and den Houting (2022) contend that there need to be adjustments in the setup of physical and social environments for neurodivergent individuals to lead fulfilling lives. They emphasise that neurodivergent individuals are not the ones who need to change or conform, but societal factors instead should be challenged. Pelicano and den Houting (2022) make recommendations to overhaul major institutions and practices, with “real world changes” to better serve neurodivergent people, they highlight the devasting costs of changes not taking place. This is in line with findings of this research, with many calling for an educational reform to benefit all children (Connolly et al., 2023).

The second theory that connects with the current research findings was Bronfenbrenner’s bioecological systems model (1979; 1998; 2005). Bronfenbrenner acknowledged the social and ecological contexts that surround individuals and created a model to share how these contexts and interconnected environmental systems interact with and influence an individual and their own positioning and understanding (1979; 1998; 2005). This model appeared most appropriate as it focuses on the social, systemic and cultural factors that influence children, their parents and the overall experience of SNA. It is hoped by exploring SNA through this lens it will redistribute accountability across other systems and context, instead of placing this on parents as prior literature has (Înoue, 2022; Sheppard, 2007).

Within Bronfenbrenner’s model (1979; 1998; 2005) there is the microsystem regarded as the individuals and systems closest to children and parents, this research found parents to describe this as schools, social care workers, healthcare professionals, immediate family and long-term friends etc. Then, there is the mesosystem which is regarded as the interactions or “proximal” process between components of the microsystem. An example of the mesosystem in this research would be how school and health professionals blamed or attacked parents, there are opportunities for support to take place within this layer as described rarely by participants. Next is the exosystem which includes larger systems that may influence children and their parents from further afar or considered more “indirectly” by instead having influences on the contexts of mesosystems and microsystems. An example of this in the current research was how local authorities did or did not offer provision and funding to schools to support a child, and the impacts of these choices on what schools can offer to children; or equally how local authorities responds to the school system for absences and whether they encourage schools to sign them off as authorised or recommend fining parents instead. Then, there is the macrosystem offering further distal influences such as cultural norms and beliefs, which for instance can influence laws, national policies and values. One example this research found was the government and education systems prioritising attendance and thus adding pressures by judging local authorities as well as school statistics. These layers may be argued to agree legislation and expectations of overall systems, and encourage values such as school attendance or having an education in school, or inclusive practices. Finally, there is the chronosystem which is seen as the final outer layer representing how context of the elements has been influenced by time, for instance moving from “truancy”, to “emotionally-based school avoidance”, to “school distress”, as well as COVID experiences. Bodycote (2022) similarly found this bioecological systems model useful when holistically considering components of SNA.

## 7.18 Appendix R – Parents Recommendations

- “Um a lot [laughs] a lot. It's so hard because I know obviously what teacher shortage. You know, we have more people that you know each county or whatever can handle… And you know, there's only so many teachers and so many schools. But for it to work, I think there needs to be obviously lots more teachers, school um classrooms smaller, you know, having thirty children. It's just it's just too much for one teacher to deal with, um, so having the smaller classes then they'd get more one to one more special time obviously with the teacher where they can be supported better”.
- “And then I think obviously looking at the curriculum, you know, the stuff that XX was learning in year three, we didn't learn till like year six. So there is a lot of pressure on the children to learn higher knowledge stuff and that's quite tricky, especially if they've got special needs as well”.
- “I think it's including them in what they want to learn and how they want to learn because obviously we all learn differently”.
- “Well frankly, if I’m honest, it’s about resources. TAs need to be valued, there needs to be investment in their training and they need to be encouraged to advocate for the children they work with”.
- “Ofsted can be intimidating it can be awful and whilst their looking at procedures, systems, outcomes, output, standards and all of those things, I think. I wonder if there should be a moral or a cultural kind of appraisal of a, of an organisation, and it's looking at the quality of relationships between pupils and staff and between staff and staff and between, you know, the outside community and the parents an all. But I'm, I'm sure there must be some mechanism within an Ofsted inspection”.
- “Obviously numeracy and literacy are important but looking at, you know, sometimes I think just just rebuild all the schools and, and then and change the school working day from, especially with climate change, from 8 till 12 (laughs) and that’s it, (laughs) I don't know. I don't know. It just feels too… (pause). It's just not flexible enough. You know what I mean? It's just, just, it’s too rigid”.
- “Um, well schools obviously are skint, and then they have some difficult decisions to make. Um, whether to fix the roof or hire a new PA, uh TA rather. I mean, again it

becomes a political question, doesn't it. Like, obviously schools, like hospitals need lots more money and in the long term it pays for itself because uh, you know, early intervention in health and education means a happier and healthier workforce later down the line".

- "Perhaps that would open up different collaborations between schools or between schools and other settings like museums or football clubs. I know those things happen already. But you know, as in… it feels like there's, you know resources, staff, happy staff, happy staff, happy motivated, motivating staff".
- "I know there's continuous professional development. I suppose um it might be about looking at that initial training of teachers and just how embedded neurodivergence is in the curriculum of, of teacher education".
- "I think the attendance requirements on schools can be quite unhelpful".
- "I got chatting to a uh retired primary school head teacher from the USA um few months ago and I told her that we home educate and she was saying, which I thought was really odd. Oh, yeah. We had some home educated kids in my school, you know. And you're like, what? Surely those are mutually exclusive. Surely you can't, and she said in my school you're allowed home educated kids are allowed to select to come in and do certain things. So for example, they could select to come in and do PE. And so those kids would be home educated, but they could come in for PE. And so they would come in on, you know, Wednesday afternoons. And they'd do PE and they do it with the class. So they were sort of part of the class. And there was certain things they could choose to do music. So then they come in on Wednesday afternoons and Monday mornings, you know, and they would do those things with the class and they could select to do certain things".
- "I think parents and teachers need to be able to talk to each other with honesty and you know, actually listen. I think communication is really really important".
- "So I think we start by the conversation and perhaps a way for them to, I don't know, get involved I suppose. Like you know how they change from the five day working week, to the four day working week, maybe we need to change the way that education system is so there's a bit more flexibility so that it's not all in class. Perhaps there's learning, outside learning as well, but they need to do other learning, things

that matter, things that will matter to them. Things like online safety, how to manage your money. . So from parents, from young people who have gone through the system to be able to tell them about some of their things, and to actually get the understanding of what life is like for her, before making these sort of judgments or learning about in other ways".

- "I think you really need to entice the children to want to go to school with lots of opportunities for, sort of an expansion like you know on their lives and how they can develop themselves and how they can learn and learn about things that are not necessarily learned within the classroom. I think that the whole education system is really, really ineffective because it tests you on the basis of a test and the way the tests are, they should have more tests in a practical sense".
- "I think, I think, I think there's a lot to be learnt about neurodiversity and I think there needs to be an overhaul of the lessons that we learn about children and young people who are neurodiverse. And, I don't think that these, I don't think professionals can be taught by a professional. These are the things you look for. And I think the only way you'd actually come is through actual lived experiences".
- "I think the SEN team needs to listen to what parents are saying when the kids go home, what their behaviours are when they go home. And say, ok, we're not seeing this in school, but they're obviously struggling from what's happening when they go home. So we know we need to adjust it in school".
- "I think schools have got a lot of power in terms of referrals to the GDA pathway. You know, autism pathways. Um, and all the referrals that come with helping schools, we couldn't get anything in place as a parent because we just got told you have to go through school. So the schools hold that, and if they don't agree with you or you get a SEN that doesn't like you or you get a SEN that doesn't agree with you".
- "I think because it's such a diverse um range that children can present with, the schools are just not set up for it. That I don't think teachers are trained well enough in that".
- "I think the expectation on people to perform at key stages should be dropped. You know the expectation that your child should be writing cursive writing by the time they're seven years of age, should drop that away. So just some kids won't learn to

read until they're seven, so forget about the writing. Or that they might learn to read by looking at a computer game. And that's going to be their go to".

- "Just to drop the expectations of when things happen and how they should happen, I think and it I think overall education is well overdue for an overhaul given the diversity of the population now".
- "I think the classroom structure as a whole needs to change. I think it needs to be more like the some of the foreign schools where the kids are allowed just to free school where the kids have an open environment and they can just move through the environments and learn that way".
- "So I think I mean with that particular school, I think there needs to be a change in ethos where actually the leadership take a role in making sure that everybody is understanding of neurodivergence… why would you accept a non autistic person telling you what an autistic person experience is?".
- "Apart from full educational reform, I mean, if I could properly, genuinely, if at the very I mean, at the very, very least, it would be putting emotional mental health and well-being at the core of everything instead of attendance and results, you know, if we if we could start with that, I think we'd make teachers happier, make kids happier".
- "So it'll be really child led. And there are some really amazing democratic schools where the kids actually hire and fire the teachers, you know you can go in. So it's really the teacher will stand there and do their lesson on history. And if the children aren't interested, they can just get up and walk out and go to something else. They stay if they're interested so the onus is on the teacher to make it interesting".
- "I really do from a practical point of view, I feel like we just need to recognise that school isn't for everyone and to start with that conversation at the start and say it's one path for education, it's not the only path. And if it isn't for you, then what will work best for you? And actually having some options there and there aren't any at the moment".
- "Oh, like ultimately it would be money. I think. I think if there was more money available then things wouldn't be so tight and there might be more support

available… Like I think teachers would be less exhausted, there'll be more resources available”.

- “Understanding different types of training have been available for people. That would be, you know, really, really good. That would go a long way to kind of helping people's understanding. But I think also probably taking some of the pressure away from the schools as well”.
- “There are 29 kids in her class. She is not the only child in her class who's autistic and of those who aren't, you know, autistic, there are other neurodivergences, and that is so much for teachers and schools to be dealing with. And there's just not a lot of other support”.
- “So, like mainstream is a bit much for XXX, but, you know, maybe a special, you know, kind of a SEN school that's too much as well. Like, she would be just as ostracised, but for other reasons, if that makes sense. So I kind of feel like there has to be something in the middle, a little bit more to help kids who are like the lower lower needs, I would say”.
- “I don't want to hear “We want to make mainstream schools inclusive” anymore because you can't. You can't change an environment. I want acknowledgement that environments, big environments, often noisy environments are never going to be inclusive”.
- “I think they should be like SENDIASS or I feel there should be more accountability for for the law to be enforced, because it is completely dismissing their needs and and a lot of that guidance is unlawful. So I think the graduated response needs to be worked in with law”.
- “Parents voices need to be respected, understood”.
- “And all teachers need training in SEND if they're going to have. If they're going to be accepting those children into their mainstream schools. The whole way the curriculum curriculum is taught needs to be looked at. I don't think it works for anyone. I just think the whole education system needs to be looked at under a different lens. The, and looked at from a child's perspective”.
- "We've failed them and I just think the whole the whole system needs to change that from and from the top down head teachers. I think they're, they're the ones that

really, really need to reassess their thinking and relearn and almost forget what they've been taught and start again".

- "The whole education system, really, I think it's way, way outdated. I don't understand it, I think. The curriculum is useless".
- "I've never used the things that I've learnt in school academically, wise and two, I've forgotten it, like I've forgotten it anyway. So I think the things that they should teach them is life skills and about money management and, and let them explore what they're interested in".
- "I think just, I think that a lot of schools should really incorporate some form of mental health support in schools. I think that would be a start".
- "I think that. I would like to see all children able to play for a lot longer. I'd like us to take this idea of University beginning in primary school and throw it out the window. I think there is a lot of learning that happens really naturally through play that we have, we've dismissed".
- "I think we should trust children that what they're interested in is probably what they're here for for as long as they're interested in it, and that's OK. And if they change their mind and they move the subject, that's also OK because learning is a lifelong thing that is actually wonderful, and there's no right or wrong about it. It's just a lesson, I think we need to stop telling children that you know, mistakes are terrible things".
- "I'm not going to say teachers, the education system has been built in a way that no longer serves the children, the parents, the workplace, the workplace, it's not serving. So that is a fundamental change that needs to happen".
- "So I'd like to see a lot more compassion. I mean, that's me really reaching there, but I'd like to see a lot more compassion in that field".
- "So we need the village. We need the village. You know, we need to be able to to help people change direction. You know, we needed my employer to be able to go. OK. You're in, you've never been a problem employee. Why on Earth would we, would we not help you".
- "I want to build that library. I want to build that library that children can access of the photographer and the astronaut, whatever interests them, the rugby field, whatever

interests them. We've already got these services out here in sports commissions and art commissions and everything. Let's use them, these are people that are passionate about the subject. They're not teachers because they need to put food on the table. They're teachers because they're natural teachers, so let's use".

- "We talk about parents supporting children, but if we don't support the parents, how on Earth can they support the child? You know they're a fundamental part of this. So I think when a child has a diagnosis like this, there needs to be that support network coming in for the family so that they can support because you can't from a place of exhaustion".

## 7.19 Appendix S – Concluding Reflections

Concluding this research, I am reminded of all the tears and hope this project brought me. Reflecting on the journey, I recognise that my knowledge, emotions and responses have developed. Before completing this research, I was aware of the detrimental impacts SNA can have on children, parents and their families, though I had hoped that this was often a rare phenomenon which could be advocated for by requesting local change and responding to particular services. However, I am saddened how frequent these experiences are nationally with such profound detrimental effects on so many. I notice such frustration and sadness that so many are harmed where prevention could take place if there was appropriate funding and support.

This research has highlighted how services, schools, and systems, are pressurised with excessive demand and limited resources or knowledge to be able to respond, as well as often responding from neurotypical lenses, which ultimately fail many children and their parents. These findings have highlighted the need for a wide systemic change, and have continued to fuel my drive for advocating.

Alongside the participants in this research and supervisors, we have thought through how this research can be meaningfully disseminated to advocate for others. The ways of disseminating include: sharing this research through a journal submission as well as a conference with many stakeholders to connect with each other; sharing the research with governmental individuals highlighting the need for change; as well as parents themselves taking over and disseminating these findings (if they still align with their experiences and values) with each other in their local support groups as well as local charities to support advocating plus validating experiences.

Despite such sadness, I was absolutely blown away by the parents. The tremendous strengths that these parents show daily responding to such experiences whilst being in the trenches are beyond what words can capture. The drive and commitment from these parents with hope to change parts of society for their own and other children is enormous. I was so touched, by the way they constantly show up for each other and offer support and any resources they have found, despite being at such depths themselves. All parents clung to hope and were keen to instil hope and resources within other parents, families and their child. These parents had such a profound impact on me, I was so honoured to have heard their stories and for them to have shared their knowledge and time with me. As part of the interview, I additionally asked parents what they would want other parents to know and to hear if they also were in similar positions, and these responses are shared in Appendix T. For me, the best advice and recommendations truly comes from the parents themselves.

## 7.20 Appendix T – Parents Advice to Each Other

- “Reach out, reach out to anyone. Anyone who's been through it, messaged them, talk to them because it is a hard, it's hard and it can be really lonely as well”.
- “Just not to not to take the blame 'cause it's not, not their fault. It's not anything you've done or didn't do, it is just because it's not right for the child”.
- “Yeah, definitely. And then obviously talking to someone because um, I think it's, it's easy to sort of shut yourself away and shut down, but um you need to talk to people, especially obviously like with ourselves, with the child being aggressive”.
- “Don’t panic, don’t panic, um, respect it, if your child can’t go to school, that is the evidence of something so take your time to understand what it is, it could be… it could be poor mental health it could be bullying, it could be whatever it is, don’t panic take a pause”.
- “Start seeking out like minded or people with similar experiences locally. I think locally is really poor. There are lots of national groups online, where the people talk about children not going to school, but it varies from local authority to local authority... seek out some advice from charities.”
- “Don’t believe them when they say when they say this has never happened before”.
- “Are you sure? Probably 'cause. It's hard, like home education is no walk in the park either. Um, I'm I'm glad that we felt like we exhausted all the options”.
- “You know you're you are best faced to know what is helpful for your child”.
- “Watch any documentary on TV”.
- “Um, Yeah, going easy on yourself as a parent and actually starting to find out who your child is”.
- “I think just really listen to them and what what is it that? What do they need? Like what? What is it that they need? Because they are all different. And um they might not need what you think that they need, the professionals don't know better. Um, you know, you know your child better. That's not to say that everything that professional says is rubbish or useless because I don't believe that either”.
- “What do you want for them? And is that what they want? Is that how they'll thrive? And that's that's the path to follow the path that they'll thrive on, or you suspect they'll thrive”.

- “Just trust your gut”.
- “Put in complaints because I do think that the more complaints I mean, particularly in the same school as, say, the more complaints that get received, the less they can overlook it”.
- “Protect your child, take them out of school. Don't don't send them in if unless you're sure they're safe to be in school”.
- “So I think once they've stopped going, you're almost too late. It's really tricky. So what I would recommend is that if you've got a child who's got one of the earlier symptoms is like after school restraint collapse. So they've come in if they're hold in all day and they come home and they fall apart. Usually what happens is the parents, they go and tell the teacher. Is everything OK in school? Because I'm seeing this at home and that disconnect is where it starts. So I think when parents start to say we're seeing problems at home that that there is an immediate reaction to right, let's do with this. Let's take off some pressure. Let's scrap homework. Let's wherever those pressures are, let's identify them and remove them so that we can get in then because by the time you get to the stage where your child is not going in, they are beyond it. And you're really looking at healing repair”.
- “Just, you know, get as much support around yourself as you can because it is definitely a marathon and not a sprint. You know, it's a long old haul and just make sure you're ok, because if you're not ok as a parent, you can do nothing for your child”.
- “The moment they're having difficulties, I think it's to understand what's causing those, so to to ask your local authority for an assessment of their needs”.
- “I’d kind of tell them to get themselves fairly well organised. I think, you know, making sure you're kind of contacting the people that you should be contacting for help, kind of educating yourself about what's going on for your child and what is available and what you can be doing at home”.
- “Do your own research, understand the law, know what the your local authorities should be doing? Because actually they don't. Often they don't do what they should be doing, and so I think it's educate yourself and get ready for a fight because most people have to fight to get what they need”.

- "If home education is an option, and that's what you feel is best, then I think maybe that, I I look back and I do wonder if we'd all be in a better place now if we'd have gone down home ed route for my eldest".
- "Get ready to fight against schools and local authority".
- "Seek legal advice if you can afford it".
- "Don't allow the school to threaten you".
- "Breathe. Take a breath. Let your child take a breath, because you've just been through, if you've been accessing school and you've decided it's not for you, you need some time to heal from that".
- "Find your tribe. Find the people who have been there and who can support you. Do your homework, like do your research just to know where you stand and what your rights are, because the school will tell you anything because they just want to put that tick in the attendance box really, that's all they're interested in. And so I think just knowing your stuff and like I say, finding the people who have been there, that was the, that was when everything changed for me and I wish I had had that sooner. I think it would have saved us a lot of stress and trauma. Yeah, those things".
- "Step back, breathe, have a look at what it actually is and everything everybody's told you about your child. Just, you know, park it to the back of your mind for a little bit and show it love and kindness. You're going to find that your child flourishes in a way that you can't see until it's settled. It's like muddy water in a glass. You need. You've spun it up. You need to give it time".
- "And it was all this stuff that we forget about, that we sell when we give our time away like that. It's, you know, there are other ways and there are innovative and incredible spaces popping up and developing all the time. There's progressive education groups. There are other parents doing this. You are not alone. And there's many ways of doing this there's no one way. That's the bit to ditch the idea that there's one way of doing this. There isn't. There's many ways of doing this and it's the way that fits your child. There's no right or wrong. It's what works for your child".
- "You'll find what your child is naturally interested in because believe it or not, they ask questions all the time. They are the only thing that is really going to change is the high level of flexibility that you are going to need and it takes a bit of time to work

out what life looks like now we talk about parents supporting children, but if we don't support the parents, how on Earth can they support the child? You know they're a fundamental part of this. So I think when a child has a diagnosis like this, there needs to be that support network coming in for the family so that they can support because you can't from a place of exhaustion".