University of Reading

The lived experiences of autistic children in mainstream primary schools in England

PhD

School of Psychology and Clinical Language Sciences

Jo Billington

May 2023

Acknowledgements

I would firstly like to thank the University of Reading Graduate School for seeing the value in my PhD proposal and awarding me bursary funding to cover my tuition fees. Without this funding, I would not have been able to undertake this project.

My further thanks go to:

- My three supervisors: Dr Fiona Knott for her enthusiasm for this project and support for me as a researcher. I have found that completing a PhD has been a perpetual exercise in doubt: doubt in my capacity as a researcher, doubt in the value and quality of the work, and at times, doubt in my ability to even finish the project. Fiona has been a constant cheerleader for me and my work and I will always be grateful for the confidence she has had in me. I would not have been able to complete this project without her expertise and encouragement.

- Dr Tom Loucas for his laser-focus on the details. By bringing a statistician's sensibility to this qualitative investigation, Tom has encouraged me to constantly question my research, thereby teaching me how to justify and defend my decisions.

- Dr Shioma-Lei Craythorne whose IPA-specific support played a key role in study 3. Shioma-Lei guided me through the detailed interpretative process in study 3, supporting me as I wrestled with key philosophical, hermeneutic and phenomenological principles along the way. Her wisdom and creativity have inspired me and helped me honour the contributions of my participants.

- My participants who generously gave their time in support of this investigation. I am particularly grateful to those who trusted me with experiences that were sometimes difficult and painful to discuss. I am hugely grateful to the children who took the time to help me understand their lives better. I am also very grateful to the parents and school staff who supported them with their participation in this study.

- My autistic mentors who read my work, discussed my findings and helped me develop my understanding of autistic culture. In particular, I would like to thank Ann Memmott, Barney Angliss and Philipa Smith for their generosity and insight.

- Professor Michael Larkin and the members of the Phenomenology of Health and Relationships research group at Aston University who provided early feedback on my IPA study and whose support was vital in the development of my interpretations of the data.

- The members of the online study group who have encouraged and motivated me through the long spells of writing this thesis.

- My fellow PhD students at the University of Reading and elsewhere whose friendship has made what can be a lonely process so much less so.

- Most importantly, my lovely family. Thank you to my husband Tim for his constant love and support; for keeping the home fires burning and doing more than his fair share of everything so I could focus on this project. And to my sons Louis and Eddie, without whom this thesis would not exist. I will continue to keep learning from you.

Declaration of original authorship

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Jo Billington

Abstract

The majority of identified autistic children in the English state school system are educated in mainstream settings. However, many autistic children and young people in such settings have difficult school experiences and impoverished educational outcomes. While a great deal is known about the particular difficulties school-aged autistic children face, how they make sense of these challenges has received less attention from researchers.

Much of the extant research relating to the school experience of autistic children involves standardised testing or parent and teacher reports, with the perspectives of autistic children occupying a less prominent position in the literature. Furthermore, the experiences of younger autistic children who attend mainstream primary schools are significantly underrepresented in the literature, especially those who do not meet the criteria for specialist support and resources.

The research in this thesis aimed to address this gap in the literature and amplify the voices of autistic children by conducting an inductive qualitative investigation into the subjective everyday experiences of autistic children in mainstream primary schools in England. Specifically, the research focused on autistic children without access to specialist support or resources and took a neurodiversity-affirming approach to exploring how such children describe and make sense of their everyday experiences of mainstream primary school.

In total, three studies were conducted which provided insight into the everyday experiences of autistic children in mainstream primary schools from three different viewpoints: 1) from the perspective of the extant qualitative literature, 2) from the perspective of autistic young adults reflecting back on their primary school years and, 3) from the perspective of autistic children currently attending mainstream primary schools. The first study comprised a systematic review and metasynthesis of the extant qualitative literature relating to the everyday experiences of autistic children and young people in mainstream schools. The second study used a focus group methodology and thematic analysis to explore the reflections of autistic young adults on their primary school experiences. The final study used interpretative phenomenological analysis and creative methods to investigate the educational experiences of autistic children in mainstream primary schools in England.

The findings of these studies suggest that autistic children frequently feel overwhelmed by the pressures of spending long periods of time in an environment which is not only not designed for autistic ways of being, but in many ways can be overtly hostile towards them. The findings also suggest that the adaptations that could make school more accessible for autistic children are likely to be environmental, cultural and attitudinal rather than interventionist in nature.

Table of contents

Acknowledgements ii

Declaration of original authorship iv

Abstract v

Table of contents vi

List of tables x

List of figures xi

List of acronyms xii

Preface xiii

- Origin of this thesis xiii
- Structure of the thesis xv

Chapter 1: Introduction 1

- 1.1. Conceptual and theoretical context 2
  - 1.1.1. The medical model of disability 2
  - 1.1.2. The social model of disability 4
  - 1.1.3. The neurodiversity paradigm 5
  - 1.1.4. The double empathy theory 7
  - 1.1.5. The minority stress model 8
- 1.2. Educational context 9
  - 1.2.1. A brief history of the Special Educational Needs and Disabilities (SEND) system in England 9
  - 1.2.2. Key educational experiences and outcomes for autistic children 12
- 1.3. Rationale for and aims of this research 17
  - 1.3.1. The lack of young autistic voices in autism research 17
  - 1.3.2. Research aims 18

Chapter 2: Methodological considerations 20

- 2.1. Introduction 20
- 2.2. The 'big Q' approach 21
- 2.3. Reflexivity and positionality 22
- 2.4. Ethics 24
  - 2.4.1. Informed consent 24

2.4.2. Privacy, confidentiality and anonymity 25
2.4.3. Minimising harm 25
2.5. Quality and validity 27
2.5.1. Sensitivity to context 28
2.5.2. Commitment and rigour 28
2.5.3. Transparency and coherence 28
2.5.4. Impact and importance 29

Chapter 3: Study 1 - The experiences of autistic children and young people in mainstream schools - a qualitative metasynthesis 30

3.1. Introduction 30
3.2. Methods 31
3.2.1. Review strategy 31
3.2.2. Search strategy 32
3.2.3. Quality appraisal 34
3.2.4. Characteristics of included studies 35
3.2.5. Synthesis process 42
3.3. Results 43
3.3.1. Peer relationships 43
3.3.2. Academic factors 49
3.3.3. Environmental factors 53
3.3.4. Emotional impact 55
3.4. Update to 2017 findings 58
3.5. Discussion 60
3.5.1. Limitations 63
3.5.2. Implications for future research 64

Chapter 4: Study 2 - Autistic young adults' reflections on their mainstream primary school experiences 65

4.1. Introduction 65
4.2. Method 66
4.2.1. Design and rationale 66
4.2.2. Ethical considerations 66
4.2.3. Participants 67
4.2.4. Data collection 70
4.2.5. Data Analysis 71
4.3. Results 72

4.3.1. Parent and teacher groups 73
4.3.2. Autistic adult group 77
4.4. Discussion.. 84
4.5. Strengths and limitations 89
4.6. Conclusion and implications for the child study 90

Chapter 5: Study 3 - Autistic children's everyday experiences of mainstream primary school.. 92

5.1. Introduction 92
5.2. Methods 93
5.2.1. Design 93
5.2.2. Procedure 95
5.3. Results 113
5.3.1. Enduring a hostile sensory environment 113
5.3.2. Aloneness: enforced vs chosen 119
5.3.3. The vital importance of trusted guardians 127
5.4. Discussion... 136
5.5. Strengths and limitations 141
5.6. Implications for future research 142

Chapter 6: Discussion 143

6.1. Summary of research conducted 143
6.1.1. Review of study 1 143
6.1.2. Review of study 2 144
6.1.3. Review of study 3 145
6.1.4. Cross-study findings..146
6.2. Research aims and contribution made by this research 150
6.3. What do these findings mean in relation to theory?..................................... 151
6.4. Implications for educational practice and policy 154
6.5. Strengths and limitations 158
6.6. Recommendations for future research.. 161
6.7. Conclusion 161

References..163

Appendices 190

8.1. Appendix A: Potentially ableist terms and discourse that commonly appear in autism research and suggested alternatives - Bottema-Beutel et al. (2020, p. 20) 190

8.2. Appendix B: Study 1 supplementary material 191

8.2.1. COREQ checklist: items and guide questions 191

8.2.2. COREQ checklist: scores for included papers 193

8.2.3. Summary of the characteristics of papers found in the 2022 updated literature search 194

8.3. Appendix C: Study 2 supplementary material 200

8.3.1. Recruitment sheet 200

8.3.2. Information sheets 201

8.3.3. Consent form 207

8.3.4. Focus group visual guide 208

8.4. Appendix D: Study 3 supplementary material 212

8.4.1. Recruitment sheet 212

8.4.2. Information sheets 213

8.4.3. Consent and permission forms..220

8.4.4. Child information pack 222

8.4.5. Selection of submitted creative materials...231

List of tables

Table 1: Metasynthesis search terms 32

Table 2: Characteristics of studies in the metasynthesis 37

Table 3: Participant demographics - autistic adults 69

Table 4: Participant demographics - parents 69

Table 5: Participant demographics - teachers 69

Table 6: Child study inclusion criteria 97

Table 7: Child study participant characteristics 99

Table 8: The four quality indicators of good IPA (from Nizza et al., 2021) 104

List of figures

Figure 1: PRISMA diagram of the study selection process for the metasynthesis 34

Figure 2: Analytical themes developed from the metasynthesis 43

Figure 3: Seven-stage procedure for the child study 96

Figure 4: Worked example of IPA exploratory noting 105

Figure 5: Worked example of IPA linguistic noting 106

Figure 6: Worked example of IPA conceptual noting 106

Figure 7: Constructing IPA experiential statements 107

Figure 8: Searching for connections across experiential statements 108

Figure 9: Naming, consolidating and organising the Personal Experiential Themes 109

Figure 10: Continuing the individual analysis of the other cases 110

Figure 11: Developing Group Experiential Themes across cases 111

Figure 12: Themes and subthemes generated for child study 113

List of acronyms

BPS	British Psychological Society
COREQ	Consolidated Criteria for Reporting Qualitative Studies
DfE	Department for Education
EHCP	Education Health and Care Plan
IPA	Interpretative Phenomenological Analysis
PE	Physical Education
SENCO	Special Educational Needs Co-ordinator
SEN/D	Special Educational Needs/and Disabilities
TA	Teaching Assistant

Preface

Origin of this thesis

The aim of this thesis is to develop a deeper understanding of the lived experiences of autistic children in mainstream primary schools from the perspective of autistic children themselves. As such, it seeks to foreground and amplify the voices of autistic children by documenting their descriptions of what it means to be autistic in an environment designed predominantly by and for non-autistic people.

My interest in this subject stems primarily from my experience of being a mother to two autistic children. In the twelve years since my children first started school, I have learned that the cliché of 'your school years are the best years of your life' does not necessarily reflect the experiences of many autistic children. I have come to this understanding through witnessing my own children's difficulties and through my extensive work with parents and teachers.

I have worked for a charity called Parenting Special Children for nearly ten years and in that time I have met thousands of parents and carers of autistic children, the majority of whom have had a near-constant struggle trying to secure a suitable education for their children. The deep and far-reaching impact of these struggles – on the child, their family, and their wider community – never ceases to astonish me, no matter how many times I hear them repeated.

I also work for the Charlie Waller Trust (a national mental health charity) and have spent periods of my career as a full-time and sessional lecturer in the schools of education at Oxford Brookes University and The University of Reading. In each of these roles I have worked with teachers and school staff to enhance their abilities to meet the needs of autistic children and young people, but again, this work has most often been set against a backdrop of autistic distress, be that in the form of academic underachievement, poor mental health or social isolation and exclusion.

I have met many committed and dedicated people who want to improve autistic children's educational experiences and are keen to learn how they can personally make a positive difference. However, despite the very best of intentions, I have observed over the years that the conversations about how to make these positive differences have tended to take place between adults; adults who are usually non-autistic and have limited access to the autistic experience. Whether these conversations are taking place at school between teachers and parents, at academic research conferences, or at local and national government level, autistic children are not usually meaningfully included in the discussion. Despite the volume and range of 'experts' involved in a conversation that has been ongoing for at least the last 50 years, arguably the true experts, autistic children, have rarely been invited to participate.

My outrage at the injustice of this and the sometimes catastrophic consequences of not listening to autistic children is what has fuelled the research in this thesis. I ardently believe that if we want to know how to create schools where autistic children can thrive rather than simply survive (or not, as is tragically sometimes the case), we need to be led by them. We need to learn how to ask the right questions and we need to listen carefully to the responses. I attempted to do both in the work which follows.

Structure of the thesis

This thesis consists of six chapters. Chapter 1 introduces the conceptual and theoretical frameworks for the research contained within this thesis and it establishes the educational context in which this investigation is situated. It begins with a discussion of some of the key terminology used throughout this work before moving on to a brief history of school provision for children and young people described as having 'Special Educational Needs and Disabilities' (SEND). After introducing the different levels of school support provided to such children under current legislation, it then moves to a review of the literature documenting autistic children's school experiences and outcomes in relation to academic attainment, exclusions, bullying, social isolation and mental health. Chapter 1 ends by highlighting the need for more research involving autistic children before discussing the overarching aim of this investigation: to explore how autistic children in mainstream primary schools who do not have access to specialist support or resources describe and make sense of their everyday school experiences.

Chapter 2 outlines the ontological, epistemological and methodological perspectives of this research. It makes the case for why a constructivist qualitative approach was most appropriate for this investigation, and in accordance with the qualitative sensibility, it contains a discussion of my positionality as a researcher including what I have brought to this project and how I have shaped it. It then moves on to discuss the overarching ethical considerations which apply to all three studies before introducing the framework used to ensure that the research conducted was valid and of high quality.

Chapter 3 begins by establishing the rationale for my first study - a metasynthesis of the relatively small number of qualitative studies into the subjective autistic school experience. It describes the steps taken to conduct the literature search and assess the quality of included papers. After outlining the characteristics of the included studies, it then describes how the data were coded and synthesised in order to construct the overarching themes. The findings of this study indicated that mainstream schools can present considerable challenges for autistic children specifically in terms of establishing rewarding social relationships, overcoming barriers to accessing neuronormative pedagogical practices and coping with sensory discomfort stemming from poor environmental fit. The cumulative effect of these challenges also had a significant emotional impact on many of the participants in these studies.

Chapter 3 continues with a brief review of papers published since the metasynthesis was conducted in 2017 before moving on to assessing the limitations of the study. The chapter ends with a discussion of how the findings of both the initial search and the 2022 update identified that most of the extant literature involves children and young people of secondary school age and/or those with access to specialist support or autism-specific resources. In doing so, these combined reviews highlighted the lack of research into the lived experiences of autistic children in mainstream primary schools who do not meet the criteria for specialist support, thereby providing strong justification for the following two studies in this thesis.

Chapter 4 details the second study in my investigation – a focus group study with autistic young adults, and parents and teachers of autistic children in mainstream primary schools. It describes how this study was designed to help me identify the most salient aspects of the autistic primary school experience in preparation for my third and final study involving young autistic children. After discussing the decision taken to focus exclusively on analysing the data from the autistic adult group, the findings are presented showing that the participants' primary school experiences were characterised by feeling undesirably different, being bullied by peers and teachers, and by feeling under pressure to behave as close to expected behavioural norms as possible, despite the resultant stress and fatigue. The chapter ends with a discussion of the impact this study had on my understanding of the autistic school experience and how the findings of this study were pivotal in the development of the third study.

Chapter 5 details the third and final study in this investigation – an interpretative phenomenological analysis of autistic children's everyday experiences of mainstream primary school. After a discussion of the how the methods employed in this study were well suited to the research aims, the chapter describes the design of the study which included photo-elicitation and other creative methods. After detailing how participants were recruited, the chapter then moves on to describe how the data were analysed and how poetic transcription was used in the construction of the theme names. The three group experiential themes are then described with detailed participant quotations exemplifying the interpretations made. The findings indicated that the participants' everyday experiences of mainstream primary school were characterised by a high degree of challenge which took significant personal resources to overcome. The chapter ends with a discussion of these findings in relation to the literature, especially in terms of autistic burnout.

This thesis concludes with a discussion of all three studies in chapter 6. The chapter begins with a brief review of each study before moving to discuss the cross-study findings. The chapter then moves to on consider the extent to which the research conducted has met the overarching research aims of this thesis, and what contribution it has made to our understanding of the everyday school lives of autistic children in mainstream primary schools. This contribution is then discussed in relation to theory and professional practice. Finally, the chapter ends with a consideration of the strengths and limitations of the research before making recommendations for future research. Thereafter, references are provided followed by supplementary information in the appendices.

1. Chapter 1: Introduction

The research in this thesis centres on the lived experiences of autistic children in mainstream primary schools and in doing so, it conceptualises autism in a specific way. To provide context for this conceptualisation, to explain my ontological position, and to describe the lens through which I interpret the data in my research, I begin this thesis with an overview of the conceptual and theoretical frameworks within which my research is located. I will then move on to consider the current educational context essential to understanding the implications of this research.

Prior to this, however, I would like to explain the language choices I have made in my writing. The terms *disability* and *disabled* are used in relation to autism and autistic people throughout this work. This is due to the fact that autism is considered a disability in education policy and practice in England (Department for Education and Department for Health, 2015). In turn, this places autistic children in a specific category of person which has implications for their experiences of school. However, it is important to acknowledge from the outset that this is not a straightforward consideration and questions exist around whether such definitions benefit so-labelled citizens or simply serve to marginalise and oppress those whose bodies and minds differ from social and medical norms (Goodley, 2016).

It is also important to acknowledge that while there are autistic people who identify with the description of *disabled*, there are others who do not (Kenny *et al.*, 2016). In considering this issue, I am reminded of the words of one of my neurodivergent students who once remarked during a seminar discussion on this subject, ‘I have a disability, but I am not necessarily disabled.’ Her comment highlights the problematic nature of binary distinctions of ability/disability particularly when externally imposed. It is for this reason that I would like to make clear from the beginning of this thesis that while my investigation into the experiences of autistic children in English schools is necessarily interwoven with the legislative and education policy frameworks relating to disability, I am aware that distinctions made within these policies may not reflect how all autistic people see themselves and are not intended to speak directly to anyone’s chosen identity.

This thesis also uses identity-first rather than person-first language, i.e. *autistic child* rather than *child with autism*. This is in light of indications that identity-first language is preferred by autistic people in the UK since it is indicative of the inseparability of autism from the person and reflects a more empowering view of autistic identity (Kenny *et al.*, 2016). It is worth noting, however, that recent research conducted with autistic people in the Netherlands has shown a preference for person-first language suggesting that expression of identity may be subject to cultural and geographical differences (Buijsman *et al.*, 2022). Nevertheless, the decision to use identity-first language has been made in an attempt to respect the wishes of the UK autistic community with which my research arguably most closely relates, but I recognise that this may not reflect the views of individual autistic people.

In terms of how I have referred to people who are not autistic, the binary distinction in the much of the autism literature between autistic and *neurotypical* people is, to me, a misleading and unhelpful dichotomy given the many ways in which a person can be neurodivergent and multiply-neurodivergent (Chapman, 2020). To be non-autistic should not imply that one is typical, and I prefer the more socially rooted distinction made by Walker (2021) between *neuromajority* and *neurominority* groups. However, to simplify my writing, I have chosen to use the terms *autistic* and *non-autistic* when making comparisons between autistic people and those whose innate ways of being most closely conform to accepted societal norms. In doing so, however, I accept that there are aspects of the range of human experience that I am overlooking in favour of simplicity of presentation.

1.1. Conceptual and theoretical context

As previously mentioned, much of the work in this thesis is intertwined with concepts of disability which are embedded in educational policy in England. I am interested in how these concepts impact on the everyday school experiences of autistic children, and theoretical models provide a helpful vehicle for this intellectual exercise. Although models may be most frequently discussed in the realm of academic inquiry, they have “a pervasive influence in the lives of disabled people” (Smart, 2009, p. 3) in terms of the powerful ways in which they influence social, political, economic and educational discourse. There have been many different models reflecting the social conditions and understandings of disability at various points in history (See Retief & Letšosa, 2018 for an overview), but for the purposes of the present inquiry, I will focus on three models which are most relevant to the investigation detailed in this thesis: the medical model, the social model, and the neurodiversity paradigm.

1.1.1. The medical model of disability

Put simply, the medical model of disability is one that makes a distinction between *normal* and *abnormal* development. It locates disability within the individual, and differences tend to be viewed as “defect[s] in or…failure[s] of a bodily system that is inherently abnormal and pathological" (Goodley, 2016, p. 7). Seen through this lens, deviations from accepted physical and psychological norms are deemed as in need of rehabilitation, treatment, and ideally a cure (Goodley, 2016). Viewed in this way, disability can be seen as a personal tragedy (Swain & French, 2000), and in the case of disabled children, a tragedy akin to bereavement:

> *"'We are still grieving for the loss of the child we thought we were going to have" (Leadbitter et al., 2020, p. 2136)*

The medical model has historically dominated the autism narrative. From the earliest descriptions of autistic children, they have been described in terms of innate deficiency:

> *"…these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps."*
> *(Kanner, 1943, p. 250)*

Furthermore, this perception of deficit has long been a primary theme in the autism literature. From notions of feeble-mindedness and retardation in the 1920s (Waltz, 2013), theories of psychological disturbance in the 1940s (Asperger, 1943/1991; Kanner, 1943), and interpretations of autism as brain damage in the 1960s (Rimland, 1964). In more recent decades, and in line with technological and scientific advancements, there has been a shift in focus to identifying genetic biomarkers of autism (Anwar *et al.*, 2018; Loth *et al.*, 2017), an area of research couched in the language of risk and burden.

Arguably central to these deficit-led understandings of autism are the two core diagnostic manuals used by clinicians and others to identify autism: the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013), and the International Classification of Diseases (ICD-11)(World Health Organization, 2022); the latter of which described autism as recently as 2019 as belonging to a group of *pervasive developmental disorders* which could be "characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations" (Word Health Organization, 2019).

1.1.2. The social model of disability

However, an autistic-led resistance to these medicalised conceptualisations of autism has been steadily growing since the advent of the social model of disability in the latter part of the 20th century. The social model of disability takes a neutral stance on impairment and separates differences of mind and body from experiences of disablement. Rather than locating disability within the individual, the social model maintains that disability is a social construction resulting from oppression and marginalisation. First proposed by the Union of the Physically Impaired Against Segregation, a group of disabled activists based in the UK in the 1970s, their publication *Fundamental Principles of Disability* stated:

> *"In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression." (UPIAS, 1975, p. 14)*

These early members of the disability rights movement considered the tragedy narrative put forth by the medical model as a further form of oppression and rejected the idea of paternalistic "experts and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the psychology of impairment. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to – far better than any able-bodied expert" (UPIAS, 1975, pp. 4-5). They particularly objected to the medicalisation of disability which synonymised impairment with illness and framed a person's disability as the source of their difficulties. Instead, their proposed social model aimed to shift the focus from the individual to the societal; to identify and dismantle discrimination and oppression, and the creation of enabling rather than disabling environments (Oliver, 2009).

1.1.3. The neurodiversity paradigm

With the advent of the internet in the early 1990s, members of the autistic rights movement began to connect and organise in novel ways afforded by this new technology. Building on ideas from the social model with the aim of challenging medicalised understandings of autism, Australian sociologist Judy Singer, proposed the term *neurodiversity* in 1998 to describe the "emerging social movements for civil rights for people with various devalued, medically labelled neurological conditions" (Milton *et al.*, 2020, p. 3). Inspired by the social model of disability but wary of its "cultish, fundamentalist tendencies" (Singer, 2017, p. 14), Singer proposed a new model that would augment the social model by recognising and celebrating neurodivergence while not rejecting the role that science and technology had played in shaping modern understandings of autism. In doing so, she argued that "it was medical researchers…who laid the foundation that allowed autistic people and families to recognise each other and form their own movement. It was neuroscience that legitimised us…"(Singer, 2017, p. 14).

The concept of neurodiversity has been interpreted in different ways over the intervening years and, being still very much in its infancy as a social movement, is the subject of much debate (Bailin, 2019; Ballou, 2018; Baron-Cohen, 2019; Kapp *et al.*, 2013). However, it is rooted in the idea that a 'normal' brain is a social construction and neurological difference is not only as natural a form of human diversity as, say, differences in ethnicity and sexuality, but is also necessary to cultural stability. In this way, the concept of neurodiversity is at the heart of a social justice movement which actively challenges the deficit model of autism (and other neurological differences such as attention deficit hyperactivity disorder and dyslexia) by "reclaim[ing] one's neuro-status as a possible position from which to claim resources, representation and recognition" (Stenning & Rosqvist, 2021, p. 1535).

The issue of resources is particularly important in the distinction between the neurodiversity movement and the social model of disability as it was first conceived in the 1970s. In line with Singer's original proposition, the neurodiversity movement does not suggest that all difficulties experienced by autistic people are the result of poor environmental adaptations. Instead, it emphasises that the most distressing experiences of disablement often stem from "living in a society which tends to be physically, socially and emotionally inhospitable towards autistic people" (den Houting, 2019, p. 271). The neurodiversity movement recognises that many autistic people require access to assistance and support, but in contrast to the normative interventionism of the medical model, neurodiversity is rooted in the idea of self-determined support which enables people to live life fully and authentically according to their own choices, preferences and aspirations, as opposed to any principle which results in making autistic people, in the words of behaviourist Ivar Lovaas, "indistinguishable from their normal friends" (Lovaas, 1987, p. 6).

In her essay 'Throw away the master's tools: liberating ourselves from the pathology' first published in 2012, autistic scholar and activist Walker called for the principles of the neurodiversity movement to be extended. She argued for a shift from what she referred to as the *pathology paradigm* to the *neurodiversity paradigm*. She claimed that this shift was necessary for the "long-term well-being and empowerment of autistics and other neurocognitive minority groups" (Walker, 2021, p. 13) and called for:

> *"…a shift in our fundamental assumptions; a radical shift in our perspective that requires us to redefine our terms, recalibrate our language, rephrase our questions, reinterpret our data, and completely rethink our basic concepts and approaches." (Walker, 2021, p. 14)*

Unsurprisingly, these concepts have been subject to criticism, namely that the neurodiversity paradigm tends to be articulated in ways that are most relevant to those autistic people with less obvious differences or lower support needs (Jaarsma & Welin, 2012), and that it potentially perpetuates an unhelpful division between neurominority and neuromajority groups (Runswick-Cole, 2014). However, despite these criticisms, there is an increasing understanding in mainstream autism research that historical approaches to studying autistic people are stigmatising and a shift is needed. Autistic scholars have led the way in highlighting ableist and oppressive aspects of autism research (e.g. Botha & Cage, 2022; Milton, 2014a; Raymaker, 2020), and there is a growing awareness among prominent non-autistic researchers of the need to change how autism research is conceptualised, conducted, and disseminated (e.g. Happé & Frith, 2020). From the potentially harmful singular focus on deficits to the lack of meaningful participation of autistic people in research, mainstream autism research is starting to take a more neurodiversity-affirming approach (Bottema-Beutel *et al.*, 2020; Fletcher-Watson *et al.*, 2019; Nicolaidis, 2012; Pellicano & den Houting, 2022).

My research aims to travel in this new direction by employing Walker's principles of the neurodiversity paradigm to provide an alternative to deficit-based ways of thinking about the school experiences of autistic children. While I will discuss my methodology in more detail in the next chapter, I will be using the neurodiversity paradigm to consider how autistic children's neurominority status plays out in a system largely set up for and by those in the neuromajority. In addition to the model described above, I will also be using two theoretical frameworks developed by autistic scholars to inform the interpretation of the data contained within the studies which follow.

1.1.4. The double empathy theory

Despite the growing awareness of the concept of neurodiversity in autism research, medicalised understandings of difference remain dominant in society and particularly within our education system (Department for Education and Department for Health, 2015). Perhaps as a result of the combination of these entrenched views and the ways in which behavioural norms are more rigorously enforced in childhood (DfE, 2022a) , many of the difficulties experienced by autistic children are usually attributed to pathologised interpretations of their innate ways of interacting (National Autistic Society, 2021). This has led to a model of autism support in schools in which the child may be subject to a range of formal (e.g. various forms of therapy, social skills programmes) and informal interventions (e.g. correction by others, disciplinary action), some with the aim of reducing autistic behaviours in favour of non-autistic behaviours (L. Arnold *et al.*, 2021).

However, the idea that autistic communication and interaction is defective and in need of modification has been challenged by autistic people for many years (e.g. Baggs, 2007; Sinclair, 1993/2012). This challenge has been theorised as the 'double empathy problem' (Milton, 2012a). This theory posits that instead of autistic interaction being *wrong* and non-autistic interaction being *right*, they are both simply different. Each has its own value and integrity but the distinct differences between them can lead to mutual misunderstanding during interaction between autistic and non-autistic people. Milton goes on to explain this as "a 'double problem' because both people experience it, and so it is not a singular problem located in any one person" (Milton, 2012a, p. 884). However, due to the power imbalances between autistic (neurominority) and non-autistic people (neuromajority), any difficulties or misunderstandings are generally attributed to the autistic person. This leads to the belief that it is autistic people who need to adjust their behaviour to more closely match the conventions and expectations of non-autistic people who, in turn, are not usually required to make adjustments because, according to the medical model, how they behave is not subject to the same scrutiny since it is considered the accepted norm.

There is growing research evidence in support of the double empathy theory. It has been found that communication is more efficient between groups of autistic people compared to mixed groups of autistic and non-autistic people (Crompton *et al.*, 2020). This suggests that autistic people may have a unique communication style which non-autistic people have difficulty interpreting. Additionally, it has been found that non-autistic people tend to make rapid social judgements (in fewer than 10 seconds) about autistic people, rating them unfavourably on measures such as likeability and attractiveness (Sasson *et al.*, 2017), thus potentially compounding social difficulties in mixed groups.

1.1.5. The minority stress model

The idea of autistic people constituting a minority group who are frequently misunderstood and viewed unfavourably by non-autistic people feeds into the second theoretical concept used in my interpretations. As will be explored in more detail later in this chapter, autistic people are much more likely to experience mental ill health than non-autistic people (Lai *et al.*, 2019). In line with medicalised conceptualisations of autism, such mental health difficulties have historically been explained as intrinsically connected to autistic impairments such as neurobiological ‘abnormalities’ (Baron-Cohen *et al.*, 2000), difficulties in understanding emotions (South *et al.*, 2005), and as a consequence of social skills ‘deficits’ (J. J. Wood & Gadow, 2010).

However, due to the shifts in thinking associated with the neurodiversity paradigm, alternative explanations for autistic distress are beginning to be explored. Rooted in the idea of autistic people constituting a neurominority, Botha and Frost (2020) argue that models previously used to understand the impact of stress on other marginalised groups e.g. sexual and ethnic minorities (English *et al.*, 2018; Frost *et al.*, 2015; Meyer, 2003) may provide insight into how stress affects the health and wellbeing of autistic people. Accordingly, minority stress is defined as the cumulative effects of a range of social stressors caused by the marginalisation of minority groups by mainstream society (Meyer, 2003). Within the specific context of autistic people’s experiences, Botha and Frost (2020) found that:

> *"Minority stressors such as victimization and discrimination, everyday discrimination, expectation of rejection, outness, internalized stigma, and physical concealment of autism consistently predicted diminished well-being and heightened psychological distress" (Botha & Frost, 2020, p. 28)*

These findings highlight the role that social stressors and stigma play in autistic distress – a consideration rarely made in the psychology literature which has historically tended to focus on within-person interventions (e.g. Lang *et al.*, 2010; Menezes *et al.*, 2020). While not wishing to detract from the value of such research, not least because autistic people themselves have called for more research on and better access to appropriate psychological interventions (Camm-Crosbie *et al.*, 2019; L. Jones *et al.*, 2014; Roche *et al.*, 2021), the impact of social stressors on autistic wellbeing is a rarely considered but important dimension of any discussion of the autistic experience.

These models and theoretical concepts have made a significant contribution to my foreunderstandings of the social determinants of autistic experiences and, as will be discussed in more detail in subsequent chapters, have played a central role in how I have designed, conducted, and interpreted the research contained in this thesis.

1.2. Educational context

Having outlined the conceptual and theoretical frameworks which underpin this research, I will now move on to consider the educational context in which my research is situated. This begins with a brief history of English policy related to the education of autistic children before moving on to an overview of the key educational experiences and outcomes for autistic children in England.

1.2.1. A brief history of the Special Educational Needs and Disabilities (SEND) system in England

In 1974, educationalist Mary Warnock was appointed to chair a review of "educational provision in England, Scotland and Wales for children and young people handicapped by disabilities of body or mind" (Warnock, 1978, p. 1). Her resulting report was influential in the development of the 1981 Education Act which mandated two pioneering changes in the UK education system: 1) a shift in focus from provision made according to diagnostic labels to individual learning needs, thereafter referred to as 'special educational needs' and, 2) the right for disabled children to be educated in mainstream schools, which had previously not been legally established meaning that many disabled children were educated in segregated settings or not at all (Wearmouth, 2017).

Since that time, English governmental policy has increasingly focused on inclusive education - a much-debated concept (De Bruin, 2020; Slee, 2018; Warnock & Norwich, 2010) that for the purposes of this thesis relates to the policy of educating disabled children alongside non-disabled children wherever possible. In this sense, English education policy aligns with similar trends internationally towards a less segregated approach to state education and society more broadly (United Nations, 2006; UNESCO, 1994).

Since Warnock's review, there have been several reforms to Special Educational Needs (SEN) legislation in England aimed at realising this inclusive ideology, the most recent of which resulted in the passing of Children and Families Act (2014) into law. In section 20, part 1, the Act defines a child as having SEN if they have "a learning difficulty or disability that calls for special educational provision to be made for them". In turn, special educational provision is defined in section 21, part 1, as "educational or training provision that is additional to, or different from, that made generally for others of the same age". However, what constitutes a learning difficulty or disability is highly contentious (Cluley, 2018; Kavale & Forness, 2000), and there has been concern around the accuracy of identification of SEN and provision of consistently high-quality support for so-labelled children and young people (Hutchinson *et al.*, 2021; Ofsted, 2010).

Furthermore, it is arguable that despite the inclusive aims of the English education system, the principle of 'different from and additional to' may underline a tendency in policy and legislation to continue to separate the perceived atypical from the typical. This notion is also evident in the guidance provided to schools in the form of the Special Educational Needs and Disability Code of Practice (Department for Education and Department of Health, 2015) which identifies SEN based on how far a child may have deviated from an expected developmental trajectory determined by peers of similar chronological age.

The theme of separation also continues to the support itself which is divided into two categories: SEN Support and Education Health and Care Plans (EHCPs). SEN Support is largely teacher-led and typically refers to adjustments that utilise the resources, equipment and expertise that are generally available to all pupils within a school. According to the DfE

(2022g), 12.6% of children and young people in English state-funded schools in the 2020/21 academic year received SEN Support.

EHCPs are provided to children and young people who are perceived as having needs which extend beyond what is possible to meet with SEN Support. EHCPs place a legal responsibility on Local Authorities to consult with a range of allied professionals including those from the health and social care sectors to assess and specify a pupil's special educational needs. The assessment process must include input from an educational psychologist and a health professional (e.g. paediatrician) but also typically involves specialists from other disciplines depending on the child's specific profile of strengths and difficulties. According to the Special Educational Needs and Disability Regulations (2014), Local Authorities have a statutory duty to make the provision required to meet the needs identified in the assessment process, and review a child's plan annually according to a legally-defined protocol. EHCPs can remain in place from birth until the young person reaches the age of 25.

The decision to issue an EHCP rests on whether the child's needs "can reasonably be provided from within the resources normally available to mainstream early years providers, schools and post-16 institutions" (Department for Education and Department of Health, 2015, p. 158), and it is often the case that mainstream schools are determined as being insufficiently specialised to meet the needs of children with EHCPs. This is borne out by data from the DfE (2022g) which shows that while 4% of all children and young people in English state-funded schools in the 2020/21 academic year were in receipt of an EHCP, this figure rose to 98% of children and young people in special schools[1].

Thus, EHCPs are not common in mainstream settings with just over 2% of children in mainstream primary and secondary schools in receipt of such support (DfE, 2022g). These data relate to all children and young people in English state schools with identified SEND, but when looking at the statistics specifically relating to autistic children, there is a different split between levels of support and type of setting. Of the 162404 identified autistic children in the English state education system in 2020/2021, 72% were educated in mainstream settings with around 75% accessing SEN Support and the remaining 25% in receipt of EHCPs (DfE, 2022g).

While outside the remit of this thesis, it is important to note that this approach to SEND provision has attracted a great deal of criticism and there is much dissatisfaction with the

---

[1] Special schools are those defined by the Education Act (1996) as "specially organised to make special educational provision for pupils with SEN"

current system (see Ahad *et al.*, 2022 for a review), particularly with regard to those children and young people who do not meet the criteria for an EHCP. After consulting with a range of stakeholders from across the special education sector in 2019, the Government's Education Select Committee concluded:

> *"Many of the 1.3 million school-age children in England who have special educational needs and disabilities (SEND) are not getting the support that they need. This is a failure that damages their education, well-being and future life chances. Half of the local authority areas inspected are not supporting children and young people with SEND as well as they should […] Education, health and care plans have become a 'golden ticket' that parents fight for to secure access to adequate support for their children. Children with SEND but who do not have EHC plans risk missing out on the support they need, especially in mainstream schools that are under significant financial pressure." (House of Commons, 2019)*

Thus, when considering the statistics above which show that the majority of autistic children in England are educated in mainstream schools without the support of an EHCP, it is perhaps unsurprising that many such children have impoverished school experiences and educational outcomes. Key aspects of these experiences and outcomes will now be introduced with the aim of providing context for the rationale for my research.

1.2.2. Key educational experiences and outcomes for autistic children

1.2.2.1. Academic attainment

Autistic children in mainstreams schools tend to be of average or above average intelligence (Public Health England, 2022) and by virtue of their placement in a mainstream rather than special school, all have been determined by their Local Authorities as capable of accessing a mainstream education with support where required as set out in the SEN Code of Practice (Department for Education and Department of Health, 2015). Therefore, one might expect that the attainment data for this particular group of children would be more or less in line with national averages.

However, the attainment gap between autistic and non-autistic children and young people is long-standing and well documented (Keen *et al.*, 2016; Kim *et al.*, 2018; Mayes & Calhoun, 2007). At the time of writing, the 2022 key stage 2 (year 6 SATs) and 4 (year 11 GCSEs) attainment data has not yet been published and figures during the height of the Covid-19 pandemic are not necessarily reliable due to the disruption caused by school closures and exam cancellations and adaptations. However, the last set of reliable pre-pandemic figures show that 32.5% of autistic children achieved the equivalent of five A* - C grades at GCSE in 2018/2019 compared with 63.9% of the general school population in the same period (DfE, 2020a). An even wider attainment gap existed at the end of Key Stage 2 (year 6) with 25% of autistic children reaching expected levels in reading, writing and maths compared with 70% of the general school population in the same academic year (DfE, 2019).

The causes for this disparity have not been clearly identified but previous research has highlighted a number of potential factors including an uneven academic profile in autistic learners (Griswold *et al.*, 2002; C. Jones *et al.*, 2009). It has been argued that this ‘spiky profile’ is often not fully identified and understood by educators resulting in subtle differences in communication, memory, information processing and sensory processing going unrecognised and unsupported (Ashburner *et al.*, 2008; Fleury *et al.*, 2014; Milton, 2012b). It has also been suggested that the ways in which academic attainment is measured (i.e. tests and exams) could disadvantage autistic students who do not consistently receive the adjustments required to make school tests fully accessible (R. Wood & Happé, 2020).

Furthermore, it is arguable that as schools have become progressively more focused on academic attainment, test results have become the most significant metric by which success is measured in schools (Bonell *et al.*, 2014). For children and young people who are less able to fully access such tests, this arguably has implications for mental health and wellbeing (Putwain, 2007; Sahlgren, 2018).

1.2.2.2. Formal, informal, and self-exclusions

In primary school, children regarded as having the highest level of needs spend the equivalent of more than a day a week away from their teacher, their peers, and the curriculum engaged in various out-of-class interventions. (Webster, 2022). These interventions are usually delivered by teaching assistants who have varying levels of training, support and access to resources (Blatchford *et al.*, 2012), and research indicates that while such approaches may be intended to provide greater support for individual learning needs, they may impact negatively on an autistic child’s social inclusion and their ability to work independently (Symes & Humphrey, 2012; Webster & De Boer, 2019).

In addition to being removed from the classroom for interventions, autistic children are more likely than their non-autistic peers to spend time out of the classroom due to reasons associated with perceptions of their behaviour. Formal exclusion in England falls under the remit of individual head teachers and takes two forms: fixed-term exclusions, which are temporary and can cover half or full days up to a maximum of 45 days per academic year, and permanent exclusions which require alternative school provision to be made for the child. Government statistics show that over half of all official exclusions in the 2021/2022 academic year were issued to children with identified SEND (DfE, 2022c), and research has shown that autistic children are three times more likely to be formally excluded from school than children without SEND (Hatton, 2018). The most common reason for exclusion is ‘persistent disruptive behaviour’ but parent advocacy groups argue that such behaviour is most often indicative of overwhelm caused by unmet need and call for a greater focus on appropriate school support to reduce such distress (Ambitious About Autism, 2022; National Autistic Society, 2021).

The same advocacy groups have also conducted research which shows a rise in unofficial exclusions. Despite being prohibited in government guidance provided to head teachers and school governors (DfE, 2022b), such unlawful exclusions include being sent home to ‘cool off’ when showing signs of distress or overwhelm, being excluded from school trips and extracurricular activities, being taught in isolation rooms, and being placed on part-time timetables due to lack of resources or staff. The extent of these exclusions is difficult to pinpoint because they do not feature in official statistics, but in a recent survey of 1867 parents, carers and autistic young people, 36% reported experiencing exclusions of this kind, with 20% of parents reporting having to give up work or reduce their working hours as a result of their child’s exclusion from school (Ambitious About Autism, 2022).

Aside from an obvious negative impact on learning and the restriction of access to academic and other support typically provided by schools (Guldberg *et al.*, 2021), there are concerns about the links school exclusion has with poor mental health. School exclusion has been associated with increased feelings of shame, rejection and alienation (Martin-Denham, 2020; R. Skiba *et al.*, 2006; R. J. Skiba, 2000), as well as negative impacts on mental and physical health which can continue long after the school years are over (Daniels & Cole, 2010).

However, access to school is not only restricted by active decisions made by school leaders. There is an increased awareness that there are some autistic children who find school so stressful that they are unable to attend regularly or at all, with possible links to burnout and exhaustion due to the unsuitability of the environment to their needs (Dalrymple, 2022; Totsika *et al.*, 2020).

1.2.2.3. Social isolation and bullying

Previous research suggests that central to the issue of attendance difficulties is the fact that autistic children and young people are considerably more likely to experience bullying, peer victimisation and social isolation than their non-autistic peers (Hebron *et al.*, 2015a; Maïano *et al.*, 2016). In fact, it has been reported that autistic children encounter greater social difficulties in school and experience lower peer acceptance and social inclusion than children with any other form of SEND (Chamberlain *et al.*, 2007; Symes & Humphrey, 2010). Consequently, they tend to spend considerably more time alone, have fewer friends than non-autistic children and children with other disabilities (Bauminger *et al.*, 2003; Dean *et al.*, 2017; Humphrey & Symes, 2011), and report feelings of loneliness and social dissatisfaction (Kasari & Sterling, 2013; Locke *et al.*, 2010).

It has been observed that social isolation can increase vulnerability to victimisation and bullying, and reviews of the literature suggest that autistic children are four times more likely to be bullied than non-autistic children (Sterzing *et al.*, 2012). Autistic children with more obvious behavioural differences are especially likely to be targeted by bullies (Hebron & Humphrey, 2014), as are those in mainstream rather than special schools (Rowley *et al.*, 2012; Zablotsky *et al.*, 2013). It has also been reported that the most common forms of bullying experienced by autistic children include teasing, name-calling and shunning (Adams *et al.*, 2014; Little, 2002), arguably all the more challenging to navigate for an autistic child who may already struggle to understand the complex neuronormative social rules of school (Myles & Simpson, 2001).

1.2.2.4. Mental health

It has been reported that frequent bullying is related to poor mental health, including increased anxiety and self-injury, and low self-esteem (Ashburner *et al.*, 2019; Cappadocia *et al.*, 2012) which may be compounded by an increased vulnerability of autistic children and young people to poor mental health more generally (Lai *et al.*, 2019). In particular, anxiety represents a considerable challenge for many autistic people and has been found to be the most commonly occurring psychiatric condition in autistic children and adolescents (White *et al.*, 2009). Reviews of prevalence rates indicate that around 40% of autistic children meet the clinical criteria for an anxiety disorder compared with around 14% of non-autistic children (Polanczyk *et al.*, 2015; van Steensel *et al.*, 2011).

Research has shown that anxiety may be more common in autistic children with average or above-average intelligence and manifests to a greater degree in adolescence. It has been suggested that this is because intellectually able autistic children develop a growing awareness of their difficulties as they become older and the pressures of meeting the social expectations of others can cause anxiety levels to increase (Gadow *et al.*, 2005; Simonoff *et al.*, 2008; Sukhodolsky *et al.*, 2008; White *et al.*, 2009).

Anxiety has also been found to relate in important ways to the differences in sensory processing experienced by many autistic people. It is estimated that between 65-80% of autistic children process sensory information differently to non-autistic children (Baranek *et al.*, 2006; Lane *et al.*, 2011; Leekam *et al.*, 2007; Tavassoli *et al.*, 2016). While some of these experiences can be enjoyable, others have been found to be distressing and can have a significant impact on wellbeing and quality of life (Acker *et al.*, 2018). In particular, oversensitivity to sensory information (e.g. light, sound, temperature etc.) has been associated with increased levels of anxiety (Carpenter *et al.*, 2019; Green & Ben-Sasson, 2010). Given the noisy crowded nature of most school settings, the sensory environment is an important consideration in the wellbeing of autistic children during their school years.

In summary, the research literature shows that autistic children are significantly more likely to experience a range of difficulties during their school years than their non-autistic peers. Their ways of learning and interacting are not always fully understood and supported, and many autistic children are formally or informally excluded from the everyday business of school, with negative consequences for their academic, social and psychological development. For some autistic children, self-exclusion or withdrawal is the only means of coping with the overwhelming academic, social and sensory demands of school.

Despite the inclusive ideology which underpins mainstream education policy in England, it would appear that autistic children frequently experience some form of exclusion. However, when looking to the literature for how young autistic children describe and make sense of these experiences, they appear to be excluded again as I will now go on to explain in the rationale for my research.

1.3. Rationale for and aims of this research

Having outlined the conceptual, theoretical and educational context in which this investigation is located, I will now go on to explain the rationale for the research detailed in this thesis.

1.3.1. The lack of young autistic voices in autism research

As highlighted in the previous section, a great deal is known about the challenges autistic children face during their school years. However, little has been documented about how autistic children experience and make sense of these challenges. Much of what is currently known about the autistic school experience comes from data collected from parents, carers and teachers (e.g. Ashburner *et al.*, 2010; Azad *et al.*, 2018; Hodges *et al.*, 2020; McDougal *et al.*, 2020). Few studies have engaged directly with the question of what it means to be an autistic child in a mainstream school environment. As Humphrey and Lewis (2008) remark, autistic children are “a group whom research is more often conducted on rather than with” (Humphrey & Lewis, 2008, p. 26).

It is arguable that autistic children’s involvement in much of the existing research has been on the basis of being passive subjects as opposed to active participants. It is possible that the relative scarcity of autistic voices in academic research is a consequence of the historical tendency in autism research to see autistic children as impaired communicators and unreliable narrators, unable to speak to their own experience. This notion that autistic children are unable to reflect on emotional experiences and motivations, or access emotional vocabulary (Frith & Happé, 1999; Lombardo *et al.*, 2007; Tavernor *et al.*, 2013) has arguably led to the assumption that the views of non-autistic caregivers and professionals offer a more valid account of the autistic experience than the views of autistic children themselves.

Not only has this view been called into question by studies in which autistic children have been shown to be able to reliably report on their own internal emotional experiences (e.g. Ozsivadjian *et al.*, 2013), it also contravenes the United Nations Convention on the Rights of the Child (1989) which states in Article 12 (respect for the views of the child):

> *"Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right applies at all times…" (UNICEF, 1989, p. 5)*

It may seem a stretch to consider autism research as coming under the UNICEF's banner of "all matters affecting them" but I would argue that autism research very much affects the everyday lives of autistic children. It has been observed that the omission of autistic voices in autism research excludes them from being "active participants in the production of knowledge on autism" (Milton & Bracher, 2013, p. 61). This knowledge informs the training of teachers, the support of families before, during and after the identification and diagnosis of autism, and the views of the communities and societies in which autistic children learn, develop and live, ultimately becoming part of how autistic children perceive themselves.

The same authors go on to note that the historical tendency to exclude the perspectives of autistic people from autism research "constitutes a significant barrier to impact" (Milton & Bracher, 2013, p. 61). Within the context of the impoverished educational experiences of autistic children outlined above, there is an urgent need for research that makes a significant and tangible impact. It is my view that research which amplifies and platforms autistic voices has the potential to contribute in these much-needed ways.

1.3.2. Research aims

As already discussed, there has been a propensity in autism research to access the school experiences of autistic children via their parents and teachers. Few studies have attempted to document the first-hand lived experiences of autistic children and as will be explored in detail in chapter 2, those that have, have tended to focus on the secondary school years and/or those children and young people with EHCPs or equivalent, with access to specialist support and resources.

Since around 75% of identified autistic children in state-maintained mainstream schools in England are not in receipt of an EHCP (DfE, 2022g) and only 7% of schools in England have specialist units or resourced provision[2] (DfE, 2022d), the published qualitative research does

---

[2] 'Specialist unit' and 'resourced provision' are terms defined by the Department for Education which refer to specialist buildings or services within mainstreams schools where pupils with SEN are taught separately for a significant portion of their time at school. They attract additional funding government funding and are usually only available to children and young people with EHCPs (DfE, 2022g).

not reflect the everyday experiences of most autistic children in mainstream primary schools in England. In fact, as the first study in this thesis will make clear, this is a population of children who have been vastly underserved by research to date.

To contribute towards this gap in the literature, my research aims to explore what it means to be an autistic child without an EHCP in a mainstream primary school who does not have access to specialist autism support or resources. It aims to investigate the everyday experience of being an autistic child in an environment that is largely designed by and for non-autistic people. I am interested in understanding the subjective experience of autistic children as expressed by them in their own words. The premise of “children are the best source of information about themselves” (Docherty & Sandelowski, 1999, p. 177) will be the guiding principle of this research project.

To this end, the following overarching aim forms the foundation for the research that follows:

- How do autistic children who do not have EHCPs or access to specialist resources describe and make sense of their everyday experiences of mainstream primary school?

2. Chapter 2: Methodological considerations

2.1. Introduction

As set out in the previous chapter, this thesis aims to explore what it means to be a young autistic child in a mainstream school. It does this by way of three separate studies: 1) a qualitative metasynthesis of the extant literature to establish what is already known about the autistic mainstream school experience, 2) a thematic analysis of reflections on the mainstream primary school experience of autistic young adults, and 3) an interpretative phenomenological analysis of the everyday school experiences of children currently enrolled in mainstream primary school.

While distinct in their data collection and analytical methods, all three studies are primarily concerned with how autistic people describe their everyday school experiences and what these experiences mean to them as individuals. I am interested in the "quality and texture" (Willig, 2021, p. 9) of those experiences and how they might contribute towards a richer understanding of what it is like to be an autistic child in a mainstream educational setting. It is for these reasons that my research has been conducted within a qualitative methodology. The specific methods used in these three studies are described in detail in each of the individual study chapters. This present chapter, however, details the key methodological considerations which underpin the whole research endeavour and provide the foundation to all three studies.

Despite having a long history and being integral to the work of such influential figures as Wilhelm Wundt, Sigmund Freud, and William James (Wertz, 2014), qualitative methods have traditionally been undervalued in psychology; a discipline which has tended to privilege positivist research practices concerned with establishing causal relationships at a population level by means of hypothetico-deductive methods (Henwood & Pidgeon, 1992). However, in recent decades there has been a growing interest in qualitative psychology, and the value of research into subjective individual human experiences is increasingly being recognised across the discipline (Sullivan & Forrester, 2018; Willig, 2021).

Within the specific context of autism studies, qualitative research is, while growing, still a minority endeavour with prominent journals such as *Autism* and the *Journal of Autism and Developmental Disorders* only beginning to recognise the value of qualitative approaches in recent years (Bölte, 2014; van Schalkwyk & Dewinter, 2020). The dominance of quantitative research in autism studies is undoubtedly connected with the larger issue of which kinds of research projects get funded and published. Autism research activity in the UK and the USA has mostly centred on biology, brain and cognition - areas of research typically associated with quantitative methods - with much less emphasis on research into services and societal issues (Pellicano *et al.*, 2014; Sweileh *et al.*, 2016).

This is in contrast to the priorities of the autistic community who have called for more research into areas that could potentially make a positive difference to their day-to-day lives, with particular focus needed on how public services can better meet the needs of autistic people (Pellicano *et al.*, 2013). Therefore, research which centres on autistic people's day-to-day lives seems to be a logical starting point in moving towards addressing the research priorities of the autistic community. Qualitative methodologies are, in essence, concerned with investigating and describing human experiences at the level of the individual (Smith, 2015). As such, they are well positioned to contribute towards understanding more about what it *means* to be a young autistic child in a mainstream school – arguably an important point of departure when attempting to identify the ways in which one of our most important public services - our education system - could be improved to better support autistic children and young people to flourish.

2.2. The 'big Q' approach

The work conducted in this thesis falls under what has been referred to as the 'big Q' approach. First coined by feminist psychologists Kidder and Fine (1987), the term refers to inductive methodologies used flexibly to explore meaning within an interpretivist epistemology. This stands in contrast to 'small q' research which refers to the collection of qualitative data in an otherwise positivist design, e.g. open-ended questions in a questionnaire which are then quantitatively scored to aid measurement, prediction, or generality of a phenomenon (Willig, 2021).

Clarke and Braun (2022) maintain that to conduct high quality big Q research, one needs a *qualitative sensibility* - a set of skills and perspectives which influence every aspect of the research process. Central to this sensibility is the focus on meaning and the ability to question the prevailing cultural assumptions in society – "being a cultural commentator as well as a cultural member" (Clarke & Braun, 2022, p. 7). They go on to say that big Q research embraces complexity, contradiction, and uncertainty rather than setting out to find neat explanations. In doing so, big Q researchers accept that there is no one universal truth waiting to be discovered. Rather, we as researchers shape and inform every aspect of our research. As such, qualitative research requires researchers to actively and transparently engage with "the impossibility of remaining ‘outside of’ one’s subject matter when conducting research” (Willig, 2021, p. 11).

2.3. Reflexivity and positionality

As already discussed, much of the extant autism research in this field has been conducted within a positivist research paradigm; one which is predicated on the notion of a single observable, measurable reality in which the researcher and researched remain independent of one another. While such approaches are appropriate to address questions involving statistical interpretations of data, they are less well suited to understanding what life is like for autistic children or how social and educational experiences might impact a child's perception of their differences.

Therefore, the present investigation takes a constructivist approach; one which assumes that the production of knowledge inevitably involves different versions of reality depending on what one chooses to focus on and how one chooses to represent it (Ponterotto, 2005). In doing so, my research approach accepts not only the subjectivity of the participants' lived experiences, but also that meaning making is a process of co-construction between the researcher and the researched (Clark, 1998).

Essential to this co-constructive process are the interrelated concepts of reflexivity and positionality. Positionality “reflects the position that the researcher has chosen to adopt within a given research study” (Savin-Baden & Major, 2013, p. 71), and relates to the ways in which the researcher’s values and beliefs are shaped by their demographics and lived experiences (Holmes, 2020). Reflexivity is an ongoing and dynamic process in which researchers openly acknowledge and interrogate how their positionality has influenced and shaped their research, “exposing and questioning [their] ways of doing” (Hibbert *et al.*, 2010, p. 48). Rather than being discrete concepts, reflexivity and positionality are intertwined, ongoing and dynamic; changing and shifting as the research and researcher develops. They inform and are informed by each stage of the research project (Holmes, 2020).

Savin-Baden and Major (2013) suggest that positionality can be developed by the researcher locating themselves in the following three ways:

1. In relation to the subject under investigation.
2. In relation to the participants.
3. In relation to the research context (i.e. acknowledging that research will necessarily be influenced by the researcher and the research context).

In addition to these general points relating to best practices in qualitative research, Stone and Priestley (1996) point out that it is imperative that non-disabled researchers conducting research with disabled communities justify their position and “open up [their] research rationale to the widest possible scrutiny” (p. 700). They go on to say that this is important because:

> *“…the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world.” (Stone & Priestley, 1996, p. 700)*

Based on these principles, it is important for me to set out my position accordingly. As I have explained above, my primary relationship to this subject is personal. This means that the experiences of autistic children in mainstream primary schools hold a personal relevance for me in terms of the difficulties I have faced within my own family. My professional experience of supporting parents in similar situations also has a central role in my thinking about this subject and places me in a position of questioning whether mainstream schools are able to meet the needs of autistic children. However, I am aware that while my personal and professional experiences are commonly shared among other families of autistic children, they are not universal. There are autistic children who thrive in school and the experiences of my family and of those I have supported are not necessarily representative of all.

In terms of my position in relation to my participants, I am a white, middle-aged, middle-class, heterosexual, cis-gendered non-autistic autism researcher who has been funded to conduct this research by a well-respected academic institution. Many aspects of my identity represent significant social privilege, and these privileges have a bearing on how I conduct and interpret my research. Arguably the most important consideration in terms of this thesis is my role as a non-autistic autism researcher. This places me in the position of being part of the majority neurotype and not only is this important due to the specific ways in which the double empathy theory might play out in my work but it also has wider implications. The steps I took towards addressing these issues in my work are discussed in more detail in the ethics section below.

Finally, in terms of my position in relation to the research context, I am aware that even with the steps I have taken to ensure a commitment to prioritising and amplifying the contributions of my participants, as previously discussed, my own personal beliefs, values, and perspectives have influenced this work. I decided the aims and objectives of this work and its theoretical orientation; I designed, conducted and reported the studies; I interpreted and reflected on the meaning of the data and connected them to what I see as the wider issues. As a result, the work contained within this thesis is personally meaningful and there have been times in the research journey which have provoked strong emotional responses in me.

At the beginning of my studies, I mistakenly assumed that I would need to compartmentalise these responses in order to maintain a veneer of objectivity. However, the principles of the qualitative sensibility highlighted the central role these responses have in my research and encouraged me to engage directly with them to explore how they could contribute to the integrity of my work. To this end, I have kept a reflective journal throughout the research process where I have attempted to inspect my reasons, reactions, and interpretations. These observations have then formed the basis of detailed conversations with my supervisors, colleagues and autistic mentors.

These actions have been part of my attempt to develop what Dahlberg and Dahlberg (2019) refer to as "heightened self-awareness…to reach that presence where we are open for the new; an improvisational openness where we don't know what will show up but are attentive and ready for it" (p. 4). It is my understanding that not only is this an essential part of the qualitative research process, it also plays a central role in ensuring the process is conducted ethically.

2.4. Ethics

This thesis comprises three separate but interrelated research studies. The specific steps taken to ensure each was carried out ethically are discussed in the individual chapters. However, all ethical considerations were underpinned by my institution's ethical guidelines and the British Psychological Society's Code of Human Research Ethics (2014) in the following ways:

2.4.1. Informed consent

All participants freely consented to take part in the studies described in chapters 4 and 5, and the process of obtaining consent was an ongoing exercise throughout. Participants were free to withdraw their consent at any time without giving a reason and they were reminded of this at every stage of their involvement. Informed consent was supported by verbal and written information about the aims of the study, how it would be conducted, and how the results would be disseminated.

2.4.2. Privacy, confidentiality and anonymity

All transcripts relating to the research in this thesis were anonymised and kept in password protected folders on a secure University of Reading server with identifying codes and demographic information stored in a separate folder. Audio recordings were destroyed after the studies had been completed and hard copies of consent forms were stored in a locked filing cabinet.

According to the British Psychological Society's Code of Human Research Ethics (2014), "participants in psychological research have a right to expect that information they provide will be treated confidentially and, if published, will not be identifiable as theirs" (p.22). To ensure this right was enacted, any identifying aspects of the data such as names of participants, schools, places and people were anonymised. However, such practices have been identified by some authors as problematic since they risk paternalising participants and depersonalising their contributions (e.g. Lahman et al., 2015; Guenther, 2009). In order to establish a middle ground between the British Psychological Society's position and that of scholars who argue against anonymisation techniques, I chose to opt for pseudonyms rather than codes or other non-nominal identifiers to retain a sense of individual identity in the presented data. Pseudonyms were selected on the basis of demographic data (i.e. gender and age) with the assistance of a web-based database listing the most popular baby names for any given year.

2.4.3. Minimising harm

While there were no plans to ask distressing questions of anyone taking part, it was possible that a participant may have found discussing their own challenges or those of their child difficult. No participant was under any obligation to share such information, but this was identified as an aspect of my research that could cause stress or anxiety. Therefore, my supervisor (a clinical psychologist with extensive experience of working with autistic people) was also available at all times when I was working with participants should further support be needed, and this support was made available after the data collection phase. Broader environmental and communication adjustments were also made to minimise the risk of stress and discomfort to the autistic participants, and these are discussed in detail in chapters 4 and 5.

2.4.3.1. Minimising harm: autism-specific considerations

While the core aspects of the BPS Code of Ethics described above formed the basis of the ethical considerations relating to my work with individual participants, I was aware that I needed to take additional steps in this research to avoid harm to the broader autistic community. Most autism research tends to be conducted by non-autistic researchers and this has consequences for what research gets funded and how it is conducted (Milton, 2014a; Roche *et al.*, 2021) – a point highlighted by the disparity in the priorities of researchers and autistic people outlined in the introduction to this chapter.

How autism research is conducted and disseminated by non-autistic researchers can also objectify, dehumanise, and stigmatise autistic people (Botha & Cage, 2022; Bottema-Beutel *et al.*, 2020), with some scholars highlighting the long history of epistemic injustice in autism research and the harm it can cause (Carel & Chapman, 2021; Catala *et al.*, 2021).

My awareness of these issues has grown over the time it has taken to complete this thesis, but there have been a number of steps I have taken to limit the possibility of my research contributing to the harm already caused by some autism research to autistic people. Firstly, as detailed previously, I have adopted neurodiversity-affirming ontological, epistemological and theoretical positions developed by autistic scholars as the principle foundations for this research.

Secondly, I have used the double empathy theory not only as a theoretical interpretive lens in my data analysis, but throughout all stages of the research. This has provided a framework in which I have attempted to question myself throughout this process in order to identify and inspect how my non-autistic perspectives may be affecting my interpretations and wider research activity. I am aware that this is not something that can be done alone, and along with the assistance of my supervisors, I have been fortunate to have a small group of autistic mentors who have supported me in this reflective process. They have challenged my thinking, reviewed my work and expanded my understanding by holding a mirror up to me and the research I conduct.

I also decided early in my PhD to avoid mainstream autism conferences and research groups in favour of autistic-led events and organisations where my research could be reviewed and questioned by experts by experience as well as qualification. I have also avoided the use of dehumanising language in my research as per Bottema-Beutel *et al.* (2020) who offer suggestions for non-pathologising alternatives to the medicalised language and ableist discourses seen in much of the historic autism literature. Their guide is reproduced in Appendix A, page 190.

Finally, as explained in the previous chapter, the work in this thesis is located within the ontology of the neurodiversity paradigm. As such, it does not frame autistic people as inherently disordered or in need of interventions designed to reduce autistic behaviours in favour of non-autistic norms. The research in this thesis has been conducted with the basic assumption that autistic children and young people are competent and capable agentic individuals. Any instances during the process of this research where an autistic participant has not been able to comfortably access any aspect of the process has been seen as a limitation of the method and/or the researcher as opposed to the participant.

2.5. Quality and validity

In a systematic review of seventy-four published sources containing explicit criteria for evaluating the quality of qualitative research, Cohen and Crabtree (2008) found that while there was some agreement about the importance of conducting ethical research and the value of clear and transparent reporting, there was much disagreement in the assessment and definition of what constitutes rigorous qualitative research. The authors suggest that the quest for a single set of criteria is based on the erroneous view among reviewers and editors of the clinical literature that qualitative research is a unified field. However, due to the variety of different epistemologies and methods employed in big Q research, there is no single agreed approach that has the required flexibility to be applied to a wide range of research methods. Furthermore, and it has been suggested that to impose one would not necessarily serve to improve the quality of such research given the extensive range of knowledge it produces (Mays & Pope, 2000).

Therefore, while each of the three studies in this thesis are based on the same ontological and epistemological assumptions (i.e. those of the neurodiversity and interpretivist paradigms), each uses a different qualitative method. As such, I have used method-specific approaches of data collection and analysis in each of them to ensure that they have been conducted in a rigorous manner so that their findings are valuable. While the specifics of these approaches will be discussed in more detail in each of the study chapters, Yardley (2000) suggests the following overarching principles for creating quality work which can be applied to any qualitative research regardless of its specific orientation: 1) sensitivity to context, 2) commitment and rigour, 3) transparency and coherence, and 4) impact and importance. These will now be introduced in turn.

2.5.1. Sensitivity to context

According to Yardley, sensitivity to context can be established by locating one's work within the relevant theoretical and empirical literature. This includes meaningful engagement with the theoretical context pertaining to the topic under investigation and the methods used. It is also suggested that while a critical evaluation of relevant previous research is usually an expected aspect of a research project, the focus on human experience which tends to be central to qualitative research makes it necessary to include related work in other academic disciplines in order to develop a greater understanding of the context in which participant experiences are situated.

Related to this is the need to demonstrate sensitivity to the socio-cultural setting in which the research is conducted, particularly in relation to participants and being sensitive to participants' relationship to the researcher and the research topic. This understanding of context applies to all stages of the research process but Yardley emphasises the specific need for analysis which shows sensitivity to the data, arguing the importance of embracing complexity and contradiction, rather than imposing researcher-led meanings and categories.

2.5.2. Commitment and rigour

Yardley's second principle underlines the importance of research that is conducted in sufficient depth and breadth to offer novel insight into the topic under investigation. The level of depth and breadth required to achieve this is determined by the research objectives and the steps taken to address those objectives. Therefore, participant and method selection must be carefully considered and fully justified. Furthermore, commitment and rigour are dependent on prolonged engagement with the research topic and the data produced during the research process. There also needs to be demonstration of "substantial personal commitment, whether to attaining methodological skills or theoretical depth, or to engaging extensively and thoughtfully with participants or data" (Yardley, 2015, p. 267)

2.5.3. Transparency and coherence

In addition to underlining the importance of reflexivity as previously described in this chapter, Yardley's third principle refers to the extent to which the written research report makes sense as a coherent whole and makes clear to the reader exactly how the research was carried out and why. Yardley argues that coherence is contingent on the articulation of a strong and consistent argument but again points to this being reliant on a good fit between the research question and the methods employed to answer that question.

In addition to providing clear and detailed accounts of all stages of the research process, Yardley places particular emphasis on transparent analysis of the data in the form of quotes, transcription extracts, and tables containing theme summaries; each of which serve to show how the interpretations were made.

2.5.4. Impact and importance

Yardley's final principle maintains that the research undertaken needs to have theoretical or practical purpose. It needs to extend our understanding of the phenomenon under investigation and make a meaningful contribution to the field of study. The research "will have impact and importance if it builds on what we already know, to take us a step further and answer questions that matter to people and society" (Yardley, 2015, p. 268).

These 4 principles guided all aspects of the research contained within this thesis. An evaluation of the extent to which my research was able to meet these principles features in chapter 6. This thesis now continues with a detailed description of each of the 3 studies I completed.

3. Chapter 3: Study 1

The experiences of autistic children and young people in mainstream schools - a qualitative metasynthesis

3.1. Introduction

As discussed in the introductory chapter, the relative absence of the voices of autistic children in the autism literature carries with it the suggestion that perhaps autistic children are unable to speak to their own experience. However, in line with the trends in autism research towards greater inclusion of autistic people at all stages, there has been a welcome increase in the numbers of papers including the voices of autistic children which collectively challenge this notion.

However, despite this positive development, through my extensive reading of the literature in the early stages of my research, I was aware that the number of papers focussing exclusively on the subjective school experiences of autistic children and young people was small. A great deal is known about the particular difficulties school-aged autistic children face but how they experience and make sense of these challenges has received less attention from researchers. Much of the research conducted in this area involves standardised testing relating to aspects of academic performance (for a review, see Keen *et al.*, 2016) or via the perceptions of ostensibly non-autistic parents and school staff (e.g. Azad & Mandell, 2016; Danker *et al.*, 2019b; Hodges *et al.*, 2020; McKinlay *et al.*, 2022). Whilst not wishing to devalue the contributions of such research, the preference for proxy accounts in the literature arguably contributes to a problem that has been described by Waltz (2005) as "…construct[ing] an official discourse about autism in which the words and views of those described are rarely heard"(p.421).

Waltz's point certainly aligned with my casual reading of the literature in which the voices of autistic children were often absent but not entirely so. Therefore, I decided that my first task in my PhD was to comprehensively and systematically review the published qualitative literature which focussed on the subjective school experiences of autistic children in mainstream primary schools who did not have EHCPs or access to specialist support or resources. The objective of this task was twofold: 1) to develop a greater understanding of the mainstream primary school experience as expressed by autistic children themselves rather than their teachers and parents, and 2) to have a detailed understanding of the research that had already been conducted in this area to identify the direction my own research should take. However, as will be made clear in the remainder of this chapter, at the time of conducting the initial search, there were no published papers which met this criteria. Therefore, I was required to expand my search to include secondary mainstream settings and participants with access to higher levels of support.

To this end, I conducted a systematic review of the extant published qualitative literature relating to subjective everyday mainstream school experiences as expressed by autistic children and young people themselves. The findings of these papers were then synthesised in order to develop a greater understanding of how autistic children and young people describe their experiences of mainstream school life. This process was guided by the following research question: how do autistic children and young people describe and make sense of their everyday experiences of mainstream school in the existing published qualitative literature?

3.2. Methods

3.2.1. Review strategy

Qualitative metasynthesis involves the integration of findings of multiple primary qualitative research studies (Hannes & Lockwood, 2011). The method aims to consolidate potentially disconnected "islands of knowledge" (Glaser & Strauss, 1971, p. 181) in order to develop new and enhanced understandings of a particular phenomenon (Sandelowski & Barroso, 2006). Qualitative metasynthesis involves a systematic approach to identifying studies from similar research traditions which meet specific inclusion criteria and, as such, shares some of the features of quantitative meta-analysis (Paterson & Canam, 2001). However, rather than being focused on the aggregation of multiple datasets in support of a deductive or hypothesis testing process as might be the case in a quantitative review, metasynthesis is inductive and interpretive; concerned primarily with meaning-making and the extension of understanding beyond the scope of the original research reports as described here by Thorne *et al.* (2004):

> *"Metasyntheses are integrations that are more than the sum of parts, in that they offer novel interpretations of findings. These interpretations will not be found in any one research report but, rather, are inferences derived from taking all of the reports in a sample as a whole" (Thorne et al., 2004, p. 1358)*

Additionally, metasynthesis relies on the interpretation of rich descriptive accounts of participant experience and thus aligns strongly with my interpretivist epistemological position and my objective to remain rooted in the lived experiences of autistic children as described by them.

Although well established in health-related academic disciplines (Barnett-Page & Thomas, 2009), qualitative metasynthesis is a relatively new method in autism research. However, over the last decade, this approach has been increasingly used to explore a range of topics involving autistic people and their families including anxiety (O'Nions *et al.*, 2017), gender and identity (Moore *et al.*, 2022), sensory experiences (Sibeoni *et al.*, 2022), parenting (Boshoff *et al.*, 2018; Corcoran *et al.*, 2015), lived experiences across different life stages (DePape & Lindsay, 2016) and, as will be discussed in this chapter, education.

3.2.2. Search strategy

Informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009), the following databases were searched: PsycINFO, MEDLINE, Linguistics and Language Behavior Abstracts (LLBA), British Education Index, The Cochrane Library, Educational Resources Information Center (ERIC), and Web of Science Core Collection. In consultation with a specialist librarian, the search strategy included the key terms displayed in Table 1.

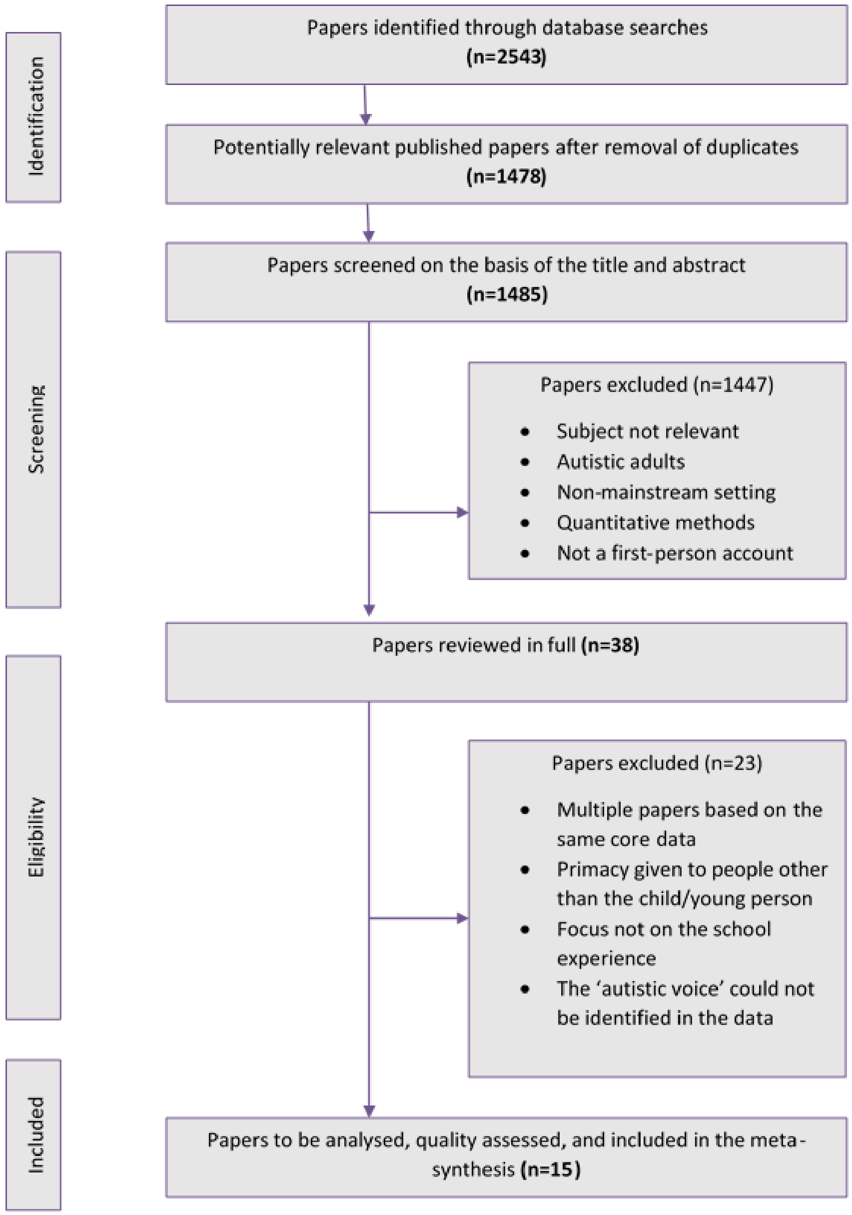
Table 1: Metasynthesis search terms

Criteria	**Search terms**
Population	autis*, asperger*, ASD, ASC
Setting	school*, education*
Method	qualitative, ethnograph*, phenomenol*, grounded theor*, purposive sample, hermeneutic*, heuristic*, semiotic*, lived experience, narrative*, life experiences, cluster sample, action research, observational method, content analysis, thematic analysis, constant comparative method, field stud*, theoretical sample, discourse analysis, focus group*, ethnological research, ethnomethodolog*, interview*

The inclusion criteria comprised peer-reviewed qualitative primary research studies or mixed-methods studies with a clearly defined qualitative component published in English between 1st January 2000 and 20th Feb 2017. Included papers focused on the lived experience of autistic children and young people in mainstream schools as expressed in their own words. Papers were excluded if they contained only quantitative data or related to students in non-mainstream settings. Papers that focused on the experiences of autistic adults, or views of teachers, caregivers or professionals were also excluded.

This search initially yielded 2543 papers. Removal of duplicates resulted in 1478 remaining. A further 7 papers were identified through hand searching which brought the total to 1485. With the support of two research assistants, I then reviewed the titles and abstracts of these articles and 1447 were excluded on the basis that they did not meet the inclusion criteria. I then read the remaining 38 papers in full in consultation with my primary supervisor. A further 23 papers were excluded at this stage because primacy had not been given to the young person's school experience or the autistic voice could not be clearly identified. My primary supervisor and I were in agreement that the remaining 15 papers met the inclusion criteria. A PRISMA diagram of the process is shown in Figure 1.

Figure 1: PRISMA diagram of the study selection process for the metasynthesis



3.2.3. Quality appraisal

I then appraised the final 15 papers for quality using the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist (Tong et al., 2007). The COREQ is an equally weighted 32-item checklist for assessing the reporting of qualitative studies using interviews and focus groups (see Appendix B page 191 for a copy of the checklist criteria). It was developed to promote the comprehensive and transparent reporting of qualitative research with specific regard to three key areas: (1) research team and reflexivity, (2) study design and (3) data analysis and reporting. As discussed in chapter 2, the issue of quality in qualitative research remains a much-debated topic, (Kisely & Kendall, 2011; Seale, 1999) and there are questions around the suitability of a standardised quality assessment tool. However, the COREQ is well-regarded and has been endorsed by a range of health, medical and psychiatry journals. It has also been identified as a suitable tool for assessing the quality of papers included in systematic reviews of qualitative studies making it appropriate for use in the present study (Booth et al., 2014).

The checklist is binary in nature, meaning that scores are allocated on the basis of the checklist item being present (or not) in the written report of each included study. Thus, the checklist scores for each paper represent the presence or absence of the reporting of each of the criteria. Accordingly, the papers in this review varied considerably in quality in terms of their COREQ checklist score (see Appendix B page 191 for a description of the COREQ items and a presentation of the full scoring). Eleven of the fifteen papers reported at least half of the COREQ items and all included papers explicitly stated their methodological orientation, reported data that was consistent with their findings, and clearly presented the major themes constructed from their analyses. Crucially, all included papers contained the similarity of methods and “thick description” (Major & Savin-Baden, 2010, p. 10) of the voices of autistic participants essential to the synthesis process.

However, there were a number of items on the COREQ checklist which were either reported rarely or not at all in the included papers. Data saturation, a term used to describe a point in qualitative research when additional data ceases to offer new insights (Clarke & Braun, 2013), was not discussed in any of the papers. Processes of inviting participants to check transcripts and give feedback on findings were only reported in two papers (Humphrey & Lewis, 2008; P. Lamb *et al.*, 2016), and perhaps most pertinent to my own epistemological position and the importance of positionality in qualitative research was the finding that only one paper made reference to the characteristics of the interviewer (Healy et al., 2013).

3.2.4. Characteristics of included studies

Table 2 contains a description of the characteristics of each study in the review. The 15 papers in this review represented 154 autistic children and young people aged 7-17 years; 106 male, 19 female, 29 gender not reported. All attended mainstream settings, some with specialist resources. The majority of studies were conducted in the UK but given the paucity of research into the lived school experiences of autistic children, research conducted in Australia, The

Republic of Ireland, The United States of America, and Singapore was included in the synthesis. This decision was made on the basis of the similarities between these countries' education systems and the UK due to their shared historical origins (Barr, 2019; Dowling, 1961; Heffernan, 2021; Nasaw, 1981). Furthermore, all included countries have education policies which mandate the inclusion of pupils with special educational needs in mainstream settings (Anderson & Boyle, 2015; Keeffe-Martin, 2001; Shevlin *et al.*, 2013; M. E. Wong *et al.*, 2015).

The children and young people in these studies had varying levels of support with their studies. Some had the highest level of support in place in the form of Education Health and Care Plans or equivalent, and access to specialist staff and facilities, whereas others had no formal supports beyond what was available to all students in the school.

Table 2: Characteristics of studies in the metasynthesis

Author, year, country	Number of autistic children/YP	Ages (years)	Gender	Level of support	Additional participant groups	School setting	Aim(s)	Method(s)	Analysis	Themes/findings
Carrington, Templeton, & Papinczak, 2003 (Australia)	5	14-18	1 female 4 male	Not reported but participants had access to specialist support	N/A	Mainstream secondary with specialist SEND unit	To investigate the perceptions of friendship in adolescents with Asperger Syndrome	Semi structured interviews	Constant comparison	Understanding of concepts/ language regarding friendships Description of what is/is not a friend/ acquaintance Masquerading
Connor, 2000 (UK)	16	11-16	1 female 15 male	Not reported	SENCOs	Mainstream secondary	To gain insight into the school experiences of CYP with Asperger Syndrome with regard to anxiety or stress	Structured interviews	Thematic analysis	The importance of not underestimating the difficulties and stress experienced by autistic children in mainstream settings
Dillon, Underwood, & Freemantle, 2014 (UK)	14	Mean = 13.57	3 female 11 male	Statement of SEN	Non-autistic age-matched peers	Mainstream secondary	To compare the experiences of autistic students to those without autism in relation to social skills, relationships with teaching staff, school functioning, and interpersonal ability	Semi structured interviews	Content analysis	The importance of teacher-pupil relationships The importance of 'integrated support'

Author, year, country	**Number of autistic children/YP**	**Ages**	**Gender**	**Level of support**	**Additional participant groups**	**School setting**	**Aim(s)**	**Method(s)**	**Analysis**	**Themes/findings**
Healy, Msetfi & Gallagher, 2013 (Ireland)	12	9 - 13	1 female 12 male	Not reported	N/A	Mainstream primary school	To gain insight into the experiences of autistic students with in PE	Semi structured interviews	Thematic analysis	Individual challenges: physical ability, fitness, sensory issues Peer interactions: camaraderie, initiation, comparison, bullying Exclusion
Hebron & Humphrey, 2012 (UK)	5	11-16	1 female 4 male	Not reported	Age and SEN-matched controls for the quantitative aspect of the study	Mainstream secondary	To identify influences on and responses to mental health difficulties	Semi structured interviews	IPA and Thematic analysis	Anxiety Internalising and externalising symptoms Self-reliance as a coping strategy Social difficulties (including bullying) Understanding/conceptualisation of autism
Hill, 2014 (UK)	6	Not specified	Not specified	Not reported	N/A	Mainstream secondary	To explore the lived experience of mainstream secondary school	Photo-elicitation interviews	IPA	Sanctuary Anxiety Young people as active agents

Author, year, country	Number of autistic children/YP	Ages	Gender	Level of support	Additional participant groups	School setting	Aim(s)	Method(s)	Analysis	Themes/findings
Humphrey & Lewis, 2008 (UK)	20	11-17	Not specified	Not reported	N/A	Mainstream secondary	To explore the views and experiences of mainstream school	Semi structured interviews, pupil diaries and drawings	IPA	Autism characteristics Understanding of Asperger Syndrome Anxiety and stress Relationships with peers Negotiating 'difference' Working with teachers and other staff
Humphrey & Symes, 2010 (UK)	36	11-16	4 female 32 male	16 statements of SEN	N/A	Mainstream secondary	to explore the role of social support and identify barriers to social support where bullying occurs	Semi-structured interviews	Thematic analysis	The role played by advocates Pupils' relationship histories A lack of trust in other people
Lamb, Firbank, & Aldous, 2016 (UK)	5	12-16	1 female 4 male	All statements of SEN	N/A	Mainstream secondary	To explore physical education (PE) from the perspective of autistic students	Photo-elicitation interviews	Thematic analysis	Interactions with the spaces of PE Anticipating barriers to PE

Author, year, country	Number of autistic children/YP	Ages	Gender	Level of support	Additional participant groups	School setting	Aim(s)	Method(s)	Analysis	Themes/findings
Marks, Schrader, Longaker, & Levine, 2000 (USA)	3	13 - 15	All male	All participants had specialist 1-1 support	Parents	Mainstream middle school and high school	To explore how students talk about themselves, their disability, and their school experiences	Interviews	Thematic analysis	Interests: benefit or hindrance? Rough beginnings, continuing struggles The difficulty of making friends and talking to people
Mayton, 2005 (USA)	1	10	Female	1-1 specialist support	N/A	Mainstream elementary school	To investigate how quality of life dimensions apply to mainstream education	Structured interview	Comparative pattern analysis	Need for physical safety, teacher acceptance, and access to materials were met Need for social skills support and an individualised learning program were not met
McNerney, Hill, & Pellicano, 2015 (UK)	6	10-11	All male	All participants had Statements of SEN	Parents, parent advisers, school staff	Mainstream primary school	To determine the factors that influence secondary school choice	Semi-structured interviews	Thematic analysis	Prominence of social relationships Anxiety towards learning

Author, year, country	**Number of autistic children/YP**	**Ages**	**Gender**	**Level of support**	**Additional participant groups**	**School setting**	**Aim(s)**	**Method(s)**	**Analysis**	**Themes/findings**
Moyse & Porter, 2015 (UK)	3	7 - 11	All female	1 participant had a Statement of SEN and 1-1 support	Parents, teachers, SENCOs	Mainstream primary school	To understand the effects of the hidden (i.e. social) curriculum	Semi structured interviews, learning walks, photo elicitation	Not reported	Areas of difficulty: class rules/working collaboratively/completing tasks/interacting with peers Modifications: control of space, objects or peers/small constant movements Hiding
Poon, Soon, Wong, Kaur, Khaw, Ng, & Tan, 2014 (Singapore)	4	12-17	1 female 3 male	Not reported	N/A	Mainstream secondary school	To understand secondary school experiences		IPA	Construction of autism Peer relationships School perceptions
Saggers, Hwang, & Mercer, 2011 (Australia)	9	13-16	2 female 7 male	Additional funded SEN support was provided	N/A	Mainstream high school	To explore the lived experience of mainstream high school	Semi-structured interviews	Constant comparison	Teacher characteristics Curriculum-related issues Support mechanisms Friendships Environmental considerations Teasing and bullying

3.2.5. Synthesis process

The findings of the 15 papers were then analysed in order to identify what Major and Savin-Baden (2010) refer to as “rich, thick description in the form of quotations from the original data” (p. 58). In keeping with my focus on the autistic voice, each instance of direct quotes from the child participants in the published studies were extracted and stored as a separate data item using Nvivo 12 software (QSR International Pty Ltd., 2018). Extracts that were not direct quotations from the children such as author interpretations or data from other participants in multi-informant studies were not included. 2096 separate data items were collected in total. These items ranged from short phrases to longer extracts.

The synthesis then followed a three step process as proposed by Thomas and Harden (2008):

1. **Line-by-line coding of the raw data contained within the findings or results sections of each paper**

The coding process started with a line-by-line review of the data from the first study in which the beginnings of a bank of codes was created. At this stage in the process, the coding was descriptive rather than interpretive. For example, in this quote from Bill in Healy *et al.* (2013), *“some people in the hall start screaming at each other…just hurts my ears”*, the descriptive code was simply ‘sensory discomfort’, whereas in later stages of the analytical process, I moved to a more interpretive approach to consider what this experience might have meant to Bill and the impact the pain and distress might have had on him. Each data item contained at least one code but some were connected to several codes, especially if the extract was longer and more detailed. These descriptive codes were then added to and refined where necessary with each additional study until all the data items from the fifteen papers had been coded.

2. **Grouping of these codes into related descriptive themes**

I then looked for similarities and differences between the codes in order to group them into descriptive themes which I converted into a tree diagram so that I could more easily visualise the connections between the data. This visual representation also enabled me to ensure a good distribution of the themes across the included papers.

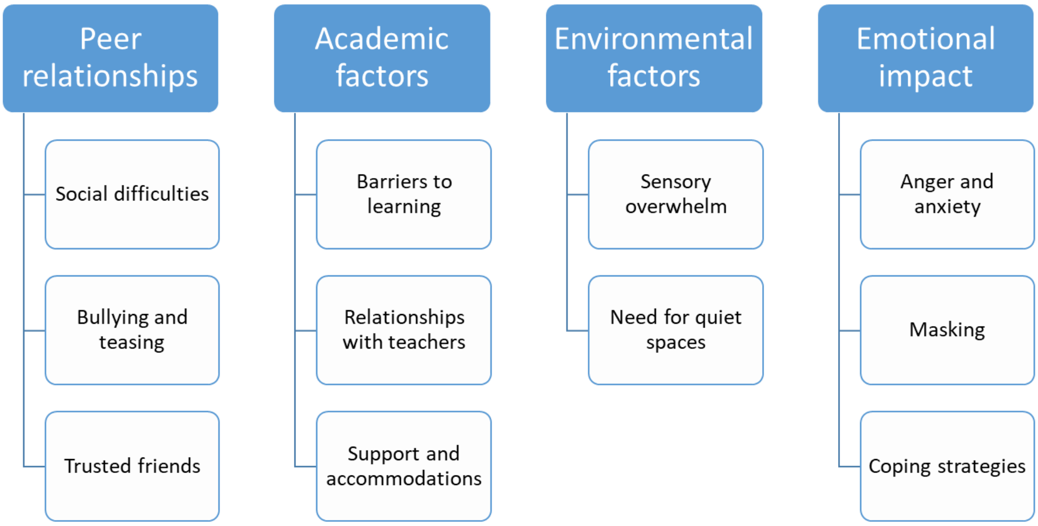
3. **Development of analytical themes that extend beyond the original remit of the primary research in order to develop new understandings of the topic in question**

Up until this point, I referred frequently to the source studies to check that my coding and descriptive themes retained a strong connection to the primary research. The construction of the analytical themes, however, involved taking the necessary step away from the source papers in order to engage in the extension process which is central to metasynthesis. It was at this stage that I moved to the more interpretive approach previously described in order to consider the meaning-making dimension of my research question.

3.3. Results

Each of the themes constructed through the analysis had strong connections with the others and there was considerable overlap and interplay between the categories. While the themes have been constructed as discrete entities, the experience of these phenomena for the children in papers included in this review were intricately interconnected. However, for the purposes of this study and as illustrated in figure 2 below, I developed four interconnecting but discrete analytical themes from the coding of the data: (1) social relationships, (2) academic factors, (3) environmental factors, and (4) emotional impact. These key themes and their subthemes will now be discussed in turn with exemplar quotes and the names of the participants where they were provided in the source data.

Figure 2: Analytical themes developed from the metasynthesis



3.3.1. Peer relationships

Relationships with peers featured frequently in descriptions of both the best and worst aspects of the school experience for the children in the included studies. It was clear that while relationships with peers were highly valued by most participants, navigating the complexities of the social world of school was also challenging and distressing at times.

3.3.1.1. Social difficulties

The data suggested that friends were a crucial part of autistic children's everyday school experience. However, many participants experienced social difficulties despite being highly motivated to develop and maintain good relationships with their peers. Across the studies, friends featured prominently when participants talked about what they enjoyed most about school. In particular, having a sense of being liked by peers was very important and was linked to a better school experience:

> *Yeah if people are nice to you, you feel better. When I was in school when people didn't like me it was rubbish and now many more people like me it's easier (Humphrey & Lewis, 2008, p. 35)*

The children represented in the included papers appeared to be highly motivated to develop friendships and most had a strong desire to connect with their peers. They wanted and valued friends and were selective about who they were friends with. They had clear ideas of the characteristics they looked for in a friend with trust, honesty and reliability being key qualities:

> *Jack: Trusting them, not turning their back on you sort of stuff and not fighting with me and my friends ... sticking up for each other ... keeping each other's secrets and promises (Carrington et al., 2003, p. 216)*

Only a small minority of students expressed a lack of interest in socialising with their peers explaining that, given the effort required, it was not an activity that was particularly enjoyable for them:

> *Oscar: I sit with my friends, but I hardly socialise with them.*
> *Interviewer: Don't you?*
> *Oscar: No. I sort of find that boring … even though it is good to socialise […] I just find it a bit, well, difficult […] I'll give you an example. It's just when somebody says hello, I sort of say the wrong thing and well, when they say hello, I hardly ever say hello such and such … (Saggers et al., 2011, p. 182)*

The effortful nature of socialising connected with some of the participant's experiences of social difficulties. The data suggested that underpinning some of these difficulties was an imbalance or mismatch between the autistic child and the member(s) of the peer group in terms of willingness to connect and establish a friendship. This is exemplified in the quote below where the child wants to form a friendship but experiences rejection by the peer group:

> *People don't get on with me and I don't really get on with them and I often try to make friends with them . . . [but] they often just go against me (Humphrey & Lewis, 2008, p. 35)*

The subject of imbalance also appeared to extend to the nature of friendships. Some participants reported that their friendships were not necessarily of the quality they would like. In the passage below, Hudson describes a 'semi-friendship' in ways that suggest it was not reliable, rewarding or equitable:

> *Hudson: I've got a sort of semi-friend, David, although he gets a bit annoyed with me at times.*
> *Interviewer: So you sort of hang around with David a little bit?*
> *Hudson: Just a little bit, yeah. You know, depending on which way the wind's blowing.*
> *Interviewer: When you feel in the mood or not?*
> *Hudson: Not really whether it's my moods, rather it's his mood (Saggers et al., 2011, p. 182)*

When exploring the data for how such imbalances and difficulties were understood and experienced, the children appeared to be very aware of how their autistic identity made them different from their non-autistic peers. Some children indicated that the ways in which their differences were perceived by others may have had a part to play in their difficulties forming relationships:

> *Maybe it's because I don't act the same as others (Connor, 2000, p. 289)*

Being different was associated not only with having more difficulties with developing friendships, but was also with experiencing negative reactions from peers. There was a sense that being different was viewed unfavourably by others in the mainstream environment which exposed the autistic children to varying levels of hostility:

> *Interviewer: So do you think it's important not to be seen to be different then?*
> *Pupil: Yeah school it is…it's very important.*
> *Interviewer: Why do you think it's important not to be seen to be different?*
> *Pupil: It's the culture. Everybody's got to…I get picked on and abused (Humphrey & Lewis, 2008, p. 40)*

3.3.1.2. Bulling and teasing

For many children, this hostility was pervasive and distressing to the point of being described as bullying. For a minority, the bullying took a physical form such as being hit, having things thrown at them or having their possessions stolen or hidden, but for most, it came in the verbal form of name-calling or being mocked in some way:

> *Andi: But there is a group of people who […] they speak to me, but I don't like that, because they don't speak to me to be friendly, they speak to me to be funny to their friends. They make funny voices and go 'well done' and they (pause), they sort of say 'hello' and things and I go sort of 'hi' and then they just laugh and things and I don't like that (L. Hill, 2014, p. 86)*

Being more socially and linguistically complex than physical acts of aggression, verbal forms of hostility were more difficult to identify and interpret which led some participants to feel confused and anxious in most social situations at school. They were not always able to tell if initiations by peers were genuine so for some participants, their experiences of being bullied by a few peers had led to distrust and avoidance of most peers:

> *It's annoying people that come near me, I just get anxious and stressed*
> *[Other pupils] make me feel stressed all the time (Humphrey & Symes, 2010, p. 87)*

> *Sally: I know now, never to respond to my name in public. It's been discarded forever and ever. … Don't respond when someone calls out your name. So I just keep on walking no matter how many times they call it — even if they're a nice person. I just won't turn around (Saggers et al., 2011, p. 181)*

There was also a sense in the data that the bullying they experienced was so commonplace that some of the children may have felt powerless to change it. When discussing help-seeking for bullying, some participants seemed to be resigned to the fact that their concerns were not taken seriously or acted upon by members of staff. In the quotes below, Daniel and James are referring to their teachers:

> *Daniel: They won't listen to me*
> *James: They never took it seriously, and then it got worse (Hebron & Humphrey, 2012, p. 7)*

Instead, the preferred strategy was to either accept or ignore the bullies:

> *I'm used to it; they do it all the time (Mayton, 2005, p. 94)*

> *I just try and ignore them and that's the best way to do it and then they'll just stop picking on you (Humphrey & Symes, 2010, p. 87)*

3.3.1.3. Trusted friends

Given the hostility experienced by many of the participants which in some cases led to a general wariness of peers, it is unsurprising that the children prioritised trust and safety in their social relationships. Those who had valued and rewarding friendships held a strong preference for smaller groups consisting of two or three peers who had typically been known to the child for a long time:

> *Not many friends, but I have a few close ones…2 or 3 (Dillon et al., 2014, p. 6)*

> *Alice: You grow up with them (Carrington et al., 2003, p. 216)*

Given the difficulties some of the children had in establishing friendships and the effort required to do so, the preference for fewer friends is understandable. It is also possible that longevity of friendship was important to establish the predictability and reliability needed in order for trust and a sense of safety to develop. This in turn may have been connected to feelings of belonging which were clear in the reasons cited by some children for their preference for friendships with other children who were different to the mainstream majority:

> *I like people who have special needs and working with them. I feel safe there (Connor, 2000, p. 292)*

The comment about feeling safe when working with friends was important as the issue of safety came up frequently with regard to friendships. The children looked to their friends for security, especially within the context of bullying:

> *Bernard: We all communicate well, while other people would have bullied me and them. We actually kind of knew when to stand up. We worked together to prevent each other from being beaten up, protect each other. We are like a hand. Without the fingers we can't do anything, but together as a hand we can do anything (Poon et al., 2014, p. 1076)*

In addition, friends offered vital social and academic support to the autistic students. When faced with a classroom learning challenge or a difficult social situation, they often turned to their trusted friends for help rather than teachers or other supporting adults. In some ways, trusted friends acted as translators, guides and protectors:

> *They can tell me things when I don't understand (Connor, 2000, p. 291)*

> *David: I like my friends because they were taking care of me, and teaching me (Poon et al., 2014, p. 1077)*

> *I ask them to go places with me in school and at home time 'cause it's safer and better . . . I like working with my friend when we have to do group stuff, he knows more people than me (Dillon et al., 2014, p. 6)*

Given the particular function of these friendships, it was possible that they were far more important than might be first assumed. For some children, it was conceivable that these friendships made it possible to cope with the more challenging aspects of mainstream school life; the implication being that school may not be bearable without this support. The reliance that some children had on their friends was clear in their descriptions of the anxiety they experienced when friends were not at school:

> *I feel worried if my friends are not in (McNerney et al., 2015, p. 1108)*

The data also showed that friends were often distinct from classmates. As illustrated above, friends were generally defined as trusted peers who offered support and guidance as well as offering companionship and being fun to be around. They were described as understanding of difference whereas some participants reported feeling misunderstood by classmates and gave descriptions which indicated a clear sense of feeling other and separate:

> *Bernard: Even though the classmates are quite accommodating, I can tell they don't actually want to be that accommodating. You can tell by the facial expression, the way they talk to me, they are actually scared of me. And that's why I hate it. I don't like to be feared . . . I hate myself when I know I caused fear in other people. I don't like that kind of thing (Poon et al., 2014, p. 1076)*

In particular, the behaviour of classmates was often described as unruly and disruptive. This was difficult for some of the participants to cope with and interfered with their ability to pay attention and engage effectively with lessons:

> *Classmates talk a lot . . . They just keep talking and talking (Dillon et al., 2014, p. 6)*

3.3.2. Academic factors

However, distraction by classmates was just one of the academic challenges described by the participants. A prominent theme in the data was the range of difficulties experienced by the autistic children and young people in relation to accessing the full range of subjects within the mainstream curriculum.

3.3.2.1. Barriers to learning

Difficulties with the academic demands of school were mentioned frequently by participants. In terms of the curriculum, there was a distinct preference for some subjects over others. Furthermore, for some participants the purpose and utility of school was unclear. This was often discussed in relation to specific academic subjects – those that were preferred were acceptable and sometimes enjoyable, whereas subjects which fell outside the child’s interests or understanding were confusing and had the capacity to impact negatively on self-esteem and self-worth. Rule-based logical subjects with limited requirement for debate and discussion such as maths, science and computing were viewed most positively:

> *I’m a bit shy which is why I like to work on the computer which has no emotions (Connor, 2000, p. 290)*

> *Simon: I like chemistry and physics because it talks about laws and how things work (Hebron & Humphrey, 2012, p. 7)*

Creative and practical subjects such as art and design were also favoured possibly due to the production of tangible results. This stands in contrast to more theoretical subjects, particularly those which involved what might be perceived as a large amount of independent reading and/or writing. Some participants struggled to understand the utility of these subjects and described them as ‘boring’:

> *Jay: You just sit there and do work, instead of actually doing experiments like in science...I like science most (Marks et al., 2000, p. 9)*

> *[Referring to social science] Well, we have to do our book a lot. After the teacher goes over it, we have to think about it, and I don't like it (Mayton, 2005, p. 96)*

Subjects which were perceived as neither practical nor interesting were described in negative terms which centred on either a perception of poor teaching or an inability or incapacity on the part of the child. The challenges associated with these less preferred subjects ranged from inattention to anxiety and frustration:

> *It's boring; the teacher is stupid; I'm no good at it; there's no point; the teacher makes you do things which I can't do (Connor, 2000, p. 289)*

As with friendship groups, there was also a preference for working in smaller groups. Activities involving joint working with large groups of peers were generally described as anxiety-provoking. The concerns seemed to be mostly related to the increased noise and social communication demands:

> *If there's too many people in my group they make noise and it puts me off…I like working in smaller groups with people I know (Dillon et al., 2014, p. 6)*

> *Scarlett: I like science but sometimes I find it a bit boring because I don't really get included in much stuff…sometimes no one listens to me, so um, we don't really work, they don't really like my ideas, so I like working on my own most of the time (Moyse & Porter, 2015, p. 192)*

The dislike of large groups also extended to physical education and sports. In addition to concerns about physical ability and the sensory challenges of the changing room, much of the anxiety around physical education seemed to be connected to the team-based nature of the activities and the potential for letting people down:

> *Josie: In a big game with lots of people then I get a bit nervous that I will urm well disappoint people (P. Lamb et al., 2016, p. 7014)*

Manging the academic workload was also problematic for some participants. Problems with organising materials and ensuring work was completed and handed in on time were mentioned frequently. In particular, ensuring timely completion of multiple longer or larger projects and assignments was a challenge:

> *Glenn: I think the hard thing is long-term projects that get assigned. And, uh, and I've learned how to take things, uh, one step at a time, and not look at the whole problem, because that's the problem. I get assigned a project, and I look at the whole thing and literally freak out (Marks et al., 2000, p. 12)*

Connected to time management was the issue of homework which was regularly cited as problematic. For many of the participants, home and school were separate and clearly distinct parts of their lives. For some, home was a place of respite from the demands of school so, for them, the problem with homework seemed to be less about the actual work and more about the intrusion on home life:

> *Homework takes away my time […] Homework's pointless…Been at school all day, then you get more work in your own time (Dillon et al., 2014, p. 7)*

For some participants, handwriting was effortful and painful. This was problematic in school but became a greater challenge when related to homework since some of the academic support available in school might not have been available at home:

> *Oscar: …well it just sort of hurts my arm when I write a lot*
> *Tom: Yeah, it eventually gets…exhausting (Saggers et al., 2011, p. 180)*

> *I get no help at home, I've got to write loads of stuff…Sometimes my helper writes it for me before and then I can copy it and do it at home (Dillon et al., 2014, p. 7)*

3.3.2.2. Relationships with teachers

The support given to students by teachers was mentioned frequently in the data. Many participants reported the positive effects of good relationships with teachers. Just as with peers, it would seem that the quality of personal relationships with individual teachers was crucial to learning and motivation:

> *He's trying to make us do well and pushing us forward. Teachers can make it good to learn and make you feel self-confidence from understanding subjects (Dillon et al., 2014, p. 5)*

In addition to the academic support and encouragement, participants discussed the importance of having caring teachers who expressed a liking for them. Even brief positive remarks from teachers could have a significant impact on overall wellbeing:

> *I went to music, I saw the drama teacher and she said, 'hello beautiful' and I was like 'oh my god!' It made me feel really, really happy (Humphrey & Symes, 2010, p. 86)*

The children in these studies were consistent in terms of the qualities they valued in teachers: having a sense of humour, being a good listener and having a clear communication style were all very important to building trusting relationships:

> *Sally: My fourth grade teacher was cool because he did magic tricks and he gave us lollies and he had fun with teaching too…He used to be a magician in the circus (Saggers et al., 2011, p. 178)*
>
> *Josie: [there's] always someone there that you can talk to and they'll listen to what you have to say (P. Lamb et al., 2016, p. 710)*
>
> *He makes learning so easy. He just explains everything super easy (Saggers et al., 2011, p. 178)*

A point that came across particularly strongly was the importance of having teachers who could be flexible and understood the needs of their students. Many students referred to teachers who were 'not too strict' as being the ones who they preferred most:

> *I don't know, she's not strict but she does her job properly and she's just nice and she's understanding (Saggers et al., 2011, p. 179)*

Although it was unclear which behaviours constituted 'strictness', many students referred to the negative impact of teachers who raised their voices or became visibly irritated. Teachers who shouted or who were perceived as angry were cited as a cause of worry:

> *I worry when the teacher gets angry (Connor, 2000, p. 291)*

> *Don: My teacher is horrible. She’s very strict and mean. She yells at people (Saggers et al., 2011, p. 178)*

3.3.2.3. Support and accommodations

In addition to teachers, other members of school staff played a key role in the lives of the children and young people in the included studies. Although the participants had varying support levels, those who had access to specific support staff appreciated the practical and emotional support they provided:

> *My helper in class helps me loads. And with my homework. She helps other people too. She’s really nice (Dillon et al., 2014, p. 6)*

> *[She] makes me feel like I’m calm and relaxed and I can get on with my work (Humphrey & Lewis, 2008, p. 38)*

However, the visibility of this kind of support seemed to be an important consideration. What came across clearly was the need for support from staff to be offered in such a way as to not mark the child out as different from their classmates:

> *Sally: I don’t like it sometimes…I don’t like teachers sitting next to me (Saggers et al., 2011, p. 181)*

> *If [my support assistants] were following me then the other students know that there’s something different about me and I don’t like it at all (Humphrey & Lewis, 2008, p. 38)*

3.3.3. Environmental factors

In addition to issues relating to the people and practices within school, the participants in the included studies frequently mentioned difficulties relating to the physical school environment. These related mainly to the sensory aspects of being in noisy and crowded spaces.

3.3.3.1. Sensory overwhelm

The data in this review suggested that the physical environment was essential to the wellbeing of autistic children and young people. Noisy spaces were consistently cited as distressing and were avoided as much as possible. These included obvious examples such as crowded corridors during transitions between classes and the playground but also included the noise of being in a large group discussion in lessons, an overlap with the previous theme. Physical proximity to others in crowded spaces was an added stressor, particularly in corridors:

> *Eddie: I feel really, really, really tiny. Cos it's very, very, very big; very, very, very, very big. Yeah. Yeah. I feel like a tiny man. A tiny man…Yeah.*
> *Louise: What feelings do you have when you feel like a tiny man?*
> *Eddie: Very nervous. Yeah…Really nervous. I feel baffled. Don't know what's happening…Just don't know, don't know who is coming. Can't see them. Don't know which direction they are coming from. That's what makes me worry (L. Hill, 2014, p. 83)*

This also extended to being in and getting to the changing rooms for physical education and could be so intense as to cause feelings of suffocation and physical pain:

> *Joe: It doesn't feel like there is room to breathe in there sometimes (P. Lamb et al., 2016, p. 708)*

> *Bill: Some people in the hall start screaming at each other…just hurts my ears (Healy et al., 2013, p. 224)*

Despite being a space where one might imagine lower levels of noise than the sports hall or changing room, classroom noise was cited as being distracting and upsetting to the point of being compelled to leave the room:

> *Learning in school is a waste of time because the classes can be noisy and misbehave and it puts me off. I can't work when things are going on (Connor, 2000, p. 292)*

> *SL: And why do you want to leave the class sometimes – what happens to make you leave the class?*
> *Pupil: Well there's too much noise and noise gets me wound up all of that (Humphrey & Lewis, 2008, p. 37)*

3.3.3.2. Need for quiet spaces

For these reasons, being allowed to work alone or in small groups where noise could be kept to a minimum tended to be preferred. Having enough physical space to work without being crowded by classmates and their belongings was also cited as being helpful:

> *I like working on my own in a big class where you can be spaced out (Connor, 2000, p. 291)*

The most important support in the case of noise and crowd-induced stress was access to quiet spaces. Given the crowded nature of most schools, this wasn't always possible and some participants had creative ways of using the space they had to better suit their needs. Here, Josie described how she preferred to change for PE in the shower cubical so to avoid the noise and chaos of the main changing room:

> *Josie: It's not so loud in there, it's nice and, it's, it's, kind of quiet…(P. Lamb et al., 2016, p. 707)*

Participants who had access to specialist resources or units were especially appreciative of having a restricted space away from the busyness of the school they could retreat to. They also commented that it was not just the quiet they appreciated but being with like-minded peers who were known to them:

> *Sammy: It's nice and quiet there [in the specialist unit] and only students who are allowed can go there. Ones that are quiet and don't like going outside (L. Hill, 2014, p. 85)*

3.3.4. Emotional impact

3.3.4.1. Anger and anxiety

It was clear from the data that although there were positive aspects of school, many participants found the daily experience of being in school stressful. The emotional impact of dealing with the challenges described above resulted in both externalised and internalised distress behaviours. Anxiety was referred to in every paper and seemed to be a common experience across the majority of participants. For some participants, the feelings of distress were overwhelming:

> *I'm upset every second, every second I've got tears in my eyes (Humphrey & Lewis, 2008, p. 38)*

Although stress seemed to be common across participants, there were marked differences in how stress presented in behaviour. In some cases, stress led to emotional dysregulation described here by Daniel as a loss of control:

> *Daniel: Sometimes I cry...I go "ughhr!" and then "warrr!" I have this stupid anger and I say stuff like "I wish I was dead", which I don't mean. Sometimes, I just say it because I'm worried about my body and the situation. [. . .] If I get angry, it's like I'm not controlling myself. Someone else is. So I'm being controlled by a remote (Hebron & Humphrey, 2012, p. 6)*

Whereas for other participants, they felt pressure to hide their emotions which led to further emotional difficulties:

> *Joanne: I feel like I want to break stuff, but I never do it....I feel like I want to run away, but I never, you don't do it....I feel angry, I feel silly, I feel confused (Hebron & Humphrey, 2012, p. 6)*

3.3.4.2. Masking

For some participants, the need to hide their feelings extended to other areas of their school life. A common theme in the data was the need felt by some participants to hide aspects of their autistic identities in order to better fit with the requirements of school and be accepted. As described by Humphrey and Lewis (2008):

> *[…]one pupil commented, 'Sometimes it's like, "make me normal'' (p. 40)*

Other participants described using mental strategies such as pretence so that they could meet the perceived academic expectations of school life:

> *Bernard: Even though I have very low expectations, I just pretend [to have] high expectations [of myself] so that I can stay happy in my mind (Poon et al., 2014, p. 1077)*

3.3.4.3. Coping strategies

However, masking appeared to be just one of the coping strategies employed by the participants to adapt to an environment that was not necessarily best suited to their ways of being. For many participants, their preferred way of coping with difficulty and overcoming challenge was to turn inward rather than to ask for help. This may have come from not knowing who or how to ask for help, or it could have stemmed from a reluctance based on previous unsuccessful experiences:

> *Ellie: I'd put my hand up and say "sir" or "miss, they're bothering me" and they just say "Ellie, just get on with your work"(Humphrey & Symes, 2010, p. 86)*

Regardless of the drivers for this behaviour, a common pattern in the data was the move to self-reliance when faced with challenges:

> *Oliver: I don't really talk to anyone. I keep to myself and try to sort it out in my own way (Hebron & Humphrey, 2012, p. 6)*

When it came to bullying and teasing, the self-reliant approach took the form of ignoring the perpetrators in the hope that they would go away:

> *I just try and ignore them and that's the best way to do it and then they'll just stop picking on you (Humphrey & Symes, 2010, p. 97)*

However in many cases, the preferred strategy was to remove themselves from the stressful situation wherever possible. Examples of using self-exclusion as a coping strategy tended to be related to social or academic difficulties:

> *James: I've been staying in every day, the last year. Not the best solution, but one I'm happy with (Hebron & Humphrey, 2012, p. 7)*
>
> *Shane: They all play football but I just watch; it's OK with my teacher if I just watch (Healy et al., 2013, p. 225)*

When self-exclusion was not possible, some participants adopted creative strategies to navigate situations they found challenging and this sometimes involved breaking the rules:

> *Corin: [Talking about the lunch queue] There are like velvet ropes and it keeps you in a line, but I don't think we should have to have a line, cos everyone gets crushed in the queue. So I skip the line, I go 'in' the 'out' (L. Hill, 2014, p. 86)*

Nevertheless, despite the effort put into finding solutions and developing strategies, they were not always successful and some children reported not always being able to find it within themselves to completely control their responses:

> *I try to count to 10 but people still annoy me and that's when I start to throw things (Dillon et al., 2014, p. 5)*

3.4. Update to 2017 findings

As the above metasynthesis was completed in May 2017, I ran the searches again in July 2022 in order to identify any relevant studies published during the intervening years. While it was not possible for me to resynthesize new data due to the time constraints of the PhD process, I was aware that a review of any new literature was needed in order to update and inform the discussion of the metasynthesis which follows in section 3.4 below.

The same criteria were used to search the same five bibliographic databases listed on page 32. These searches provided 3046 results, and after removing duplicates and applying inclusion criteria, 13 papers were identified. A detailed summary of the characteristics of these most recent papers is provided in Appendix B page 194, but they included 123 autistic participants between the ages of 8 and 19 years, all in mainstream settings with varying degrees of access to specialist autism or SEND resources.

While the 2017 metasynthesis allowed me to continue with the subsequent two studies that form the empirical component of this thesis, the 2022 literature review allowed me to check if my original themes were still salient and reflected young people's experiences as expressed in studies published in the intervening years. Prior to discussing the review in detail, I will first provide some general observations and a summary of the findings of the 2022 literature search in order to extend the scope of this chapter and frame the metasynthesis findings within the context of more recent research.

What was immediately clear when conducting the 2022 search was that there had been a greater research focus on the lived experiences of autistic children in mainstream schools in recent years. What was most notable about the latest search was that, although covering a period of only five years, it yielded almost as many papers matching the inclusion criteria as my initial search which covered a period of 17 years. The gender balance in the original collection of papers was difficult to judge accurately because gender was not consistently reported, but in the papers where it was, the ratio of male to female participants was 6.5:1. In the collection of papers retrieved in the 2022 search update, the ratio of male to female participants was 3.7: 1 which is more in line with current evaluations of the diagnostic gender split in autism (Loomes et al., 2017). Also, three studies focused specifically on the female perspective (Halsall et al., 2021; Jacobs et al., 2021; Tomlinson et al., 2022) which was not evident in the first search. This arguably reflects attempts in recent years to address the paucity of research involving autistic women and girls who have historically been overlooked in autism research (Bennett & Goodall, 2022).

In the main, the findings of the most recent papers echoed the themes in the metasynthesis. Sensory challenges were the most consistently cited difficulties with Aubineau and Blicharska (2020) commenting that they present the greatest impact on inclusion and wellbeing for the participants. In keeping with my original findings, noise and crowds were identified as particularly distressing with the playground, corridors and lunch halls frequently given as examples of the most overwhelming places in school from a sensory perspective (Aubineau & Blicharska, 2020; Birkett *et al.*, 2022; Danker *et al.*, 2019a; Hummerstone & Parsons, 2020; Jacobs *et al.*, 2021; Tomlinson *et al.*, 2022). In addition to sensory stimuli already discussed in this chapter, Cunningham (2020) found that temperature also played a part in the sensory discomfort of her participants, something that has not been identified in other studies included in this chapter. Eguiguren Istuany and Wood (2020) also found that sensory discomfort could prompt extreme distress and even violent responses, a finding that expands on the theme identified in the metasynthesis and makes an important connection between the distress of sensory discomfort and behaviour which may be described as challenging or disruptive.

Also in line with the findings of my metasynthesis were difficulties with peer relationships. These were common as was the stress and uncertainty involved in maintaining friendships (Aubineau & Blicharska, 2020; Haegele & Maher, 2022; Halsall et al., 2021; Jacobs et al., 2021; Tomlinson et al., 2022). The tendency to have a small number of trusted long-standing friends was another consistent finding (Haegele & Maher, 2022; Warren et al., 2021).

Relationships with teachers were again cited as important and central to participants' educational and emotional wellbeing, but some of the later studies expanded on this finding by highlighting that perhaps in relation to some of the social difficulties experienced by the participants, teachers were sometimes regarded as friends rather than members of staff (Danker *et al.*, 2019a; Halsall *et al.*, 2021).

Bullying and peer exclusion were also consistent with the metasynthesis. Aubineau and Blicharska (2020) found that bullying was a significant problem for some participants necessitating changing classes and a withdrawal from school, while Haegele and Maher (2022) found that bullying was associated with extreme distress and self-harm in some of their participants.

A finding alluded to in the metasynthesis but more prevalent and more greatly expanded on in the latest set of papers was the issue of fatigue. Aubineau and Blicharska (2020), Birkett et al. (2022) and Halsall et al. (2021) all commented on the level of exhaustion experienced by their participants. They attributed this to the pace of school life, meeting academic demands, finding the practical and mental strategies to deal with sensory challenges, and camouflaging aspects of autistic identities in order to fit in more easily (Mesa & Hamilton, 2022). Aubineau and Blicharska (2020) also found that some of their participants resisted interventions and support because they were simply too tired and overwhelmed to be able to engage with them.

The findings of the 2022 literature review reinforce and extend the results of the metasynthesis. In particular, and perhaps due to a growing interest among researchers in the subjective experience of being autistic as opposed to the historical tendency to rely on the observations of non-autistic supporting adults, these most recent studies shed light on how effortful school can be for autistic children and young people. The findings of these studies highlight how autistic children and young people are required to expend a great deal of energy managing sensory discomfort and navigating the neuronormative social curriculum – aspects of school life that may have negligible or significantly less impact on non-autistic children and which may not be fully appreciated by non-autistic educators and caregivers.

3.5. Discussion

This metasynthesis and 2022 literature review identified four interconnected themes relating to the mainstream education experience of autistic children and young people: (1) social relationships, (2) academic factors, (3) environmental factors, and (4) emotional impact. The data illustrated the significant level of challenge experienced by many autistic children in mainstream schools. While having a clear desire to form friendships, many of the children in this review experienced difficulties in forming meaningful relationships with peers. Central to these difficulties were experiences of peer rejection and bullying. However, for those children who reported having good friendship experiences, they tended to describe having small friendship groups comprised of peers they trusted and had known for many years who provided vital social and academic support.

In terms of the academic aspects of school, many of the children reported a number of barriers to learning, not least a lack of understanding of the purpose of much of what they were being required to learn. Success and enjoyment of subjects appeared to be contingent on the children's interests rather than their inherent academic abilities, and pedagogic approaches (e.g. group work, theoretical vs. practical instruction, amount of writing required) may have also had a part to play in how accessible the teaching was to autistic children.

Relationships with teachers appeared to play a crucial role in the success or otherwise of the children's school experience. In particular, feeling liked by the teacher was of central importance. Teachers and staff who were flexible and provided support in discrete and subtle ways were most valued.

Whereas personal relationships with peers and staff moderated some of the social and academic challenges of school, the environmental challenges presented by the physical properties of school were arguably more difficult to find solutions to. The sensory demands of being in a crowded noisy space were particularly distressing and the need for quiet respite was clearly expressed but not necessarily readily available.

The emotional impact of these challenges came across strongly in the data. Stress expressed externally as anger or internally as anxiety was common. The perceived need to hide these feelings and indeed the behaviours connected to their autistic identity was also a common thread, as was the tendency to attempt to cope alone with the difficulties they experienced.

A key finding from this review is the critical importance of trusting relationships with peers and staff. It is arguable that all children benefit from supportive relationships but in the case of autistic children, these relationships may make the difference between a child being able to access school or not; or the difference between coping and floundering. This idea is further supported by the finding that particular friendships may perform an important supportive function for autistic students: one of protection from, and translation of, the complexities of the largely normative culture of mainstream school.

The vulnerability of autistic children is clear within all the themes in this review, each of which shows that distress is experienced when the necessary supports are not provided or are unavailable or restricted: when a relied-upon peer is not at school for whatever reason; when a teacher becomes angry or raises their voice; when there is nowhere quiet to retreat to when the crowds and the noise becoming overwhelming. It is possible that what appear to be seemingly minor challenges to some observers can be very disturbing for autistic children. The fact that staff and classmates may not be able to empathise or identify with the intensity of these feelings is perhaps part of a larger issue and connects with the Milton's double empathy problem discussed in the previous chapter.

In terms of implications for educational practice, it is clear from this review that more focus needs to be placed on the importance of relationships within schools. There also needs to be greater consideration given to the impact of the physical environment on autistic learners. The impact of sharing a physical space with several hundred other people, and the associated sensory challenges this involves, is a significant problem for many autistic children and young people that may not be fully recognised by school staff and other pupils. While this finding may seem as uncontroversial as to be obvious, it stands in contrast to the legacy of interventionist approaches to autism support in schools which are often focused on the child as opposed to the people and the environment around the child.

The children in this review said that they valued supportive relationships with staff and peers who they could trust to guide them through the complexities and challenges of an environment and system that is not designed for them and their unique ways of thinking and being. They wanted to be taught by flexible teachers who were sensitive to their individual needs and recognised their difficulties, and they wanted to be able to retreat to quiet predictable spaces when they were overwhelmed by the sensory demands of school life.

When viewed within the context of the more recent research published between 2017 and 2022, although there has been a welcome upward trend in research on the subject experience of being an autistic child in a mainstream school, it is disappointing to see that the challenges they experience have remained largely unchanged for at least the 22 years covered in this review. Given the international contributions included here, it could also be possible that these experiences are universal and not confined to just our domestic education system. This gives rise to the question of whether the policies, processes and cultures of mainstream schools are best suited to the needs of autistic children and young people.

This question was central to a recent metasynthesis conducted by Horgan et al. (2022) who investigated the lived experiences of autistic children in mainstream secondary schools in relation to whether the current preference for full inclusion in mainstream settings provides autistic children and young people with good outcomes. Horgan and colleagues identified thirty-three studies published between 2005 and 2021, seven of which featured in the present metasynthesis and eleven which were published after 2017. Inclusion criteria were similar the present review but also included studies in which participants were no longer attending mainstream school because they were either being educated at home or in Alternative Provision (e.g. Goodall, 2018, 2020; Goodall & MacKenzie, 2019).

Due to methodological differences, some papers in Horgan's review were excluded from my study for not providing sufficiently rich and substantial accounts of the child experience as expressed by the child themselves (e.g. Hay & Winn, 2005). Regardless of these differences, the findings of Horgan's review are highly relevant to this chapter and our findings naturally overlap in many areas. In line with my study, they found that the academic and sensory demands placed on autistic children in mainstream placements were significant, as were relationship difficulties with peers, social isolation and having to hide aspects of one's autistic identity in order to be accepted. Relationships with teachers were cited as having a crucial influence on academic performance, emotional wellbeing and sense of belonging, and bullying and verbal harassment again featured heavily.

Worryingly, and in line with some of the findings from my updated search, Horgan's review extended on the emotional impact theme in my metasynthesis in terms of the negative impact of school on the mental health of autistic children. In particular, feelings of dread and even suicidal thoughts were evident in their data. However, the authors note that there is still very limited published research on the mainstream school experience from the perspective of autistic children. They end their review by concluding that mainstream schools can be "complex, chaotic and demanding" (Horgan *et al.*, 2022, p. 10) environments for many autistic children and their voices need to be central to decisions relating to inclusive policy and practice. They also note that more research is needed into the views and perspectives of autistic children in order to improve outcomes.

3.5.1. Limitations

The children and young people represented in the studies reviewed here were verbal, academically able, and predominantly male. Participant characteristics relating to ethnicity were not reported in the primary research. Future investigations are required to address the dearth of research relating to autistic girls, those with co-occurring learning disability and/or productive language differences, and those from minority ethnic groups (Bennett & Goodall, 2022; Gilbert, 2004; Lovelace *et al.*, 2021; Singh & Bunyak, 2019).

In order to conduct a synthesis across several studies, there needs to be sufficient similarity between the included studies (Harris, 2011). Therefore, all the studies included in this metasynthesis used methods from similar traditions to produce rich spoken data from verbal participants who were in similar circumstances in as much as they were attending a mainstream school setting at the time of their involvement in the research. Studies which employed methods that produced different types of data such as artwork and drawings (e.g. J. Williams & Hanke, 2007), or who included participants who were in different educational settings such as those who had left mainstream due to formal exclusion (e.g. Brede et al., 2017; Sproston et al., 2017) were not included. Such studies provide valuable insight into the autistic experience and the decision to not include them in this study is rooted in methodological practicality rather than any issue of quality or value. Indeed, studies employing methods which include those who are non-speaking or prefer to communicate in alternative ways are much needed in autism research. Therefore, this synthesis provides a systematic and substantial but necessarily partial review of the available qualitative literature on the autistic mainstream school experience determined by the limitations of the method used.

3.5.2. Implications for future research

As set out above, the present study and the papers listed in the update section provide compelling justification for more focused investigation into the autistic lived experience of mainstream schools, particularly involving those in primary schools whose voices are underrepresented in the existing literature. Of the 78 papers featured in the reviews listed in this chapter, only nine featured primary-aged children (Calder et al., 2013; Cunningham, 2020; Healy et al., 2013; Mayton, 2005; McNerney et al., 2015; Mesa & Hamilton, 2022; Moyse & Porter, 2015; Stack et al., 2020; Warren et al., 2020) and of those, only four were specifically centred on the everyday primary school experience (Cunningham, 2020; McNerney et al., 2015; Moyse & Porter, 2015; Warren et al., 2020). However, all of these studies involved children attending schools with specialist autism resources and/or those with the highest level of support in the form of an Education Health and Care Plan or equivalent.

To my knowledge, there are no published papers with the specific aim of documenting the everyday experiences of autistic children in mainstream primary schools without specialist resources or access to the level of multi-disciplinary support offered by an Education Health and Care Plan or equivalent. This is an important gap in the literature given that approximately 75% of identified autistic children in state-maintained mainstream schools in England do not meet the criteria for an Education Health and Care Plan (DfE, 2022g) and only 7% of schools in England have specialist units or resourced provision (DfE, 2022d).

Currently, there is a paucity of contributions in the literature from autistic children in mainstream primary schools who do not have access to specialist support. These children constitute the majority of autistic children in primary schools in England but that majority status has not been reflected in the research to date where they remain an under-researched population. Therefore, the process of conducting this review guided the direction of my subsequent research. It provided the foundation and rationale for the study into the lived experiences of autistic children in mainstream primary schools which features in Chapter 5.

4. Chapter 4: Study 2

Autistic young adults' reflections on their mainstream primary school experiences

4.1. Introduction

As demonstrated by the metasynthesis in chapter 3, previous research has shown that many autistic children find school to be a difficult experience, with peer relationships, academic difficulties, and the physical school environment being particularly problematic. The previous study also identified that much of the extant qualitative research on the subjective school experiences of autistic children involves participants who are of secondary school age or who have access to specialist support and/or resources. Much less is known about the everyday school lives of primary-aged children who do not meet the criteria for specialist support. Therefore, in an attempt to address this gap in the literature, a study involving autistic children attending mainstream primary schools without access to additional support was conducted and is detailed in chapter five (hereafter referred to as 'the child study').

However, given the paucity of research into the lived school experience of primary-aged autistic children, I was aware that more consultation was needed in order to inform the interview schedule for the child study. I was reluctant to assume that the needs and experiences of primary-aged autistic children were identical to those reflected in the literature relating to secondary-aged children and I wanted to extend my understanding prior to embarking on the child study. To this end, the present study was designed to explore the everyday experiences of autistic children in mainstream primary schools with three key stakeholder groups: parents of primary-aged autistic children, teachers of primary-aged autistic children, and autistic young adults who had attended mainstream primary schools. This exploration was supported by the following research question: what are the most salient aspects of the primary school experience for autistic children? The results of this study were then used to inform the design and development of the interview schedule for the child study in the next chapter.

4.2. Method

4.2.1. Design and rationale

4.2.1.1. Rationale for using focus groups

This study was concerned with the experience of being an autistic child in a mainstream primary school. As such, it was iterative in nature and aimed to engage with what Willig (2013) refers to as the “quality and texture” (p.16) of the participants’ contributions. In light of this and given the range of possible support needs represented, and the potential for widely differing experiences, I chose a focus group method in order to accommodate the broadest range of views and offer participants a greater degree of control and flexibility over the topics under discussion. The focus group method was also chosen for the facility it has for encouraging interaction between participants thus providing the opportunity for the discussion to move into areas most salient to those taking part (Wilkinson, 2015).

4.2.1.2. Rationale for recruiting autistic young adults, parents and teachers

Given how difficult school can be for many autistic children, and the fact that my subsequent study is specifically focused on primary aged children, I took the decision in this present study to consult with autistic young adults who had completed their compulsory school years. This decision was informed by the assumption that examining primary school experiences with the benefit of some distance and from the position of early adulthood could potentially lead to a greater degree of reflection. Additionally, since the objective of this study was to inform the topic guide for the child study, I decided to also consult with parents and teachers in order to extend the range of different perspectives on the subject.

4.2.2. Ethical considerations

Ethical approval was received from The University of Reading Research Ethics Committee (2017-196-FK) in November 2017. In addition to the foundational aspects of ethical research highlighted in chapter 2, I took particular steps in this study to ensure the comfort and safety of all involved.

While previous research has shown focus groups to be a suitable method of eliciting the views of autistic people (e.g. Benevides et al., 2020; Knott & Taylor, 2014; Robertson & Simmons, 2015), there was a possibility that some of the participants may find a group discussion with unfamiliar people in an unfamiliar setting challenging and potentially stressful. Therefore, in addition to speaking with each participant about their individual access requirements, the option of one to one semi-structured interviews was also offered.

One participant from the autistic adult group chose this option. This particular participant was keen to take part in the study but found conversation with unfamiliar people difficult. Therefore, a more structured and personalised approach was taken to ensure the participant's inclusion and comfort. This approach included close involvement with the participant's parent who facilitated early communication between me and the participant via email in the initial stages of the study, and an informal familiarisation visit to the Psychology department at the University of Reading in which the interview room was introduced but no research questions were asked. At the time of the visit, the participant was given a copy of the interview topic guide so they could review the questions in advance. The participant then responded to these questions via email in the first instance. These answers were then used one month later to form the basis of the one to one interview.

Adaptations in the interview included using reduced language (i.e. avoidance of long and convoluted questions), increased pauses and periods of silence to assist processing, and side-by-side seating positions rather than face-to-face to reduce the demand for eye-contact could that have been stressful for the participant. These adaptations were also employed during the focus group discussion although due to the seating involving a circular table, I was mindful to adjust my eye contact accordingly. In light of research indicating that sensory aides can help autistic people to self-regulate and cope in times of anxiety or overwhelm (Felepchuk, 2021; Kapp et al., 2019), I also provided stationery (coloured pens, paper, post-it notes etc) and a range of sensory items (e.g. fiddle toys, Blu-Tack, Lego, chewing gum, ribbons, elastic bands, and fibre-optic LED lights) which most participants in the autistic adult group made use of.

In addition to the general privacy protections outlined in chapter 2, I also ensured that the participants in each group were unknown to participants in the other groups e.g. none of the teachers would be discussing the children of people participating in the parent group. Furthermore, participants were required to protect other group members' confidentiality and not discuss the contributions of other participants outside the focus group sessions.

4.2.3. Participants

4.2.3.1. Eligibility criteria

The aim of this process was to recruit autistic young adults who had attended mainstream primary schools, parents of autistic children currently attending mainstream primary schools, and teachers currently teaching in mainstream primary schools with autistic children in their classrooms. To establish a level of diagnostic consistency, all participants in the autistic adult group had received confirmed diagnoses of an autistic spectrum condition as had all the children of the participants in the parent group. The teachers were asked to refer to their diagnosed autistic pupils in their responses for the same reason.

In accordance with the rationale established in the metasynthesis study in the previous chapter, I started the process with the objective of recruiting participants who could reflect the views and experiences of children and young people without access to specialist resources or EHCPs. However, this constraint significantly reduced the number of eligible potential participants to the point where there were too few to provide a broad range of experiences. Therefore, the decision was taken to extend the criteria to include those with EHCPs. Details of the level of support provided to participants in the autistic adult and parent groups are detailed in tables 3 and 4 below. These criteria were not applicable to the teacher group since they were required to support children with a wide range of needs, and it was not practical to ask them to only comment on their experiences of teaching children without EHCPs.

4.2.3.2. Recruitment process

I used purposive sampling - a non-random recruitment process designed to "seek out groups, settings and individuals where...the [phenomena] being studied are most likely to occur" (Denzin & Lincoln, 2011) to find participants with the lived experience necessary to address my research question. I advertised the study on social media, with local autism family support groups in Berkshire, student networks at the University of Reading, and through professional teacher contacts (Morgan *et al.*, 1998). A copy of the recruitment sheet is included in Appendix C on page 200.

After initial expressions of interest, information sheets and visual guides about the study were sent to applicants (copies of which are also in Appendix C on pages 201 and 208) which were followed up with an email or telephone conversation depending on the preference of the participant. The purpose of this conversation was four-fold: 1) to check eligibility, 2) to gather demographic data, 3) to ascertain any access requirements, and 4) to establish rapport between the researcher and the participant prior to data collection taking place (Scott-Barrett *et al.*, 2018).

A total of 19 participants were recruited. Demographic and descriptive information about the participants is detailed in tables 3, 4 and 5 below. In accordance with the rationale set out in section 2.4.2, pseudonyms are used in the following tables and throughout this chapter.

As previously discussed, in terms of the relationships between participants, each of these groups were separate and none of the people in one group knew people in the other groups. However, the parent group did contain both parents of one child, and the teacher group contained a number of participants who worked together in the same schools as indicated in table 5 below. The participants in the autistic adult group were all unknown to each other prior to this study.

4.2.3.3. Participant demographics

Table 3: Participant demographics - autistic adults (n=6)

Pseudonym	Sex	Age at interview	Age at dx [3]	Level of SEN support in school	Occupation at time of discussion	Choice of interview method
Daniel	Male	19	7	SSEN (equivalent to EHCP)	University Undergraduate	Focus group
Georgia	Female	19	15	None	FE College Student	Focus group
Holly	Female	22	18	None	University Undergraduate	Focus group
Callum	Male	19	13	None	University Undergraduate	Focus group
Katie	Female	25	15	SSEN (equivalent to EHCP)	FE College Student	1-1 interview
Sophie	Female	21	16	No additional learning support but received speech and language therapy	University Undergraduate	Focus group

Table 4: Participant demographics – parents (n=7)

Pseudonym	Relationship to child	Child age	Child sex	Age at dx	Time spent at current school	Level of SEN support in school
Charlotte	Mother	11	Male	8	1 year	SEN Support
Harriet	Mother	7	Male	5	3 years	EHCP
Martin	Father					
Isabella	Mother	6	Female	5	1 year	EHCP
Peter	Father	10	Male	9	5 years	SEN Support
Rebecca	Mother	9	Male	8	4 years	EHCP
Sheila	Mother	9	Female	8	4 years	SEN Support

Table 5: Participant demographics – teachers (n=7)

Pseudonym	Sex	Age	Age of pupils currently taught	School	Years teaching experience	Years spent at current school	Number of identified autistic children in current class(es)
Barney	Male	26	7 – 8 (year 3)	D	3	2	2
Chris	Male	30	7 – 8 (year 3)	B	6	3	2
Denise	Female	43	8 – 9 (year 4)	D	20	17	4
Elizabeth	Female	37	9 – 10 (year 5)	A	15	2	2
Jenny	Female	52	7 – 8 (year 3)	B	25	18	2
Julie	Female	38	7 – 11 (years 3 – 6)	C	6	2	6
Shaun	Male	27	9 – 10 (year 5)	B	3	2	3

---

[3] ‘Dx’ is an abbreviation of ‘diagnosis’

4.2.4. Data collection

4.2.4.1. Topic guides

In order to generate data that could address my research question, the topic guides for the focus group discussions needed to centre on the everyday experiences of autistic children in mainstream primary schools. With the social, academic and sensory challenges described in the metasynthesis in the forefront of my mind, I created the topic guides with the aim of exploring possible areas of difficulty while also attempting to identify any positive or supportive aspects of primary school life.

Rather than restrict the questions to the topics raised in the metasynthesis, the topic guides for the discussions were purposefully broad to offer the maximum flexibility to the participants and to allow for the conversation to move into potentially novel areas not already identified in the existing literature. The topic guides for each focus group were identical and focussed on the five core questions below. The only differences related to time and the nature of the relationship to the autistic child i.e. the autistic adults were asked questions relating to their own previous experiences (as shown below) whereas the parents and teachers were asked about their child's/pupils' current experiences respectively:

- How would you describe your experiences of primary school?
- Which aspects of primary school did you enjoy?
- Which aspects of primary school did you find challenging?
- How would you describe the support you received at primary school?
- If you could go back and change any aspect of your primary school experience, what would you change?

4.2.4.2. Focus groups and interview procedures

I moderated each focus group supported by two research assistants who took field notes and provided practical assistance with the running of the sessions. The moderation process involved gaining informed consent, setting out the purpose of the discussions and the wider study, posing questions, asking participants to elaborate or clarify where necessary and ensuring that everyone was given the chance to participate.

In the case of the parent and teacher groups, the participants were keen to interact with one another and frequently asked questions of each other which extended the topics of conversation. Although naturalistic participant discussion one of the key benefits of using a focus group approach, my moderator role also sometimes involved bringing the conversation back if it had strayed too far from the central topic under investigation. This happened less often in the autistic adult group where my role in facilitating the interaction between participants was more active than in the other groups. The autistic adults answered my questions fully and expressively but they tended to do so individually. They spontaneously interacted with each other's contributions less frequently than the parents and teachers so my moderation of the autistic adult group involved an element of making connections between participant contributions in a way that I did less of in the parent and teacher groups.

The focus groups were scheduled according to the availability of the participants resulting in the following order of occurrence: 1) parents, 2) teachers, and 3) autistic adults. The one-to-one interview with the final participant from the autistic adult group came after the third focus group discussion and concluded the data collection process. I conducted this final interview alone. The interview and focus group discussions were audio recorded and yielded a total of 5hrs and 53mins of discussion which was then transcribed verbatim.

4.2.5. Data Analysis

The transcripts were coded and thematically analysed using Nvivo 12 (QSR International Pty Ltd., 2018). Thematic analysis is one of the most well-established and widely-used qualitative analysis methods in psychological research (Kiger & Varpio, 2020), and provides a flexible method of analysing, organising, and interpreting patterns across qualitative data. This approach involves coding data in order to generate themes which represent common ideas or concepts constructed from the data across a range of participants (Clarke & Braun, 2022). As such, it is well suited to the analysis of data at a group level as is required in a focus group study. Of particular relevance to the present study, thematic analysis has also been shown to be an effective analytical method in other studies into the lived experiences of autistic people using focus groups (e.g. Cai & Richdale, 2016; Cheak-Zamora *et al.*, 2015; Knott & Taylor, 2014; Koffer Miller *et al.*, 2018; Moseley *et al.*, 2020).

Braun and Clarke (2006) provide a clear and concise six-phase process which I followed to identify meaningful patterns across the data in response to my research question. Firstly, the familiarisation phase involved re-reading the transcripts and listening to the audio recordings several times so that I could immerse myself in the data. I also reviewed the field notes taken during each of the focus groups and engaged in discussions with my research assistants to establish a shared understanding of their notes. At this stage, I made primary analytical notes based on my initial observations and interpretations. I then moved on to the second phase of the process which involved systematically identifying and labelling the data to generate codes that were most relevant to my research question. The third phase involved the construction of provisional themes by identifying patterns within the codes. The fourth stage of the process involved reviewing the provisional themes to ensure that they were clearly defined and represented the lived experiences of the participants. This stage was done in collaboration with my supervisors in a process where the themes were discussed individually and in relation to the dataset as a whole. This phase of the process was facilitated by printing the codes and their provisional themes onto different coloured paper so that the three different participant groups could be easily identified.

In addition to their research roles, my supervisors are a clinical psychologist and a speech and language therapist, respectively. Each has worked clinically with autistic children and their families for many years. As such, their backgrounds and experiences differ considerably from my own and during this collaborative stage of the analysis, this occasionally gave rise to each of us arriving at a slightly different interpretation of the data. Rather than being problematic, these differences were viewed positively since the purpose of this stage was to engage more deeply in reflexive practice rather than achieve a consensus (Clarke & Braun, 2022). Each analyst brought different skills and experiences which, when working collectively, enabled us to interpret the data from a range of perspectives. Therefore, where different understandings were encountered, they were valuable for engaging with a richer and more nuanced understanding of the data. The fifth phase involved clearly defining the themes to generate their final names, and the sixth and final phase of the process was the writing of the results presented in this chapter.

4.3. Results

Even as the focus group discussions began, it was clear that the contributions from the parent and teacher groups mirrored many of the findings from previous research into stakeholder perspectives on the education of autistic children. Participants in both the parent and teacher groups shared views and experiences that while meaningful, were already well documented in the existing literature and appeared to be more rooted in their own experiences than those of the children in their care. This was in stark contrast to the autistic adult group who provided novel and first-hand insights into the autistic experience of primary school. It was for this reason that at phase four of the analysis process, I took the decision that the remaining analysis and subsequent write up would focus on the data from the autistic adult group only as they addressed my research question most closely and provided the most useful precursor to the child study. Therefore, this results section begins with a brief overview of the major themes identified in the parent and teacher groups before moving on to a detailed presentation of the findings from the autistic adult focus group and one to one interview.

4.3.1. Parent and teacher groups

Although each group was asked questions about the everyday school experiences of the autistic children in their care, the discussions tended to focus on the participants' own struggles and difficulties. In particular, the theme of difficult parent-teacher relationships was central to the data collected from both groups. It is important to emphasise again that the two groups were not connected i.e. the teachers were not involved in the education of the children being discussed in the parent group. However, both groups discussed the tension between home and school at length and it was clearly a major concern to all involved. The prominence of this theme was evident from the very beginning of each the discussions, as exemplified by the following extracts which came as I posed the first question to the group after the initial introductions:

Parent group:

> *Jo: […] so a general question to start us off, and it's quite a big one...how would you describe your child's school experience?*
> *Charlotte (parent): In one word? Horrific.*
> *Jo: What do you mean?*
> *Charlotte (parent): From the word go...they've said there's nothing wrong with...them, it's the parents….it's all my fault. Yep.*

Teacher group:

> *Jo: I'm going to kick things off with quite a broad question and that is how would you describe your autistic pupils' school experience?*
> *Elizabeth (teacher): Varied…I think it's very much dependent on the parents sometimes.*
> *Jo: Hmm mmm. Chris, you were agreeing with that. What are your thoughts on that?*
> *Chris (teacher): Yeah...very much so. Very much the same really. It's quite variable. As you said, erm...really dependent on sort of...parent engagement.*

In terms of engagement, there was a sense in the parent data that interaction with school was excessively frequent and often challenging. There was a strong sense of stress and fatigue in their contributions and many used language of conflict to describe their experiences of trying to secure appropriate school support for their child:

> *From the moment we've been diagnosed...it's been a battle. All the time. Every...every day...there seems to be something. (Peter, parent)*

Whereas, for the teachers, there was a perception that parents were not always helpful and perhaps had unrealistic expectations of school staff:

> *Denise (teacher): Sometimes parents can be...you get parents who are very good and supportive and will give you tips and things to help…and others that you don't seem to get anything from, almost more denial.*
> *Shaun (teacher): Yeah....It's almost like they expect you to know it all, because you're their teacher.*

Despite the seemingly adversarial nature of these tensions, they appeared to stem from similar challenges. One major area of shared frustration related to a perceived lack of understanding of autism in schools. For the teachers, this manifested in the struggles they had experienced in establishing a consistent approach to supporting autistic pupils among their colleagues:

> *So, some teachers and teaching assistants and...anyone…any adult working with school...some get autism and some don't. Some will accept autism and some won't… (Jenny, teacher)*

> *Some teachers in school don't always necessarily agree with perhaps the child's diagnosis and it's kind of like…'I don't see X, Y and Z behaviours so surely they…can't be on the spectrum because I don't see those things'…so just because they don't see it they then don't believe it exists so therefore don't put anything in place to deal with that. (Elizabeth, teacher)*

From the parent perspective, inconsistent levels of understanding among school staff had the capacity to impact negatively on their child and added to parental feelings of stress and frustration:

> *Martin (parent): When there's other people...like,...that don't...understand. Don't have any experience…and if [the child has] a meltdown because they can't get the ball or something...then they just treat them as a naughty child. And...it normally makes the meltdown worse. And that's where I think part of the*

> *playground issue...comes from. So, it's not only the noise...well, it is the noise, it's everything. And people not understanding.*
> *Charlotte (parent): And then, as you said, later...they're reprimanded…or suspended for...their behaviour which they can't actually control.*

Perhaps as a result of these negative experiences, some parents appeared to assume a level of personal responsibility for improving staff understanding of their child. There was a sense in their contributions that this was unreasonable and effortful but necessary if they were to improve their child's school experience:

> *Harriet (parent): Did you feel like you [were] teaching the staff? Cus sometimes, I feel...I'm teaching the staff about autism.*
> *Peter (parent): All the time.*
> *Isabella (parent): Oh, completely.*
> *Charlotte (parent): In the last reports we did, I did actually ask them to [attend local autism training] courses cus I just got fed up with taking stuff in and printing stuff off […] I had to put that together. And put all his visual aids together. And put the stuff for the classroom together. It got ridiculous.*

The comment regarding autism training made by Charlotte in the parent group above also featured in the teacher data. The teachers recognised the need for good quality autism training for all school staff but described how difficult it was to access such training given the financial and time constraints in their schools:

> *Elizabeth (teacher): I think the training that I've had previously has been very kind of...yeah, very generic… I think sometimes in school it's kind of like y'know, you have a 2 hour staff meeting and it's kind of, that's that box ticked sometimes…there's so much to fit in.*
>
> *Denise (teacher): You ask to go on [training] but there's no money in school to put you on anything or the TAs, y'know.*
> *Jenny (teacher): Or one person's sent on and the information has to be cascaded back down.*
> *Elizabeth (teacher): And it's finding the time to do that because your staff [...] is*

> *all filled up with other things.*
>
> *Denise (teacher): Yeah, that's it. It's not seen as a priority.*

The teachers frequently mentioned the scarcity of resources needed to support their autistic pupils. In addition to the lack of training mentioned above, this scarcity also extended to classroom teaching assistants and specialist staff:

> *Chris (teacher): [We have] a reward system where...we've got tokens. So 5 spaces and if [autistic pupil] fills 5 spaces with tokens, there will be some sort of reward...which he will choose but…if he's only just achieving it at, say…just before lunchtime...and you don't have adult support in the afternoon…and he wants to do something outside, then that's not going to be possible.*

> *Barney (teacher): We're going through an interesting phase…at the moment where, erm, we don't have a full time SENCO, we actually have a SENCO on loan […] er, one day a week at the moment, so, as it stands, er, we're sort of fending for ourselves as teachers.*

As discussed in the introduction to this thesis, there is a large literature on the experiences of parents and teachers of autistic children, and many of the themes raised by the parents and teachers illustrated above align with findings from previous research. These include: the lack of understanding of autism in schools (DePape & Lindsay, 2015; Galpin *et al.*, 2018; National Autistic Society, 2021), difficult home-school relationships (Hodge & Runswick-Cole, 2018; McKinlay *et al.*, 2022), the challenges parents experience in trying to secure suitable education support for their child (Hasson *et al.*, 2022; McCarthy *et al.*, 2022; Parsons *et al.*, 2009; Ryan & Cole, 2009; Tissot, 2011), and lack of funding, training and resources for teaching staff (Humphrey & Symes, 2013; Ravet, 2018; Roberts & Simpson, 2016).

These topics are important, have a long history (B. Lamb, 2009; Warnock, 1978) and continue to dominate SEND policy discourse to the present day. For example, all of the themes identified above feature prominently in the UK Government's most recent review into the SEND system in England (DfE, 2022e). However, within the context of my aim to learn more about the everyday experiences of autistic children, the data from the parent and teacher groups were rooted in the participants' own experiences rather than those of the children involved, as exemplified here by Rebecca, a member of the parent group, when describing her child's relationship with his class teacher:

> *Last year, we've just had a teacher that was just...horrid to me. I thought she...she didn't like...children. She always had a face on her. I was quite...I...I kept it calm but she said some really horrible things. She was horrible. This year...I didn't think much of this teacher when my other son had him but he's...quite, calm. [My son] seems to find [the teacher] quite interesting. He's not in your face. My son likes him and he's just...quite nice to me. (Rebecca, parent)*

For Rebecca, and indeed all of the participants in the parent and teacher groups, the experiences of the autistic children in their care were described in relation to their own experiences of supporting those children which, due to various limitations of the education system, was often stressful, upsetting and frustrating. It seemed that these powerful emotions were most salient when taking part in the focus group discussions. All participants talked compellingly about the challenges of educating an autistic child in a school system that has high aspirations for children but ever-decreasing means with which to meet those aspirations. While I gained a vivid insight into what it was like to be a parent or teacher of an autistic child, it was difficult for me to ascertain a meaningful sense of what school was like for the children themselves. However, this was not the case for the data generated by my discussions with the autistic adult group whose contributions now form the remainder of this section.

4.3.2. Autistic adult group

Following the decision to centre my attention on the data collected from the focus group discussions and interview with the autistic adult participants, four themes were constructed through the analysis process: 1) the undesirability of difference, 2) the various guises of bullying, 3) the emotional labour of 'being good', and 4) looking back. The first theme, *the undesirability of difference*, relates to how the participants felt different from a very early age and how this difference was perceived negatively by many of the people around them in school. The participants described these negative perceptions as connected with acts of hostility towards them which are discussed in the second theme, *the various guises of bullying*. The third theme, *the emotional labour of 'being good',* details how the hostility they experienced put pressure on the participants to behave as typically as possible in order to be accepted by their peers and teachers, and the final theme, *looking back*, documents the lasting impact these difficulties have had on the participants which is still being felt in early adulthood.

4.3.2.1. Theme 1: The undesirability of difference

Although most of the participants did not receive their autism diagnoses until their adolescence, all reported feeling different from a very early age. This was largely remembered in negative terms with one participant describing their sensory responses and social interests within the context of being ‘not normal’:

> *I had, like, a…realising in year 1 that I was not normal. I would go to the school discos and I would cry because it was too loud and the lights were too bright […] I knew I was different in the way that I hung out with boys rather than girls and I was very interested in like specific things but those weren't things I could talk about with the other children (Holly)*

Participants discussed how this sense of feeling ‘not normal’ may have been constructed in part through the negative evaluations they received from peers and school staff. Participants reported that their natural approaches to communicating, learning, and socialising were often misunderstood by others, and they all described situations in which their differences were perceived as wrong or ‘bad’ in some way by the people around them. Some participants suggested that they sometimes felt that the people around them became irritated with them and perhaps felt that they were intentionally trying to be difficult or disobedient. These points are exemplified in the quote below in which Georgia describes her ways of socialising as ‘bad’, and how her behaviour was perceived as wilfully deviant in ways that could lead to sanctions or admonishment:

> *Because of my bad social skills, I often did things which the teachers would think was bad behaviour, but it was just me misunderstanding what we were meant to be doing…[I was] always being told off for things which I didn’t understand were wrong (Georgia)*

Much of the data in this theme relates to experiences in which the people around the participants perhaps lacked empathy or understanding of their needs. There was a sense in the data that much of the participants’ early school lives were spent with people who had little appreciation for the ways in which autistic behaviour may differ from non-autistic behaviour. This may have been compounded by the fact that only one of the participants, Daniel, was formally identified as autistic during his primary school years. However, as expressed by Daniel below, even in situations when school staff were trying to be understanding and supportive, being treated differently tended to be experienced negatively, regardless of the intentions and motivations of the people involved:

> *I was always very aware there were people treating me differently and either for positive or negative, and I didn't particularly like going through it really (Daniel)*

In general, the feeling of being undesirably different seemed to be a defining characteristic of the participants' school experiences to the extent where their earliest memories of primary school were of a place where they did not belong and were not necessarily welcome:

> *I was just so different from everyone else that not even the teachers really knew how to address me, and I just felt really...like I wasn't meant to be there at all (Sophie)*

4.3.2.2. Theme 2: The various guises of bullying

For most participants, being perceived as different by others was intrinsically connected with experiences of bullying. Unquestionably, bullying was the most prominent and emphatic theme in the data for this group. Most participants could recall numerous instances of overt bullying such as name-calling or physical assaults:

> *…from kids it was mostly name-calling or…they'd hit me on the back with a stick or something...then run away. (Daniel)*
>
> *Kids…are just so cruel. They would like call me weird... "who'd be friends with her?" and like just really horrible stuff (Sophie)*

However, much of the bullying reported involved acts of hostility that were much less explicit or immediately obvious. Typically, these more subtle forms of bullying involved varying degrees of social exclusion which possibly made them more difficult for the participants to clearly identify. There was a sense in some of the participants' accounts that they were simply disregarded by their peers. In the case of Holly, her recollections of social exclusion carry with them a sense of being invisible or existing in a liminal space quite separate from their peers:

> *…being picked later for sports teams or just not having people to sit with at lunch...or kind of having difficulties like finding the right things to talk about that people would be interested in...or not being invited to birthday parties (Holly)*

This idea of visibility extends paradoxically to the level of support that was available to the participants. Despite not necessarily being formally identified as autistic in primary school, several participants had access to certain accommodations in order to support their learning, such as permission to leave the room when feeling overwhelmed or access to a teaching assistant. However, instead of contributing to a greater sense of inclusion, the visibility of this support tended to magnify participants' differences and increased their vulnerability to bullying to the extent where they would often avoid using the support available to them:

> *Sometimes I was allowed to leave [the class] and pace in the corridor but I often didn't do that cus...people would bully you then because of that. Or like, pick on you for leaving (Sophie)*

> *I had a teaching assistant [mimicking peers] "oh yes, he's different. He's got a teaching assistant" and people would bully me because of that. (Daniel)*

The participants reported not only bullying from their peers, but also from their teachers. All participants recounted experiences where a teacher had behaved in ways that were perceived as hostile and aggressive. There was a sense among the participants that they were not particularly liked by their teachers and, as expressed by Callum below, this was as confusing as it was painful:

> *The main person that put me off in primary school was my year 5 teacher who used to bully me quite a lot… I don't know why she had such a problem with me but...she just seemed to have this real dislike for me and I don't know why (Callum)*

In the case of Sophie, the hostility she experienced led to her feeling so afraid of her teacher that she would experience overwhelming anxiety which led to a reluctance to attend school:

> *My…teacher really bullied me really...um...and made me scared to go to school every day…it got to the point where like...every day…I was...literally shaking (Sophie)*

When invited to describe the kinds of teacher behaviour which constituted bullying, the participants recounted experiences that were distinctly different to the bullying from peers. As already explored above, the bullying from peers tended to take the form of verbal and physical assaults where the intention to cause harm and upset was clear, along with more subtle forms of social exclusion. However, when exploring the nature of the bullying by teachers, the participants described behaviour which may have had a different motivation. Rather than behaving in obviously harmful or exclusionary ways, much of the participants' recollections centred on teachers implying that if they were 'less autistic', life would be easier for them. As exemplified in this contribution from Daniel, teachers were instrumental in reinforcing the idea that participants were 'not normal' and to rectify this, their behaviour needed to conform more closely to non-autistic expectations:

> *[I] remember a teacher...basically saying...the way that you'll get bullied less if you act like a normal person...and the reason he said that was that I liked to just sit read a book erm, and not go play football (Daniel)*

Daniel's recollection here also carries with it a hint of blame; the idea that he is in some way responsible for being bullied by his peers. This is also evident in Georgia's quote below in which she describes how her teacher claimed to be acting in her best interests by highlighting what she perceived as Georgina's selfishness. However, regardless of the teachers' intentions, they actively contributed to the participants' anxiety and sense of marginalisation:

> *[The teacher] told me that she was doing it for my own good. I was very clear I didn't want friends and she thought that made me, like, selfish, like 'one day you're going to regret you didn't make friends when you were younger' (Georgia)*

4.3.2.3. Theme 3: The emotional labour of 'being good'

Given the hostility experienced by the participants which sometimes involved explicit references by people in positions of power and authority (i.e. teachers) to the unacceptability of their behaviours, preferences and choices, it is unsurprising that most participants reported feeling under significant pressure to behave in ways that could be seen as more neurotypical or 'normal'. In the case of Daniel, this led to increased anxiety and feelings of self-consciousness:

> *I was always very nervous about trying to fit in potentially so like, making sure I didn't go do anything that would be not normal (Daniel)*

Like Daniel, some participants' attempts to be accepted by those around them involved considerable effort. Holly's account below offers insight into the effort she expended while trying to mask her differences in an attempt to be socially accepted:

> *I was always aware that I was different and so I always strived to be similar, which was obviously really hard as I'm not similar... I had to go to school*

> *knowing that I was not going to fit in that day and things were going to be hard and teachers were going to be hard…I was putting everything on, you know, and trying so hard to please everyone because to me, it did matter and I really did want to make friends (Holly)*

One notable exception to this theme was expressed by Callum. As shown in the quote below, he shared Holly's strong desire to make friends, but he wanted to do so on his own terms and thus rejected the pressure to conform. However, he acknowledged that this left him isolated and has possible links to the notion of invisibility expressed earlier in this section:

> *I did want friends, but I didn't want to change for anyone…I mean…I'm not going to like...change myself and be like...fake just to make friends with people […] I just kind of [had] no interactions with the other kids, because I kind of acted like they weren't there and they acted like I wasn't there (Callum)*

Nevertheless, all participants reported feeling often overwhelmed by the emotional labour involved in either blending in or coping with the fallout of non-conformity. Invariably, the effort expended in attempting to disguise their authentic identities or cope with others' hostility led some participants to supress their emotional responses while in school and wait to release some of the tension in the safety of their homes. In the case of Sophie, this led to challenges and tensions in her relationship with her mother:

> *In school, I would bottle it up. And try and be good to kids and good to teachers. And that's probably why me and my mum never got on because I probably just exploded on her really. Like, just let rip (Sophie)*

This idea of 'trying to be good' as expressed by Sophie appeared to be central to the participants' experience of primary school. They wanted to have a good school experience and they knew that pleasing the people around them was central to that so most of the participants worked hard to try to win the approval of others. However, they lived with a pervasive sense of somehow always failing to meet the required standard, despite their efforts. Stemming from this was a sense of frustration that their attempts to fit in were not matched by comparable efforts on the behalf of school and peers to include them or adjust to their needs:

> *I liked school, but school didn't like me (Katie)*

4.3.2.4. Theme 4: Looking back

It was clear in the data that looking back on their primary years from the position of early adulthood had considerable significance for the participants. Many of the challenges they experienced had only been fully understood and articulated with the passing of time. For some participants, it was only now in early adulthood that they realised how difficult their primary school years had been:

> *I thought I was happy but I wasn't really (Georgia)*

For many participants, this growing realisation went hand in hand with discovering their autism and developing a deeper understanding of what that meant to them. This included acquiring the necessary vocabulary and awareness of concepts to fully understand what had happened to them. For some, they felt that they had had to develop this awareness on their own because they had not received the necessary support in their younger years:

> *I think my change of awareness of how I was in primary school kind of comes from…learning. I knew it was difficult to make friends, but I didn't kind of have a way of saying like "well, that could've been social anxiety." There was no one to kind of help figure that out (Holly)*

For some participants, looking back on their primary years and the lack of support they had experienced brought about strong emotions. The difficulties they had faced and the long-term impact those difficulties resulted in ongoing feelings of anger and resentment:

> *Looking back, like, it just makes me angry. I'm just, like, full of anger because if they'd just intervened a bit earlier, y'know…maybe I wouldn't have gone through all that mess (Sophie)*

Looking back on their challenges also meant that the participants were well placed to comment on how improvements could be made to the education system. All participants had strong views about what they would change. All agreed that more needed to be done to create more tolerant school cultures with more awareness and understanding of autism on the part of teachers and parents. Arguably connected to the idea of an autism-friendly school culture, participants commented on how they wished they had been able to be themselves more authentically during their primary school years. In the case of Callum, there is a suggestion that this would have involved the rejection of the notions of normality which were pervasive throughout the group's recollections of their early school experiences:

> *To some extent I still, kind of, wasn't really being myself the whole time and sometimes I would try to pretend to enjoy stuff when I didn't, just to try and kind of feel like I was doing something normal when in fact I was just lying to myself. So, I should have started being myself earlier (Callum)*

4.4. Discussion

On a surface level reading, many of the findings of the present study align with the results of the metasynthesis. Feeling undesirably different, being bullied, and the emotional impact of having to cope in an unsuitable environment were themes also evident in the metasynthesis. However, as already detailed in the previous chapter, most of the literature included in the metasynthesis related to the secondary school experience whereas the data from this present study was rooted exclusively within the context of primary school. As such, it extends my understanding in several important ways which I will now discuss.

As has already been explored in this thesis, we know that autistic children experience significantly greater difficulties in school than their non-autistic peers. In accordance with the predominant medicalised view of autism, much of the extant literature attributes many of these difficulties in some way to perceived impairments and deficits associated with autism. For example, academic difficulties have been attributed to impaired cognitive processes (Mayes & Calhoun, 2007; Oswald *et al.*, 2016), social difficulties to communication and interaction deficits (Chamberlain *et al.*, 2007; Kasari *et al.*, 2011), and psychological distress to an inability to regulate emotions and differences in neurobiology (Baron-Cohen *et al.*, 2000; Cibralic *et al.*, 2019).

My own research does not and cannot challenge the veracity of these ideas but it suggests that there may be important social and environmental factors at play that have not been adequately investigated or taken into consideration in much of the historical research relating to the education of young autistic children. As such, the findings of this study invite us to consider the extent to which the social and medical models of disability influence everyday practices in schools in relation to autistic children. Indeed, this is a consideration which arguably applies to all three studies in this thesis and is explored in more depth in the chapter 6.

In the case of the present study, the autistic participants spoke clearly of how difficult primary school was for them. When invited to reflect on these difficulties, they spoke mainly of their interactions with peers and teachers. They reported feeling disliked and othered by the children and adults around them. They spoke of feeling unwelcome at school and gave examples of situations where peers and teachers were openly disapproving or critical of them. In particular, the importance given in their primary schools to the appearance of 'normality' and the negative attention they received whenever they strayed from accepted behavioural norms seemed to be central to their experiences of stress and difficulty.

This aligns with research which suggests that non-autistic adults can view autistic people unfavourably, describing them as unlikeable and awkward (Sasson *et al.*, 2017), as behaving in ways that "violate societal norms" (Huws & Jones, 2010, p. 336), and even as dangerous and potentially threatening (John *et al.*, 2018). Within the specific context of child peer relationships in primary school, it has been suggested that autistic children experience lower reciprocity and acceptance than non-autistic peers (Chamberlain *et al.*, 2007). They are more likely to be rejected and actively excluded by their peers (Dean *et al.*, 2014), and as a result, autistic children have been observed to spend significantly more time alone in school than non-autistic children (Rotheram-Fuller *et al.*, 2010). There are also a number of studies showing that non-autistic children may have negative attitudes towards autistic children (Campbell *et al.*, 2004; Swaim & Morgan, 2001) and favour children with intellectual and developmental disabilities less than those with more obvious physical disabilities (Nowicki, 2006).

This has led to the long-held view of some observers that the negative attitudes of typical peers constitute one of the most significant barriers to the inclusion of disabled children in mainstream settings (De Bruin, 2020; Nowicki & Sandieson, 2002) , with key commentators on the English SEND system remarking that "simply having a mainstream placement is not the same as inclusion" (Brian Lamb OBE, cited in Webster, 2022, p. iii).

With regard to negative staff and peer responses to their innate ways of being, the participants in the present study reported feeling under significant pressure to change their behaviour so as to appear more 'normal'. There was a sense in their responses that if they could adjust their behaviour to align more closely with typical norms, they would be more liked and accepted by their teachers and peers. With the exception of Callum who actively resisted the pressure to change or adapt to the expectations of others, they each gave insights into how much effort they expended in order to mask aspects of their autistic identity which could mark them out as different from their peers.

Although research on autistic masking is still in its infancy (Cook *et al.*, 2022), it has been defined as the range of conscious and unconscious strategies used by autistic people to adapt to and cope with predominantly non-autistic societal norms and expectations (Hull *et al.*, 2017; Lai *et al.*, 2017; Pearson & Rose, 2021). These strategies tend to involve suppressing aspects of one's autistic identity while trying to adopt more typical social linguistic and behavioural conventions in order to be more socially accepted (Cook *et al.*, 2021). While these strategies have been shown in small-scale qualitative studies to be adaptive methods for avoiding potential awkwardness and conflict in social experiences with non-autistic people for some autistic adults (Hull *et al.*, 2017; Livingston *et al.*, 2019), the costs of using such strategies have been shown to be significant.

Essentially, masking has been associated with feelings of not belonging which, in turn, are associated with poor mental and physical health outcomes including exhaustion, poor sense of self, and suicidal behaviours in autistic adults (Bradley *et al.*, 2021; Pelton & Cassidy, 2017; Pelton *et al.*, 2020). Furthermore, the participants in the present study reported that despite their effortful attempts to try to fit in, they continued to experience social exclusion and bullying and so experienced none of the adaptive effects of masking identified by some adults in the literature.

Sadly, the extent of the bullying experienced by autistic children in schools is well-documented (e.g. Humphrey & Hebron, 2015; Maïano *et al.*, 2016; Rowley *et al.*, 2012) and, as such, I had anticipated that participants may share experiences of bullying by peers. However, the discussions relating to bullying by teachers were unexpected and, to my knowledge, not reported elsewhere in the autism education literature. Extending my search to the broader education and psychology literatures, it is notable that school bullying is conceptualised as a uniquely child-to-child phenomenon. It is defined as a form of repeated aggression on the part of someone who is socially or physically more powerful (Olweus, 1993) and more recent conceptualisations also include the intent to harm as part of the definition (Maïano *et al.*, 2016; Schroeder *et al.*, 2014).

It is certainly the case the teachers referred to in this study were in positions of power over the participants. However, while not naive to the possibility, I would hope that the intent to harm is not commonplace among teachers. Furthermore, some participants described the bullying they had experienced by teachers as potentially driven by misguided but nevertheless good intentions. As such, the definitions of bullying in childhood found in the literature did not align fully with the phenomena my participants were describing and did not capture the stigma inherent in the recounts of their experiences. In terms of a identifying a suitable theoretical lens through which to understand these experiences, the literature around bullying in childhood was arguably less suitable than the concepts of microaggression and microinvalidation found in the literature on discrimination in ethnic minority groups.

Microaggressions are defined as frequent subtle verbal, behavioural or environmental hostilities directed towards a person on the basis of an aspect of their social status (Sue *et al.*, 2007). They can be intentional or unintentional and can be perpetrated at both an individual and institutional level (Sue, 2010). Sue explains that microinvalidation, a particular form of microaggression, is characterised by hostilities that “exclude, negate, or nullify the psychological thoughts, feelings, or experiential reality” (Sue *et al.*, 2007, p. 274) of a person because of a particular characteristic.

These forms of hostility have been most widely studied within the context of discrimination on the basis of ethnicity and while there are relatively few published studies on microaggressions in the autism literature, there have been some studies conducted with disabled adults which show the pervasive erosion of identity that can occur with repeated exposure to such experiences (Eisenman *et al.*, 2020; Keller & Galgay, 2010; Olkin *et al.*, 2019). Of particular note are the categories of microaggressions towards people with disabilities as identified by two of these studies. Keller and Galgay (2010) identified the following: *denial of personal identity*, *denial of disability experience*, *denial of privacy*, *helplessness*, *secondary gain* (when providing support to a disabled person is seen as a good deed), *spread effect* (when expectations about a person are closely tied to a specific aspect of their disability), *infantilisation*, *patronisation*, *second-class citizen*, and *desexualisation* (denial of being regarded as a sexual individual). Olkin *et al.* (2019) suggested a further two categories: *symptoms not being believed by a medical professional* and *disability being discounted by others based on looking healthy and young*. Given the fact that these categories were derived from research with adults, some do not fully relate to the lives and experiences of young children as is the focus of this discussion (e.g. desexualisation). Nevertheless, there are some strong alignments between the above classifications and the experiences described by the participants in the present study.

In particular, the category of *denial of disabled identity* related to many of the participants’ experiences of being told in subtle and overt ways that their innate ways of engaging with the world were wrong or in need of modification. It also extends to the negation of their experiences of distress and the implication that if they simply tried harder to be like everyone else, their school experiences would improve. Keller and Galgay (2010) define the category of *denial of privacy* as involving demands for information that a disabled person may wish to keep private. In the case of hidden disabilities such as autism, they note that “…the request may not be for information about [someone’s] disabilities but rather for them to simply identify themselves as people with disabilities in order to explain why they might do something differently” (Keller & Galgay, 2010, p. 252). Arguably, this particular category of microaggression could be said to relate to the participants’ experiences of being criticised for their personal preferences such as Daniel’s preference to read a book instead of playing football with his classmates during break times, or Georgia’s experience of being told she was selfish for preferring her own company over that of her peers. It is clear in the contributions from these two participants that in the absence of an acceptable explanation for their preferences, they were met with irritation or concern.

Given that the majority of participants were not identified as autistic until their adolescence, it is also possible that Olkin et al's category of *symptoms not being believed by a medical professional* could be adapted to include educational professionals. Each of the participants described experiences of disablement in primary school which were either dismissed, overlooked, or attributed to some form of character fault or attitudinal problem. While not being solely responsible for identifying autism, teachers occupy a position of influence in the diagnostic process (Hosozawa *et al.*, 2020) and this form of microaggression may have played a part in the time it took for some participants' to access diagnostic services.

Most relevant to this discussion, however, are the findings of Hodge *et al.* (2022) whose study with autistic adults and parents of autistic children into the impact of the casual (and often unconscious and unintended) ways some teachers talk about autistic children found that the categories described above did not adequately represent the "unbridled ferocity and cruelty" (p.26) of how some of their participants (or their children) had been spoken to while at school. Their participants reported being talked about and to in a range of ways so dehumanising as to have had, for some, a lifelong negative impact on their sense of self. To this end, Hodge and colleagues suggest the novel category of *denial of personhood* to reflect acts of aggression which they argue are "more than a failure to recognise a person's identity; rather it is the denial of them as a person" (p.32).

Therefore, the experiences described by my participants might be most clearly interpreted as a form of disablism in which the inherent characteristics of the autistic child may be seen by some members of school staff as undesirable and unwelcome. I will discuss this in more detail in chapter 6, but this interpretation chimes with previous research on the negative attitudes held by some primary school teachers towards the inclusion of children with special educational needs and disabilities (De Boer *et al.*, 2011). It also connects with observations that the enforced homogeneity and focus on normativity in schools can actively disadvantage autistic children (E. Williams *et al.*, 2017). The findings of this study are also supported by previous research which indicates that autistic people can be misunderstood by non-autistic people, resulting in their behaviour being misperceived as awkward and unlikable (Alkhaldi *et al.*, 2019; Sheppard *et al.*, 2016). This has serious implications for wellbeing across the lifespan, but it is arguable that experiencing misunderstanding of this nature on a daily basis during a formative developmental period could have very serious implications for child mental health and school-related outcomes.

The findings of this study call into question the veracity of interventionist approaches to autism support in schools, as these tend to be predicated on the autistic child needing to adapt to the predominantly neurotypical expectations of mainstream school culture. As highlighted above, the potential for such approaches to lead to the suppression of autistic behaviours and increased masking is considerable and the unintended consequences could be harmful. Instead, the findings of this study suggest that adjustments are required on the part of school staff and peers to create school cultures that are more understanding, accepting and welcoming of autistic ways of being.

4.5. Strengths and limitations

This study makes a novel contribution to the literature on the autistic school experience. As discussed above, there are very few published papers on autistic experiences of microaggressions and only the work of Hodge *et al.* (2022) addresses this topic within the context of compulsory education. However, their study does not discuss specific stages of education, therefore it is possible that the present study is the first to focus specifically on such experiences within the context of primary school.

However, this study does have some notable limitations. Firstly, the order in which the focus groups were conducted may have had a bearing on the results. Due to participant availability, the autistic adult group discussion and one-to-one interview took place after the parent and teacher groups. Because of this, I did not ask the parent and teacher groups about some of the important (and hitherto unknown to me) topics raised by the autistic participants. It is possible that the parents and teachers may have provided valuable contributions on the subjects of bullying and stigmatising attitudes had they been asked. In retrospect, the contributions of the autistic adults should have provided the foundation to how I conducted the other group discussions.

In addition, it is possible that had I conducted one-to-one interviews with the parents and teachers rather than group discussions, I may have been able retain a more child-centred focus for the discussions. It is possible that being in a group of peers with similar experiences, possibly for the first time, encouraged more sharing of personal challenges and took the focus away from the children in question. The results of this study have also led me to question whether it is ever possible to access an individual's experience via another person, and whether speaking to predominantly non-autistic teachers and parents is an effective way of collecting data relating to the everyday experiences of autistic children.

It is also important to point out that due to taking a break from my PhD for career purposes, the analysis of the data in this study was delayed. This meant that I was not able to check my findings with my participants and they were not given the opportunity to comment on the constructed themes. As such, I have not checked that my participants were in agreement with my understanding of the data and the findings above are based solely on my own interpretations in collaboration with my supervisors.

Finally, the autistic adults in this study were looking back on their primary school experiences from the position of some distance. This was an intentional aspect of the study design and featured prominently in the fourth theme, *looking back*. However, to some observers the fact that participants' perceptions of their childhood experiences may have changed over the years could be seen as a limitation of the study. I would argue though that it is possible that the challenges they experienced could only be rationalised when the bullies no longer had influence over them and when they no longer had to mask in order to cope day by day. It is possible that these experiences took years to process so it is arguable that exploring difficult experiences retrospectively may also have considerable advantages.

4.6. Conclusion and implications for the child study

The results of this study show that the participants' primary school experiences were largely negative with few participants sharing positive reflections on their early school years. Their experiences appeared to be characterised by routine invalidations and hostilities which led to anxiety about fitting in and social acceptability. These experiences had long lasting implications in terms of self-esteem, self-concept and general wellbeing. From an early age, the participants felt a strong sense of being 'other' which was largely mediated through their interactions with peers and school staff. In particular, the participants cited some peers but mostly teachers as instrumental in their invalidation at primary school.

While the primary purpose of this study was to inform the interview schedule for the child study in the next chapter, the findings were unexpectedly enlightening in ways that have played a major role in shaping not only the child study but also my thinking around my PhD topic as a whole. Prior to conducting this study, I knew that autistic children tended to have more difficult school experiences than non-autistic children. I imagined that what might be needed to address those difficulties possibly involved the provision of more support or resources. I was not sure of the specific nature of that support but I thought, in the spirit of the SEN Code of Practice (Department for Education and Department of Health, 2015) and its philosophy of 'different from and additional to', it would likely be something that needed to be *provided to* autistic children.

The results of this study changed my perspective on that. The data from this study suggested that providing more resources or support to autistic children was not necessarily the way to address their difficulties since focusing on the child without looking at the environment in which they live their lives is not necessarily helpful. Furthermore, we know that the current interventionist approach to autism support in schools is not achieving its intended goals because it has been in place for decades but outcomes for autistic children and young people continue to be poor. This study made me curious about shifting the focus of intervention to factors beyond the child in the school setting.

Historically, the impact of environmental and cultural factors in education on autistic children has received very little attention. The idea that school environments and the attitudes of the school community could be at the heart of the challenges an autistic child is experiencing is not one that is openly discussed. It is these issues that played a key role in the design, development and execution of the study which now follows.

5. Chapter 5: Study 3

Autistic children's everyday experiences of mainstream primary school

5.1. Introduction

Thus far, the research described in this thesis has shown that autistic children in mainstream schools routinely experience significant levels of social, emotional, and academic challenge. The metasynthesis in chapter 3 included 78 qualitative studies on the subjective experiences of autistic children in mainstream schools published between 2000 and 2022. Collectively, these studies involved a total of 277 autistic children and young people aged between 7 and 19 years old (203 male, 45 female, 29 gender not reported). The findings of the metasynthesis suggested that developing and maintaining rewarding peer relationships, meeting the academic demands of school, and coping with the sensory aspects of the physical school environment were particularly difficult for autistic pupils. The second study, as detailed in chapter 4, described how the normative culture of school can be particularly difficult for autistic young people who can experience bulling and hostility as a result of being perceived by others as undesirably different.

While the findings of these studies link with similar themes in the existing literature (e.g. Calder *et al.*, 2013; Humphrey & Lewis, 2008; Kim *et al.*, 2018; Locke *et al.*, 2010; Mallory & Keehn, 2021), much less is known about how these challenges are experienced by young autistic people and what they mean in terms of impact on day-to-day school life. This is particularly so for autistic children of primary school age who do not meet the criteria for an EHCP or have access to specialist resources. As demonstrated by the metasynthesis, such children are an underrepresented group in the extant qualitative literature. It is arguable that without a better understanding of what it means to be such an autistic child in a mainstream primary school, efforts to improve outcomes for this group of children are necessarily limited and perhaps even misguided.

To contribute towards this gap in the literature, the present study explores the lived experiences of autistic children in mainstream primary schools by way of an inductive qualitative investigation. The following primary research question guided this study: how do autistic children describe and make sense of their everyday experiences of mainstream primary school? In addition to this, I was interested to know the extent to which the experiences of primary-aged autistic children aligned with those of the predominantly secondary-aged children in the literature reviewed in the metasynthesis in chapter 3. Therefore, this study also considered the following secondary research questions: 1) what are the challenges experienced by autistic children in mainstream primary schools?, and 2) which strategies do autistic children use to overcome any challenges they encounter?

5.2. Methods

5.2.1. Design

Interpretative phenomenological analysis (IPA) is a qualitative research approach which although first introduced the field of health psychology in the mid-1990s (Smith, 1996), is rooted in the theoretical philosophy of the early to mid-20th century. In particular, IPA is underpinned by phenomenology – the study of human experience, and hermeneutics – the theory of interpretation (Smith *et al.*, 2022). As such, IPA is committed to a detailed examination of how individuals experience and make sense of important life events.

Central to this process is the 'double hermeneutic' – the process by which the participant makes sense of their experiences while the researcher makes sense of what the participant is describing. Smith (2004) underlines the key role of the researcher in the double hermeneutic element of the approach by noting that "the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (Smith, 2004, p. 40). This process is centred on the idea that interpreting what is meaningful is a co-constructive act between participant and researcher with the aim of coming to a deeper understanding of the phenomenon in question. In short, this process is centred on the researcher attempting to "understand what an experience…is like from the participant's perspective" (Pietkiewicz & Smith, 2014, p. 8).

In contrast to positivist methodologies in psychological research in which the eradication of bias is a central concern, IPA's hermeneutic approach to interpretation "acknowledge[s] the inevitability of biases, preoccupations and assumptions when conducting research" (Eatough & Smith, 2017, p. 6) and requires the researcher to actively and consciously engage with their assumptions in order to enhance and develop their understanding of the participant's experience. This stepping outside one's cultural heuristic is referred to as 'bracketing' and has been regarded as a central aspect of the "qualitative sensibility" (Clarke & Braun, 2013, p. 9).

However, as opposed to the principles of descriptive phenomenology which requires the researcher to bracket all their presuppositions in order to observe the essence of experience (Van Deurzen, 1997), IPA recognises that meaning-making is a dual process in which both the participant's and researcher's perspectives on the world are an integral part (Smith *et al.*, 2022). Being conscious of one's perspectives and how they influence the research process is referred to by Dahlberg and Dahlberg (2019) as 'bridling' which they describe as "a sort of self-reflection, a continuous investigation of one's own point of departure, one's presumptions and presuppositions." (pp. 3-4). They posit that the researcher is required to continually question their interpretations to interrogate how and why they have come to their particular understandings. To support me with this, I had additional supervision from an IPA expert who, in addition to my usual supervisors, guided me through the process of interrogating my interpretations in a rigorous way which will be discussed in detail in the methods section below.

IPA also has an idiographic focus, meaning that it is committed to the detailed examination of individual experiences from the perspective of the individual. According to Eatough and Smith (2008), "IPA has a…microscopic lens arising from its idiographic commitment, emphasizing the way in which the study of how psychological meanings are constituted can be very usefully pursued through the detailed examination of unique individual lives" (Eatough & Smith, 2008, p. 182). As such, IPA stands in contrast to the majority of methods in psychology which are primarily concerned with measuring and understanding phenomena at a group or population level.

It is this combination of the experiential, interpretive and idiographic theoretical underpinnings of IPA which make it distinct from the thematic analysis in the previous chapter. I could have used thematic analysis for this present study because it can be used to analyse qualitative data in relation to a wide range of research questions and collections methods and this flexibility allows for the detailed examination of lived experience. However, IPA's *compulsory* focus on the individual lived experience is arguably more suited to a study of this kind. As described below, IPA requires a detailed analysis of each case before turning to cross-case comparisons. Commonly, thematic analysis regards all participant data as one dataset from the outset, making it appropriate for the focus group study but arguably less so for the child study (Spiers & Riley, 2019).

Furthermore, because of the theoretical foundation outlined above, IPA is well suited to research with autistic people. The critical focus on researcher reflexivity, the attention given to the lived experience of individuals as expressed by those individuals, and the co-construction of meaning between participant and researcher all go some way towards addressing the double empathy problem that can be a significant barrier to meaningful interpretation between autistic participants and non-autistic researchers (Howard *et al.*, 2019; MacLeod, 2019).

5.2.1.1. Photo-elicitation

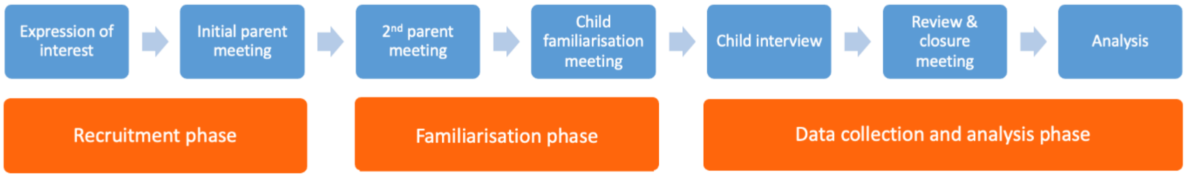
Attempting to overcome the double empathy problem was a central concern when designing and conducting this study. Semi-structured interviews are the primary method of data collection in IPA, and this approach was taken in the present study. However, I was aware that some autistic children may find the cognitive and linguistic aspects of an in-depth interview challenging or even stressful (Harrington *et al.*, 2014; Preece & Jordan, 2010). Furthermore, research with autistic adults has shown that verbal communication can be effortful and tiring for some autistic people, regardless of their perceived productive speech abilities (Donaldson *et al.*, 2021). Therefore, without wanting to make assumptions about my participants' cognitive and communication abilities, I took the decision to offer the choice of non-speaking forms of communication to provide a means for participants to share their experiences in a way that felt most acceptable and comfortable to them. Not only was this option intended to support any participants for whom verbal communication may have been difficult or not preferred, it was designed to create alternative opportunities for all participants to express what was meaningful to them in their school lives.

Photo-elicitation refers to the process by which photographs are introduced into research interviews to gain insights into participants' experiences and perspectives (Bates *et al.*, 2017). In addition to the accessibility benefits outlined above, it has been suggested that due to the evocative and sometimes emotional nature of human responses to photography, this research approach can lead to a level of understanding of experience that might not be readily accessible through verbal discussion alone (Croghan *et al.*, 2008). The photographs used in such interviews can be sourced by the participants or the researchers (Clark-IbáÑez, 2004). However, it has been noted that participant-led photography can address some of the power differentials between researcher and researched – resulting in greater autonomy and control over the interview for the participant, and hold more meaning for the participant than researcher-sourced images (Croghan *et al.*, 2008; Scott-Barrett *et al.*, 2018; Van Auken *et al.*, 2010). This participant-driven approach appealed to me given the potential it offers for a greater degree of co-creation of knowledge and how this aligns with the double-hermeneutic principles of IPA.

5.2.2. Procedure

As set out in figure 3 below, this study followed a seven-stage process involving three distinct phases: recruitment, familiarisation, data collection and analysis. I will now expand on each of these phases in turn.

Figure 3: Seven-stage procedure for the child study



5.2.2.1. Recruitment phase

(a) Sample and selection criteria

Given IPA’s idiographic focus, it is best suited to small groups of reasonably homogenous participants who all share a particular experience (Smith *et al.*, 2022). The detailed experiences of each participant are then analysed across the group in order to identify areas of convergence and divergence. In terms of sampling, these areas of similarity and differences are best analysed “within a group that has been defined as similar according to important variables” (Pietkiewicz & Smith, 2014, p. 9). In the case of this study, these important variables formed the inclusion criteria listed in table 6 below:

Table 6: Child study inclusion criteria

Criteria	Rationale
Aged 9 – 11 years old	I selected children in the last 2 years of primary school to maximise the length of primary school experience and the potential to articulate that experience either verbally or in writing.
Equal gender split	There is some evidence to suggest that gender differences may impact on the school experience of autistic children (Dean *et al.*, 2017; Mandy *et al.*, 2012). In order to provide as much scope for any such differences to be identified in the data, the decision was taken to recruit equal numbers of boys and girls.
Clinical diagnosis of autism as confirmed by parent-carer	Children with a confirmed diagnosis of autism from a suitably qualified NHS or independent health professional/clinician were selected in order to establish a level of diagnostic consistency in the group.
Child is aware of their diagnosis	The autism-specific focus of this study was transparent throughout so it was necessary that participants were aware of their neurodivergence and were comfortable with discussing it should it come up in the course of the investigation.
Not in receipt of an Education Health and Care Plan, or in the process of being assessed for one	Autistic children who do not meet the criteria for an Education, Health and Care Plan and do not attend schools with autism units or have access to specialist resources represent the majority of children in the English education system but are underrepresented in the qualitative research to date. This study focuses on this particular population in order to contribute towards this gap in the literature.
Currently enrolled in a mainstream primary school without specialist autism resources	

In addition to these criteria, there were some methodological and practical considerations central to the selection process. In the first instance, it was decided that while IPA is well suited to case studies and samples of just a few participants, I would aim to recruit ten; a small enough sample to be able to analyse the data in depth but large enough to provide a broad range of experiences while still keeping the analytical focus on the idiographic. Additionally, this figure broadly aligns with the numbers of participants in previously published IPA autism studies, potentially enhancing the possibility of future publication (Howard *et al.*, 2019).

This study began in July 2021 as schools were beginning to reopen after the closures of the Coronavirus pandemic. However, infection control was still a significant concern and there were strict rules in place within schools to enforce social distancing including restricted access to visitors. In light of this, it was decided that in the interests of safety and comfort, interviews would be conducted remotely rather than in person. As a result, it was important participants had access to, and familiarity with, an internet-enabled device with video conferencing software e.g. Microsoft Teams, Zoom, Skype, Google Meet etc. Fortunately, due to need to switch to online learning in the early months of the Coronavirus pandemic, all participants had developed a good level of competence using video conferencing tools and told me they were comfortable conducting the study by these means. Furthermore, the use of such technology rather than meeting in person meant that the participants had a range of ways of communicating with me (video, voice-only, text-only) and could avoid any aspects of social communication (e.g. eye contact) which may have been uncomfortable or stressful for them (Scott-Barrett *et al.*, 2018).

While remote interviews were initially viewed as a necessary but potentially inferior alternative to face-to-face interviews as a result of the coronavirus pandemic, they proved to be enormously beneficial to this study. In addition to the advantages listed above, it was clear that being able to participate in the study from the comfort and familiarity of their own homes was instrumental in helping the participants feel more at ease during the data collection process. At various points during the interviews, participants introduced me to family members, pets and cherished objects and possessions which enabled me to develop a greater sense of their personalities and understand more about what mattered most to them. Participants were also able to achieve sensory comfort by wearing whichever clothes they preferred and choosing rooms and seating or lying positions which suited them best. It would have been very difficult, if not impossible, to recreate a similar level of comfort in a typical university research setting and it is my assertion that the benefits of conducting the interviews remotely are reflected in the richness of the data collected.

(b) Recruitment process

Ethical approval was obtained from The University of Reading Research Ethics Committee (2021-080-FK), after which the recruitment sheet (Appendix D, page 212) was distributed across parent-carer and school networks via email and social media. Parents were the primary gatekeepers in this study, therefore they were targeted directly and schools were asked to share the recruitment sheet with any eligible parents in their communities. After the initial expression of interest (telephone or email), parents were invited to an initial telephone or video conversation (their preference) with me in which the study was discussed in more detail. At this stage, the child's suitability for the study according to the inclusion criteria above was determined. If the child met the criteria, and the parent verbally consented, the demographic information contained in Table 7 below was collected.

At this stage, the parent was sent via email information sheets for themselves and the head teacher of their child's school, a consent form, and a head teacher permission form (copies of which are contained in Appendix D, pages 213 and 220). These documents included an explanation of the nature and aims of the study and an outline of the photography element of the project. Parents were asked to give consent for their children to take part in the study whereas schools were asked to give permission for participants to photograph any aspect of their school life they perceived to be meaningful. However, to maintain the privacy of the school community, no photographs were permitted to be taken of people or parts of the school that could lead to the identification of the school or the people within in. Parents were also sent an information pack for their child (Appendix D, page 222) which contained an easy-read information sheet, an assent form, and a graphic 'how-to' guide relating to the photographic aspect of the data collection. Video recorded introductions made by me were also available for children if preferred and two children chose that option.

(c) Participant characteristics

Participant characteristics are detailed in table 7 below. Pseudonyms are used throughout.

Table 7: Child study participant characteristics

Name	**Sex**	**Age at interview**	**Age at diagnosis**	**School year group**	**School size (classes per year group)**	**Communication preference**	**Choice of creative medium**
Amelia	Female	9	7	5	2	Speech	Photography
Chloe	Female	10	5	6	3	Writing/type	Hand-written notes
Emily	Female	10	10	6	2	Writing/type	Photography and digital book
Harry	Male	10	9	5	1	Speech	Photography
Isabelle	Female	9	9	5	2	Speech	Photography
Jack	Male	11	10	6	1	Speech	Photography
Joshua	Male	11	8	6	1	Speech	Photography
Lily	Female	10	7	6	1	Speech	Photography
Oliver	Male	9	9	5	3	Speech	Photography
Thomas	Male	10	8	6	1	Speech	Photography

5.2.2.2. Familiarisation phase

On return of the completed forms from parents, children and head teachers, parents were invited to attend another telephone/video meeting where any questions could be raised and any issues arising from the documentation could be addressed. This second parent meeting was also used as an opportunity for me to learn more about the child's understanding of and attitude towards the study and the materials provided, their access requirements, and communication preferences. I also spent some time asking the parents about their child's general school experience to date, and their hobbies and interests so that I could base the conversation in my familiarisation meeting with the child around subjects they were most interested in.

I then had a familiarisation meeting with each child. The purpose of this was to introduce myself and build rapport and mutual familiarity. I also took this opportunity to discuss the purpose of the study and explore which creative medium the child might want to use to augment their interviews. The primary invitation was to take photographs but other options were explored such as writing and drawing. For those children who expressed a preference for photography, I then reviewed the photography ‘how-to’ guide with them to confirm understanding of the boundaries of the exercise. This initial meeting with the child was also the first instance of the ongoing process of gaining verbal assent and underlining the right of the child to withdraw this assent at any time.

Assent/consent for child participants

Given the ages of the participants, formal consent for taking part in the study was given by parents. However, it was important to me that the participants also actively consented to the process at every stage of the data collection process. Also, given my motivation to not make any assumptions about my participants' communication or cognitive abilities, it was important to ensure that communication of consent was possible in a range of different ways along the entire data collection process. Loyd (2013) offers guidance on how to obtain consent from autistic participants who may communicate and process information differently. They recommend that three specific questions should guide the issue of informed consent in research with autistic children: 1) is consent given freely? 2) is consent given on the basis of adequate information? 3) is the consent ongoing?

In terms of the first question, Loyd maintains that freely given consent is contingent on participants being able to say no; either to taking part in the study or in some other aspect of their participation. However, for autistic participants, saying no may be communicated in non-verbal ways. Therefore, saying no or declining to take part was discussed several times at every meeting with each participant and I attempted to remain alert to non-verbal indicators of whether consent was being given. For example, while no participants withdrew from the study once the interview process began, some participants declined to answer certain questions I posed them. Some participants said openly at points in their interview that they did not want to discuss certain subjects any further, whereas others simply remained silent or changed the subject. I tried to ensure that I was sensitive to both verbal and non-verbal forms of expression of consent and was careful to redirect the conversation once a participant had expressed a wish for it to go elsewhere. Not only was this appropriate in terms of consent, but it also aligned with the iterative and child-directed nature of the methodology.

Participants were also able to say no in very definite ways using the technology we employed for conducting the interviews. They were reminded at the start of each of the three meetings we had together that they could terminate the meeting at any point if they felt uncomfortable or no longer wished to participate. While none of the participants ultimately chose to end any of our meetings, we practiced terminating the online meeting so that participants knew the process for doing so, and they were reassured that they would not be causing any offence and there would be no negative repercussions should they chose to terminate at any point. They were also reminded in each meeting that they could withdraw from the study at any time without giving a reason. In this way, these measures apply to Loyd's third question because they formed part of the ongoing process of gaining consent.

With regard to Loyd's second question relating to the provision of adequate information, consent was gathered in the first instance by providing information about the study in textual, graphic and video forms. The information was also covered verbally in our introductory meeting meaning that there were four different modalities used to express the information. The aim of this approach was to provide information about the study in a range of ways so that participants could access whichever form suited them best (Preece, 2002). All modes of information were piloted for clarity and accessibility with two autistic children who were not taking part in the study prior to being used with the participants. The textual, graphic and video information was then sent to the parents after their expression of interest in the study for them to share with their children and discuss. The children were then asked to complete an assent form and this was discussed with the children at the first meeting with the researcher to address any questions or concerns.

5.2.2.3. Data collection and analysis phase

(a) Topic guide

The topic guide for this study was strongly influenced by the findings of the focus group study in the previous chapter, which in turn was influenced by the findings of the metasynthesis. In particular, the focus group study in the previous chapter particular drew my attention to the role of the teacher in the wellbeing or otherwise of autistic children. The results of that study highlighted the central importance of the pupil-teacher relationship not only to a child's academic success but also their sense of self. Consequently, the child's relationship with their teacher was something I chose to pay close attention to when developing the topic guide for this study.

The previous two studies also emphasised the impact of masking and conforming to behavioural norms. The following comment from Callum in the previous study was particularly instrumental in my thinking about how to approach the subject of being one's authentic autistic self with the participants in the current study:

> *To some extent I still, kind of, wasn't really being myself the whole time and sometimes I would try to pretend to enjoy stuff when I didn't, just to try and kind of feel like I was doing something normal when in fact I was just lying to myself. So, I should have started being myself earlier (Callum)*

Callum's regret about not being himself led me to the importance of the issue of authenticity. Therefore, the questions I was guided by when considering my topic guide for the present study were to what extent are the participants able to be authentically themselves? Do they feel able to engage in their own interests, for example, or do they feel under pressure to conform to the expectations of others? To what extent is their authentic expression of self-supported in their school environment?

Therefore, when developing the topic guide for the present study, I wanted to create a structure to my questions which, while still underpinned by an iterative and participant-led approach, would enable me to address my research questions and build on the research I had previously conducted from a primary-school perspective. Given the children's ages and the potential sensitivity and complexity of these subjects, each interview began with broad open questions relating to most/least enjoyable aspects of school, and the parts of school life where participants felt most/least competent and comfortable. At this point, the participant-created photographs or written materials were introduced and formed the central focus of each interview. In line with the iterative and interpretative nature of IPA, the questions about the photographs were led by the participants and were designed to explore and expand on what the photographs/materials represented in terms of what was most meaningful to each participant. However, the topic guide below was helpful for asking questions that may have not been answered by the children spontaneously in the course of our discussions of their photographs and other contributions.

Topic guide questions:

- What do you enjoy most about school?
- Which parts of school do you find tricky or difficult?
- Who are the people you like to spend time with at school?
- Who do you not enjoy spending time with?
- What is your teacher like?
- What do you like best about your teacher?
- How does your teacher help you?

(b) Interview procedure

The interviews took place between one and four weeks after the initial meeting I had with each child, providing time for the child to plan, take and select 3 to 4 images they wanted to use as part of the interview discussion. One participant, Chloe, chose not to use photographs of her school in her interview but wrote her key points in notes which were then photographed. Another participant, Emily, supplemented her photographs with a self-written digital book. A selection of the submitted materials is shown in Appendix D, page 231. In each case as an additional privacy precaution, parents were asked to email materials to me after ensuring that no photographs or supplementary material containing images of people or other identifying features were submitted. I then created a

PowerPoint slide containing the numbered photographs for use in the interview (example slide in Appendix D, page 233). The interview was semi-structured according to the topic guide above but was led by the child and their images/supplementary materials.

The interviews ranged from 41 to 69 minutes in length and generated 10.5 hours of data in total. These interviews were transcribed verbatim as were the written notes and book contributed by Chloe and Emily respectively. I then carefully reviewed each participant's transcript in order to identify the most salient aspects of their school lives. At this stage of the process, the aim was to ensure that I had understood their words and contributions in enough detail to continue with an in-depth analysis. To this end, once I had identified these key aspects in each of the transcripts, the child was invited for a final checking interview where these observations were discussed in more detail to support a greater level of understanding. Eight participants attended online interviews and two participants chose to complete this part of the project in writing via email. The interviews generated an additional 3 hours of data, and these were transcribed and added to the participant's data files along with the content of any email exchanges.

(c) Analysis

Throughout the study but particularly in the analysis phase, I followed the guidance below as set out by Nizza *et al.* (2021) relating to indicators of good IPA research.

Table 8: The four quality indicators of good IPA (from Nizza et al., 2021)

Quality indicator	Brief description
Constructing a compelling, unfolding narrative	The analysis tells a persuasive and coherent story. The narrative is built cumulatively through an unfolding analytic dialogue between carefully selected and interpreted extracts from participants
Developing a vigorous experiential and/or existential account	Focus on the important experiential and/or existential meaning of participants' accounts gives depth to the analysis
Close analytic reading of participants' words	Thorough analysis and interpretation of quoted material within the narrative helps give meaning to the data and the experience it describes
Attending to convergence and divergence	Idiographic depth and systematic comparison between participants creates a dynamic interweaving of patterns of similarity and individual idiosyncrasy

How I practically worked to meet these quality standards will now be explained with regard to the seven-step IPA process as described by Smith *et al.* (2022). While the founders of this method emphasise that it is not prescriptive, I chose to follow this multistep process in order to provide a structure to my analysis and subsequent writing of the results. I was supported in this process by my internal supervisors but I also had the benefit of an external supervisor who had specific expertise in conducting IPA studies.

Step 1: Reading and re-reading the first case

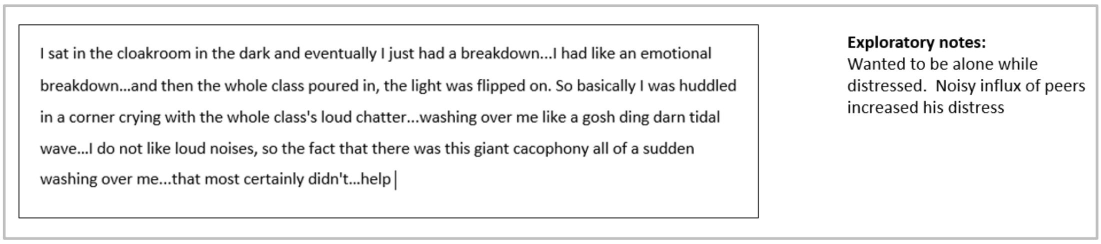
In keeping with IPA's commitment to the sense-making process of each individual participant, the analysis began with me reading and re-reading the first transcript and watching the interview video recordings a number of times so that I could immerse myself in the data. I also reviewed any photographic or textual materials submitted by the participant, but I did not analyse these. Instead, they were used to augment my understanding of the interview data.

Step 2: Exploratory noting

This stage of the process involved line-by-line coding of the data. This can be done electronically or manually, and I chose to do this by hand with the aim of remaining as close to participant experience as possible. This step comprises three distinct aspects which I will demonstrate below with a worked example from one of the participants.

1. In the first instance, this process involves noting anything of interest in the data with the purpose of identifying aspects of the data that are particularly meaningful to the participant.

Figure 4: Worked example of IPA exploratory noting

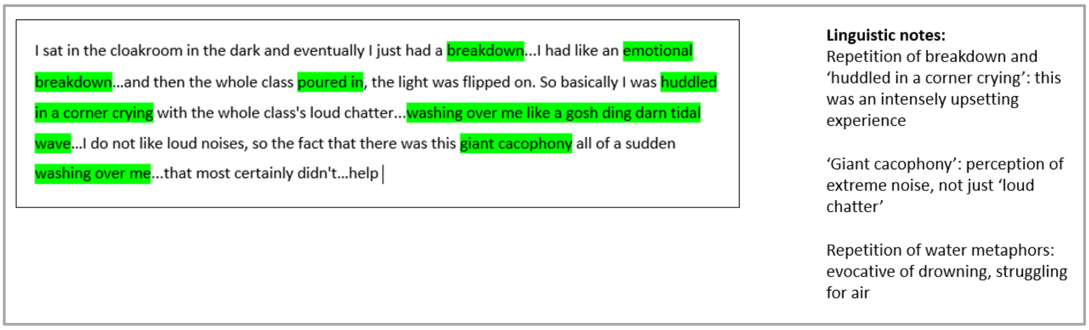


I sat in the cloakroom in the dark and eventually I just had a breakdown...I had like an emotional breakdown...and then the whole class poured in, the light was flipped on. So basically I was huddled in a corner crying with the whole class's loud chatter...washing over me like a gosh ding darn tidal wave...I do not like loud noises, so the fact that there was this giant cacophony all of a sudden washing over me...that most certainly didn't...help

Exploratory notes:
Wanted to be alone while distressed. Noisy influx of peers increased his distress

2. From this point, the noting becomes more detailed with a specific focus on any interesting linguistic elements such as particular grammatical constructions, metaphors, pauses and emphasis.

Figure 5: Worked example of IPA linguistic noting



I sat in the cloakroom in the dark and eventually I just had a breakdown...I had like an emotional breakdown...and then the whole class poured in, the light was flipped on. So basically I was huddled in a corner crying with the whole class's loud chatter...washing over me like a gosh ding darn tidal wave...I do not like loud noises, so the fact that there was this giant cacophony all of a sudden washing over me...that most certainly didn't...help

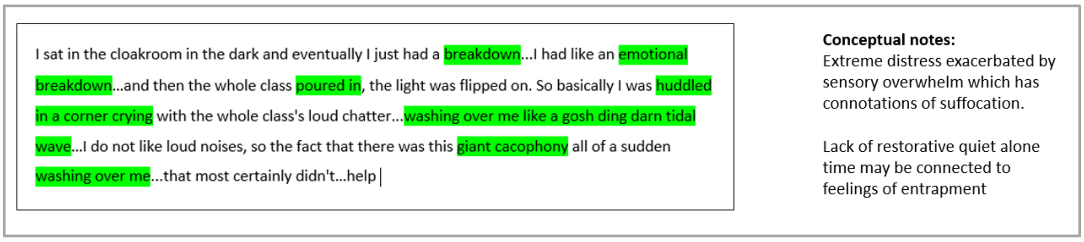
Linguistic notes:
Repetition of breakdown and 'huddled in a corner crying': this was an intensely upsetting experience

'Giant cacophony': perception of extreme noise, not just 'loud chatter'

Repetition of water metaphors: evocative of drowning, struggling for air

3. Finally, the noting moves on to a conceptual level which involves shifting from the participant's explicit contributions to consider their meaning in the wider context of the participant's school experience. This part of the process involves considerable reflection on the part of the researcher; a cyclical process of questioning and revisiting both the parts and the whole of the transcript in a process of sense-making and interpretation.

Figure 6: Worked example of IPA conceptual noting



I sat in the cloakroom in the dark and eventually I just had a breakdown...I had like an emotional breakdown...and then the whole class poured in, the light was flipped on. So basically I was huddled in a corner crying with the whole class's loud chatter...washing over me like a gosh ding darn tidal wave...I do not like loud noises, so the fact that there was this giant cacophony all of a sudden washing over me...that most certainly didn't...help

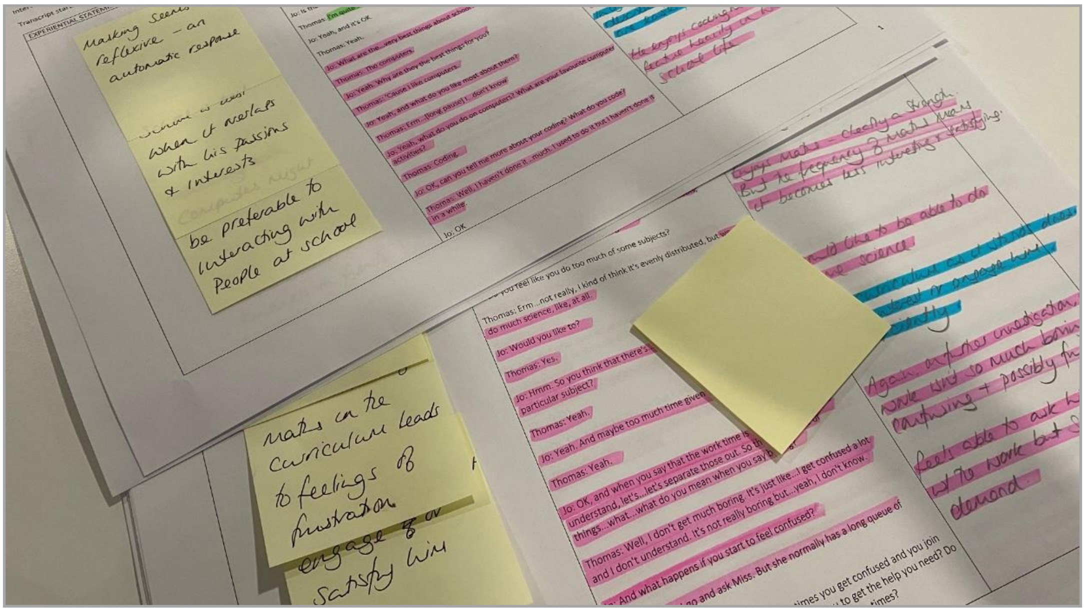
Conceptual notes:
Extreme distress exacerbated by sensory overwhelm which has connotations of suffocation.

Lack of restorative quiet alone time may be connected to feelings of entrapment

Step 3: Constructing experiential statements

The aim of this step is to distil the content from exploratory notes into statements which succinctly describe the participant's experiences while retaining a clear link to the nuance and complexity of their lived experience as expressed in the transcript. These statements are expressed in such a way as to reflect both the participant's words and my interpretation of their words as arrived at through the three levels of analytical noting in step two.

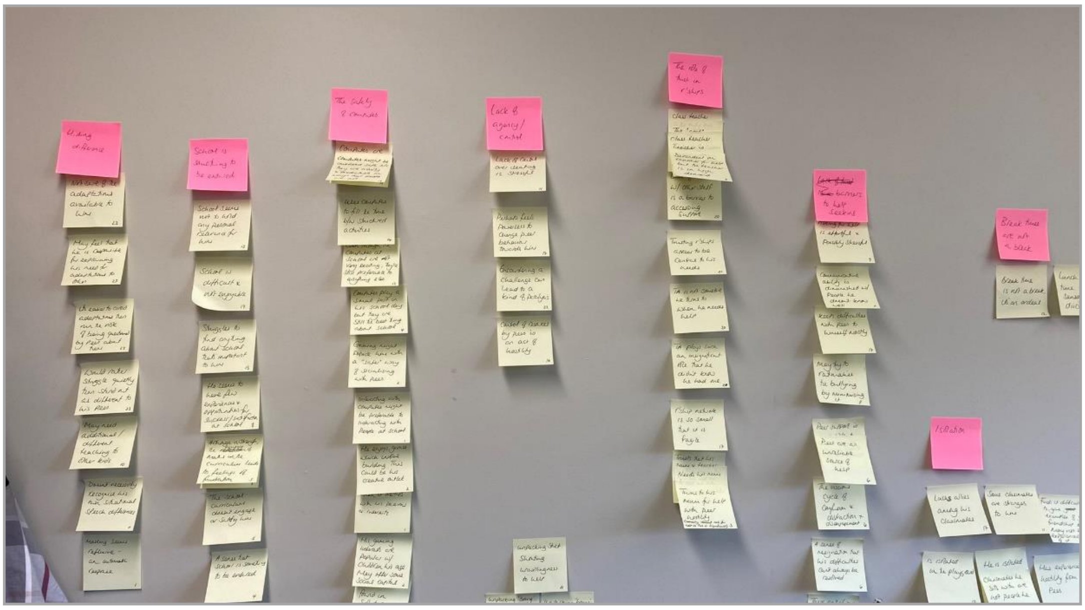
Figure 7: Constructing IPA experiential statements



Step 4: Searching for connections across experiential statements

This stage of the analysis process involves looking for patterns across the experiential statements for this first participant. I did this by transferring all the experiential statements to post-it notes and sticking them to my office wall in no particular order. I then started to group the statements into ‘clusters’ (Smith *et al.*, 2022, p. 94) according to shared ideas or concepts. Using my exploratory notes and the transcript, I was then able to create a structure of connections which represented the most salient and meaningful aspects of the participant’s experience according to my interpretation of the data and in relation to my research questions. As a result, not all experiential statements were included in the structure.

Figure 8: Searching for connections across experiential statements



Step 5: Naming the Personal Experiential Themes and consolidating and organising them in a table

Each of the clusters identified in step 4 is given a descriptive title and these become the participant's Personal Experiential Themes. At this stage, I transferred my hand-written themes to Microsoft Word where they were defined further by being broken down into appropriate subthemes. These subthemes were supported by quotes from the transcript along with their page number so could can be linked directly to the source data. The figure below represents the completion of the interpretative analytical process for one individual.

Figure 9: Naming, consolidating and organising the Personal Experiential Themes

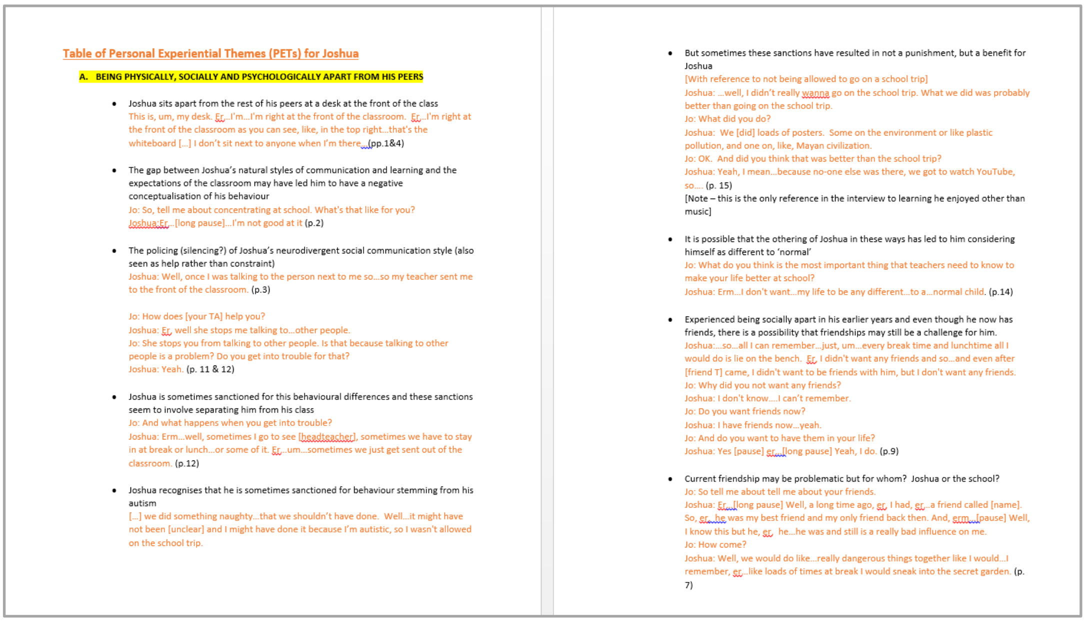


Table of Personal Experiential Themes (PETs) for Joshua

A. BEING PHYSICALLY, SOCIALLY AND PSYCHOLOGICALLY APART FROM HIS PEERS

- Joshua sits apart from the rest of his peers at a desk at the front of the class
  This is, um, my desk. Er...I'm...I'm right at the front of the classroom. Er...I'm right at the front of the classroom as you can see, like, in the top right...that's the whiteboard [...] I don't sit next to anyone when I'm there...(pp.1&4)

- The gap between Joshua's natural styles of communication and learning and the expectations of the classroom may have led him to have a negative conceptualisation of his behaviour
  Jo: So, tell me about concentrating at school. What's that like for you?
  Joshua:Er...[long pause]...I'm not good at it (p.2)

- The policing (silencing?) of Joshua's neurodivergent social communication style (also seen as help rather than constraint)
  Joshua: Well, once I was talking to the person next to me so...so my teacher sent me to the front of the classroom. (p.3)

  Jo: How does [your TA] help you?
  Joshua: Er, well she stops me talking to...other people.
  Jo: She stops you from talking to other people. Is that because talking to other people is a problem? Do you get into trouble for that?
  Joshua: Yeah. (p. 11 & 12)

- Joshua is sometimes sanctioned for this behavioural differences and these sanctions seem to involve separating him from his class
  Jo: And what happens when you get into trouble?
  Joshua: Erm...well, sometimes I go to see [headteacher], sometimes we have to stay in at break or lunch...or some of it. Er...um...sometimes we just get sent out of the classroom. (p.12)

- Joshua recognises that he is sometimes sanctioned for behaviour stemming from his autism
  [...] we did something naughty...that we shouldn't have done. Well...it might have not been [unclear] and I might have done it because I'm autistic, so I wasn't allowed on the school trip.

- But sometimes these sanctions have resulted in not a punishment, but a benefit for Joshua
  [With reference to not being allowed to go on a school trip]
  Joshua: ...well, I didn't really wanna go on the school trip. What we did was probably better than going on the school trip.
  Jo: What did you do?
  Joshua: We [did] loads of posters. Some on the environment or like plastic pollution, and one on, like, Mayan civilization.
  Jo: OK. And did you think that was better than the school trip?
  Joshua: Yeah, I mean...because no-one else was there, we got to watch YouTube, so.... (p. 15)
  [Note – this is the only reference in the interview to learning he enjoyed other than music]

- It is possible that the othering of Joshua in these ways has led to him considering himself as different to 'normal'
  Jo: What do you think is the most important thing that teachers need to know to make your life better at school?
  Joshua: Erm...I don't want...my life to be any different...to a...normal child. (p.14)

- Experienced being socially apart in his earlier years and even though he now has friends, there is a possibility that friendships may still be a challenge for him.
  Joshua:...so...all I can remember...just, um...every break time and lunchtime all I would do is lie on the bench. Er, I didn't want any friends and so...and even after [friend T] came, I didn't want to be friends with him, but I don't want any friends.
  Jo: Why did you not want any friends?
  Joshua: I don't know....I can't remember.
  Jo: Do you want friends now?
  Joshua: I have friends now...yeah.
  Jo: And do you want to have them in your life?
  Joshua: Yes [pause] er...[long pause] Yeah, I do. (p.9)

- Current friendship may be problematic but for whom? Joshua or the school?
  Jo: So tell me about tell me about your friends.
  Joshua: Er...[long pause] Well, a long time ago, er, I had, er...a friend called [name]. So, er...he was my best friend and my only friend back then. And, erm...[pause] Well, I know this but he, er, he...he was and still is a really bad influence on me.
  Jo: How come?
  Joshua: Well, we would do like...really dangerous things together like I would...I remember, er...like loads of times at break I would sneak into the secret garden. (p. 7)

Step 6: Continuing the individual analysis of the other cases

Steps one to five were then repeated for the remaining nine participants. Care was taken to ensure the idiographic focus on each participant. I kept a journal in which I made notes on connections and observations between participants so that I could keep my attention firmly rooted on each individual child during the first five steps of the analysis.

Figure 10: Continuing the individual analysis of the other cases

Step 7: Working with Personal Experiential Themes to develop Group Experiential Themes (GETs) across cases

This final stage of the analysis involved identifying patterns of convergence and divergence across the Personal Experiential Themes of all participants. The purpose of this is not a find a unifying narrative which represents all participants, but to "highlight the shared and unique features of the experience" (Smith *et al.*, 2022, p. 100) across the sample. I did this by printing out each participant's table of Personal Experiential Themes and pinning them side-by-side on my office wall. This then allowed me to make connections across the whole group. I then used coloured highlighter pens to group the themes into clusters in much the same was I had done in step four for each individual participant. These clusters then became the foundation for the Group Experiential Themes presented in the results section below. However, due to the iterative and reflexive nature of qualitative research, these themes were further refined during the writing up process.

Figure 11: Developing Group Experiential Themes across cases

5.2.2.4. A note on poetic transcription

The phenomenological and ideographic nature of IPA means that although there is a gradual move from the level of the individual to the level of the group throughout the seven stages of the analysis, the individual experiences of each participant are still very much central to this process. While working on the last of the seven stages outlined above, I found it difficult to assign names to the Group Experiential Themes that remained rooted in the everyday experiences of the children.

I am a member of the Phenomenology of Health and Relationships research group led by one of the founders of IPA, Dr Michael Larkin at Aston University. I raised the issue of naming the Group

Experiential Themes in this study at one of our group meetings and was advised to look at poetic transcription as an alternative and creative way of returning to the individual experiences of my participants.

Poetic transcription aims to find the ‘essence’ of experience through the “creation of poem-like compositions from the words of interviewees…filtered through the researcher" (Glesne, 1997, pp. 202-206). Research poems of this nature are usually created from interview transcripts and have been described as providing researchers with “an opportunity to write about or with people in ways that honor their speech styles, words, rhythm and syntax" (Richardson, 2002, p. 880). Therefore, I have used poetic enquiry as a way of retaining the ideographic integrity of my data while developing my theme names. By "getting back to the things themselves" to paraphrase one of the founding fathers of phenomenology Edmund Husserl (Husserl, 1976), I anchored the process of naming my themes in the lived experiences of my participants. I did this by asking myself "what did this experience feel like for this participant" at each stage of the process.

The purpose of this exercise was simply to enable me to name the Group Experiential Themes in such a way as to communicate the experience of my participants more authentically. However, the power of these poems was unexpected and while I had not anticipated including them in my thesis, I do so because of how illuminating they are. Therefore, in the results section that follows, each of the Group Experiential Themes is introduced with one of these poems in order to amplify the voices of my participants and provide a context for each theme using their words.

5.3. Results

Through my analysis, I constructed three group experiential themes from the data: 1) Enduring a hostile sensory environment, 2) Aloneness: enforced vs. chosen, 3) The vital importance of trusted guardians. I will now present these themes and their subthemes in turn in this section.

Figure 12: Themes and subthemes generated for child study

5.3.1. Enduring a hostile sensory environment

She shouted a lot
hurt my ears
huddled in a corner crying, loud chatter washing over me
like a gosh ding darn tidal wave
it can be a little scary
one loud word is going around in my head
I told them to stop, knocking or stamping
this giant cacophony
echos in my head, distracts me
it gets on your nerves
it's not a very good feeling
(Emily, Jack, Lily, and Oliver)

The participants in this study frequently refer to school as a place of sensory discomfort. It is clear from their descriptions that the sensory aspects of school are stressful and sometimes overwhelmingly so. The participants describe these uncomfortable experiences in terms of the significant physical, emotional, and cognitive impact they have on them, which I will discuss in greater depth in this theme. While participants discuss a range of sensory discomforts, three main topics seem to be most meaningful to them: noisy people and places, the lunch hall, and school uniform.

5.3.1.1. The anguish of loud spaces and people

The participants frequently comment on the distress they experience in loud spaces in school or when around loud people. Loud noise is not merely uncomfortable for them, but is sometimes experienced in intense ways as exemplified here by Jack in his description below of a time when he had was overwhelmed at school, and the addition of the noise of his classmates increased his feelings of distress:

> *I sat in the cloakroom in the dark and eventually I just had a breakdown...I had like an emotional breakdown…and then the whole class poured in, the light was flipped on. So basically I was huddled in a corner crying with the whole class's loud chatter...washing over me like a gosh ding darn tidal wave (Jack)*

Jack uses the metaphor of a tidal wave to describe the suffocating effect of the noise of his class while he is already in a state of extreme distress. He has tried to escape their noise by going to the cloakroom, arguably a quieter place than the classroom, but even here he cannot escape the noise. His use of phrases associated with water such as '*poured in'* and '*washing over'* conjure powerful imagery of drowning and convey a strong sense of frightening overwhelm.

> *I do not like loud noises, so the fact that there was this giant cacophony all of a sudden washing over me...that most certainly didn't…help (Jack)*

In this later recounting of the experience, Jack repeats the phrase '*washing over me'* and describes how abruptly the comfort of the dark quiet cloakroom is transformed by what he terms as a '*giant cacophony'*, a phrase which illustrates the magnitude of the impact of the noise of his peers.

Emily also comments on the noise of her peers. In the example below, she describes the intense physical discomfort caused by large groups of classmates:

> *I…don't like it when it's loud because it hurts my ears. It's normally loud in the dinner hall at school and in the playground at school (Emily)*

Here, Emily is explaining how loud spaces cause her physical pain (*hurts my ears*). She is also referring to spaces in school (*dinner hall* and *playground*) that are typically regarded as places of fun and free expression; places where children are released from any requirement to be quiet which might govern their behaviour during lessons. It may be for Emily that the enjoyment and freedom typically associated with these aspects of the school day are not how she experiences these spaces.

Both Jack and Emily refer above to the collective noise of large numbers of children but isolated and singular sounds can be equally challenging. In the example below, Lily talks about the impact of knocking and stamping sounds:

> *If I tell someone to stop making, like, a certain noise, like if someone's knocking or stamping, I would...if I told them to stop, I would get really mad and it would echo in my head and I would just get really mad (Lily)*

Lily is expressing frustration with not only the sound of the noise but also with the fact that she is asking '*someone to stop'* but still the noise continues. The duplication of the word '*stop'* suggests multiple requests for quiet, and repetition of '*mad'* reflects her growing frustration with the lack of respect for her requests. The phrase '*echo in my head'* also suggests that the impact of hearing the noise may continue long after the noise has stopped resulting in reverberations of annoyance. It suggests that it may take considerable energy and concentration to disregard the noise. The idea that noises can occupy a significant amount of space in the mind is also supported by Emily:

> *…when someone says something loudly It's like that one word they say will repeat in my head repetitively. Because that one loud word is going around in my head for so long it distracts me from concentrating (Emily)*

Like Lily, Emily is explaining how just one loud noise, in this case a spoken word, can '*repeat in my head'*. Emily's description shows how even brief auditory triggers can endure long in her mind, making concentration on whatever task might be required of her difficult.

As well as the peer-generated noise described by Emily, Jack and Lily above, some participants expressed a dislike of teachers shouting. In the case of Oliver, he describes this experience as frightening:

> *[Mrs Howes] shouted a lot. Even though my year two teacher promised that she, she never shouts, she shouted loads […] not only does it get on your nerves and stuff, but it can be a little scary […] it's not a very good feeling. (Oliver)*

In addition to any sensory discomfort, Oliver's comments suggest the possibility of betrayal or being let down (*Even though my year two teacher promised that she, she never shouts, she shouted loads*) by a teacher who promised not to shout but in fact did shout frequently (*loads*). His use of the modifier 'little' in '*little scary'* might accurately reflect low-level anxiety but it also might indicate that he is trying to downplay the impact of the shouting. Nevertheless, he clearly articulates the level of his negative feelings triggered by adults shouting.

The theme of loud noises being problematic represents most participants, but Isabelle stands in stark contrast. For her, her noisy class was not only unproblematic but also fun:

> *Jo: What's the best thing about your class?*
> *Isabelle: It's funny and loud […] we're the loudest in the school…so we have lots of fun (Isabelle)*

Isabelle uses the superlative phrase '*loudest in the school'* to refer to the noise her class makes. This suggests a sense of pride, but perhaps more importantly, Isabelle is referring to an activity where she is joining with her teachers and peers. She refers twice to '*we'* which is suggestive of belonging, something which contrasts with the exclusionary aspects of noise experienced by other participants. This quote from Isabelle not only diverges from the experiences of the other participants who dislike noise intensely, but is also distinctive because of the element of autonomy expressed. The exemplars from the other children all relate to experiences where they were subjected to noise from others and over which they have limited control. In this example from Isabelle, she is an active noise-maker rather than a passive noise-experiencer, and the differences in autonomy and choice in this distinction may play an important role in why she has a very different perception of class noise to the other participants.

5.3.1.2. The multi-sensory overwhelm of the lunch hall

The subject of control over sensory experiences also appears in participants' experiences of the lunch hall. For many of the participants, this particular space is cited as especially uncomfortable. Not only is it described as loud but also as a place where there is an assault on a range of different senses all at the same time. This intersection of overlapping different sensory discomforts was compounded by a lack of choice and the increased social demands that accompany shared eating experiences, as exemplified by Thomas below:

> *Jo: […] lunch times you say are very loud.*
> *Thomas: Yeah.*
> *Jo: Can you tell me more about that?*
> *Thomas: Well, everyone's speaking and like...and like…you sit together. You don't get to choose where you sit though... it's quite annoying. (Thomas)*

In this quote, the noise of the lunch hall is arguably Thomas's central concern. However, he also says '*you don't get to choose where you sit*' which suggests that his discomfort is amplified by his perceived lack of agency. The frustration of not being in control of the lunch time experience is one that is shared by Chloe who also comments on the added stress of not knowing who she is going to sit next to. Besides the noise, uncertainty and social demands, Chloe also talks about the additional sensory discomforts of unpleasant odours and the visual disturbance of dropped food:

> *I don't like eating lunch in the school hall - you have to sit next to people you don't know, it smells bad, there is food on the floor, chairs and table which makes it dirty. (Chloe)*

In this extract, Chloe describes how bodily (*you have to sit next to people you don't know*), olfactory (*it smells bad*), visual and possibly tactile (*there is food on the floor, chairs and table)* sensory stimuli combine to create a space in which eating is difficult and unpleasant for her. This experience is similar to Emily who offers another description relating to the smell of the food in the lunch hall. She describes it as '*disgusting*' and so overwhelming that it stops her from trying to eat:

> *Some of the foods I just won't try because they smell disgusting. I know that sounds unusual and hard to believe but I don't like the taste of any food…that's just how my autistic brain works! (Emily)*

Her comment '*that's just how my autistic brain works!'* is simultaneously minimising what could be seen by some observers as a significant problem (i.e. not being able to eat her lunch) but also suggests that she is accepting of her different perception. There is also perhaps a sense of being resigned to the situation, another possible example of feelings of powerlessness in the data.

As with the effect of loud noises, the impact of the lunchtime experience seems to extend well beyond lunchtime itself. In this quote from Lily, even the thought or memory of aspects of the lunchtime experience can lead to feelings of disgust:

> *I find it kind of gross when we do PE [in the lunch hall]. We eat there, so many food gets dropped. I know they clean it but we have to sometimes, er, in gymnastics we have to take our shoes off and like walk on the floor that everyone dropped their food on. (Lily)*

Lily is describing here how, even though she knows the floor is clean, the memory of the dropped food remains and impacts negatively on her experience of other times in that same space. Her use of the word "*gross*" highlights her disgust and gives an insight into the level of challenge she may need to overcome in order to participate in her physical education classes.

5.3.1.3. Unpleasant, itchy and ticklish: the discomfort of school uniform

As discussed above, much of the sensory discomfort in school described by the participants relates to specific places, people, and times of day. However, for some participants, the sensory discomfort of their school uniform is an ever-present concern. In the example below, Jack describes how the uniform is a key aspect of finding going to school difficult each morning:

> *Jo: What's school like for you?*
> *Jack: Well…I don't particularly want to go to it, like, in the morning…*
> *Jo: Why is that? What is it about the mornings that are tricky?*
> *Jack: Well...you'd rather sort of just lay around and be like, ahhhh, weekend! Except not, you know? Like...that is more appealing than dressing up in...warm, like, unpleasantly toasty clothing, and going to a place filled with boring lessons (Jack)*

Jack is suggesting here that there is a significant distinction between the relaxed weekend mornings (*lay round…ahhhh, weekend*!) and weekday school mornings which is tied in some way to the discomfort of his uniform (*warm, like, unpleasantly toasty clothing*). Emily also talks specifically about how the texture of the fabric of her uniform is particularly uncomfortable, especially when new:

> *I don't like [new school uniform] because the feeling of new material and different textures irritates my skin. I cut labels out of new clothes because they rub against my skin and therefore makes it itchy and ticklish (Emily)*

Her use of *irritates*, *rub*, *itchy* and *ticklish* all suggest unpleasant sensations with labels being so problematic that she needs to remove them before she can tolerate the clothes. Both Jack and Emily describe their school uniform as causing them bodily discomfort – an experience that is consistent across all the contributions in this theme. Each of the participants expresses at least one aspect of the sensory environment at school which causes them discomfort or pain. The level of discomfort is enough to distract them to the point of being unable to focus on what was going on around them, or to separate them in some way from the everyday business of school. Furthermore, many of their contributions describe experiences that many of their peers and teachers might not be able to understand or anticipate, further distancing the autistic child from others around them. This sense of separation and distance is the central focus of the second theme below.

5.3.2. Aloneness: enforced vs chosen

I'd rather not go outside
at break and lunch
I try and think of something that I can do to stay inside
my friends are always playing things like tag and I don't like that sort of playing
I just stand there doing nothing
nothing
on my own
it's quite bad
(Chloe, Isabelle, and Thomas)

Most of the participants in this study describe experiences of feeling or being alone while at school. These experiences vary considerably in terms of their impact on mood and wellbeing. Central to this variation appears to be the question of whether the experience of being alone is enforced or chosen. Experiences of enforced aloneness are described as painful and confusing, particularly when resulting from being actively excluded by peers or indirectly by the systems and processes of school not suited to autistic ways of being. However, participants also describe some instances of being alone as restorative and calming. These positive experiences of being alone are sometimes craved for in the busy and noisy day-to-day of school life but access to this form of retreat is often difficult to negotiate.

5.3.2.1. The pain and confusion of exclusion

Some participants comment on being excluded by peers. In the case of Thomas, he describes the exclusion he experiences as bullying:

> *[My classmates]...they're mean…They say bad stuff about you behind your back. [It's] upsetting...they've bullied me before […] they...they kinda like...just at play time...follow us around and like....watch us and me. Say things about me. (Thomas)*

Thomas describes his peers as '*mean'* and connects them to acts of hostility which he perceives as bullying. The behaviour he describes such as being followed, watched and talked about in the playground are threatening but they are also subtle, especially when contrasted with more obvious forms of bullying such as physical assaults. It is possible that this subtlety makes the behaviour of his peers even more difficult to understand and navigate. Nevertheless, Thomas feels the negative emotional impact of this behaviour and describes it as '*upsetting'*. Below, Harry describes how he is excluded in similarly subtle ways:

> *They'll let me play [football]...it just...it's just a bit like they won't pass. I actually don't know [why]… It actually makes me pretty sad. (Harry)*

Harry explains how his classmates '*let'* him play football with them at break times. The choice of the word *let* suggests that some sort of permission to join the group is conferred upon him by his peers. In turn, this implies that he is not an automatic member of the group, he is an outsider and can only join when invited. As well as this having a potentially damaging effect on Harry's sense of belonging and self-esteem more generally, it could also be interpreted that these invitations are not necessarily genuine because once in the game, Harry's peers continue to exclude him from playing an active part by not passing the ball to him. He is present in the game but not actually included as an equal. His comment that *'I actually don't know [why*]' indicates how confusing this is for him, and '*it actually makes me pretty sad*' expresses the emotional toll this takes on him

The playground featured frequently in the participants' experiences of isolation. Typically, the playground is seen as a place of freedom and joyful escape from the classroom, and this was certainly the case for some of the participants in this study. Jack, for example, gives the impression that every minute of his break time is precious:

> *Like, if I trip and hurt myself, it used to be like... that I'd burst into tears if I got a single scratch on my knee from falling down, but now it's just, oh, I've fallen down. Well, it's fine, best go continue playing…[I] don't want to waste my 15 minutes (Jack)*

However, Jack represents a minority view in this group. Most participants express concern over the playground and find the relative lack of structure, sensory overwhelm and social demands challenging. In some cases, the pressures of the playground are seen as insurmountable and are regarded as the least enjoyable aspects of school life:

> *Jo: [what's] the absolute worst thing about school?*
> *Thomas: Break time […] I just stand there doing nothing…on my own… [it's] quite bad. (Thomas)*

Thomas tells me here that he regards break time as the worst part of his school experience. His feelings of isolation are clear from his description of doing '*nothing'* at break time, a word also used by Chloe:

> *Jo: What are the kind of things you get up to in break time?*
> *Chloe: nothing*
> *Jo: So, during break times do you prefer to be alone or do you prefer to be with your friends?*
> *Chloe:…my friends are always playing things like tag and I don't like that sort of playing*
> *Jo: So, when they're playing tag, what are you doing?*
> *Chloe: nothing*
> *Jo: OK. And are you OK with doing nothing or would you rather be doing something else?*
> *Chloe: I'd rather not go outside*
> *Jo...is there anything at all that you can do in the playground that you enjoy?*
> *Chloe: no (Chloe)*

Chloe explains that she cannot join in with the games that her friends like to play and there is nothing about the playground she enjoys. Her repetition of the word '*nothing'* gives a sense of the emptiness the playground holds for her. It would seem that the play preferences of her friends do not align with her own and there appears to be no alternative activity available so she does nothing. It is clear that the playground is not a place where she feels at ease, resulting in her preferring not to be there at all. It is possible that this wish to not be there stems from boredom but it is also possible that being alone in a highly social place highlights how different Chloe is from her friends and this might be something she would want to avoid. In this context, complete withdrawal from the playground might seem like a solution to a painful problem. This is a sentiment shared by Isabelle who not only prefers to remain indoors during break time but also actively tries to find ways to avoid the playground:

> *At break and lunch...I try and think of something that I can do to stay inside. (Isabelle)*
>
> *When asked to expand on her experience of break times, Isabelle explained that:*
>
> *I finish my lunch first and I have nothing to do (Isabelle)*

Isabelle's contribution indicates that aside from the act of eating, it is difficult for her to fill the time during the lunch break. Like Harry and Chloe, it is possible that the lack of structured, preferred and accessible activities during breaks is a challenge for Isabelle which is why she tries to avoid them.

Both Thomas and Harry above talk about being excluded by peers in ways which are experienced negatively. However, other participants discuss how being separated was preferable at times to being included in whatever activity was being undertaken by the group or the class, as exemplified by Joshua below:

> *[…] we did something naughty…that we shouldn't have done. Well…it might have not been [unclear] and I might have done it because I'm autistic, so I wasn't allowed on the school trip…well, I didn't really wanna go on the school trip. What we did was probably better than going on the school trip…We [did] loads of posters. Some on the environment or like plastic pollution, and one on, like, Mayan civilization. [it was better]…because no-one else was there…. (Joshua)*

In this example, Joshua is discussing being sanctioned for being '*naughty*' although he is uncertain if the trigger for this sanction might stem from his autism. This indicates that Joshua is learning that there are aspects of his autistic behaviour that may be misunderstood by others as misbehaviour. In any case, his sanction is to be excluded from a school trip; an event his classmates might perceive as a fun and exciting alternative to the usual school day, but this is a perception not shared by Joshua who did not particularly wanted to go. '*What we did was probably better than going on a school trip'* suggests that being able to work creatively and without the sensory and social demands of a full class around him ('*no-one was there'*) is a better arrangement for him. What is telling about this quote is that it stands in contrast to the boredom Joshua expresses consistently in his interview. School holds little interest for him. He endures it. In this particular case though, being excluded from the class trip enables him to engage in something meaningful and enjoyable. This could be because he has more one-to-one attention from an adult, the opportunity to direct his own learning, and fewer distractions from others in the class.

The issue of distraction is also relevant in Harry's case. He is also one of the participants for whom being separated from peers in the classroom context is perceived as an advantage. Below, Harry describes his workstation which is different to the desks used by his peers:

> *Jo: OK, so you...do you have a desk on your own?*
> *Harry: Yeah, it's uh...basically at the back of the class.*
> *Jo: And is that better than being on a table with other...other children?*
> *Harry: Yeah, I prefer it 'cause when you're on a table with other people, their books get in the way.*
> *Jo: So why do you think this new desk was given to you?*
> *Harry: It was probably like it was given to me so that, erm, I would like concentrate more and I had my own little area to work with.*
> *Jo: And does it help you to concentrate more?*
> *Harry: Yeah. (Harry)*

In this example, it is clear that Harry finds sharing a table with his peers difficult ('*their books get in the way*') and distracting. He says that he '*prefers'* his new desk and claims that this helps him concentrate more easily on his work. Therefore, not being included at a shared desk is not a problem for him whereas not being included fully in the game of football was upsetting. It is possible that being separated from his peers in class is not as upsetting because Harry does not see it as a social context in the same way as the playground. Alternatively, the presence of the teacher in the classroom may be associated with comfort and safety while the absence of the teacher in the playground may have a part to play in its perceived hostility and unpredictability.

What is clear from these examples is that adapting to the neurotypical social conventions of school is often effortful and frustrating for these participants. The sense of fatigue related to these issues is strongly connected to the topic of retreat which is explored in the following sub-theme.

5.3.2.2. Cultivating comfort through retreat

As shown above, many of the participants in this study describe experiences of being alone that are painful and confusing. However, it is also clear from the data that being alone is also restorative. Engaging in solo activities is described as joyful and many of these experiences offer a restorative retreat from effort and discomfort of being at school. For Harry, his retreat is visual and imaginative. He talks about his books and the artwork he has pinned around his workstation as especially soothing:

> *So basically it's like if I get really stressed or something, I read my reading book [and] when the teacher's talking something really boring [quotes a maths question as an example] I just look over here [at my art posters] like...wow...wow. (Harry)*

Harry finds an escape from the pressure and boredom of the classroom in the stories of his reading book. He uses this escape to counter the stress he feels from time to time. His sense of awe at the artwork is clear in his expression of '*wow…wow*'. Oliver also finds comfort in visuals, especially when they are familiar and connected to his interests. In this example, he is referring to a space known as the 'calm corner' where he and his teacher have displayed pictures of his favourite Pokémon characters:

> *...when I lie on the beanbag and look at the sleeping Pokémon, I feel little sleepy myself and it makes me feel a little happier and calmer. And then I come out a lot more happy and ready to learn and things. (Oliver)*

In this extract, Oliver describes how retreating to a comfortable space slightly apart from the rest of his class, surrounded by images of his favourite characters, has a positive effect on his mood (*makes me feel a little happier and calmer*). His description also shows how he connects this restorative activity with a renewed ability to engage with his school work (*I come out a lot more happy and ready to learn*).

Other participants sought retreat from different activities. For Lily, her comfort was found in retreating into quiet spaces:

> *Just when I'm a bit stressed out or like I've been spending the whole day with my friends. I...and I normally go to the bathroom too. Sometimes I just sit in the stall and just like wait for five minutes and just go back out…it feels just quiet. And just no-one…just me, like, in there. (Lily)*

Here she describes how socialising with her friends, an activity she enjoys, is tiring for her and can leave her feeling depleted. She also describes how even a short break of only a few minutes can be restorative. Being alone in the toilet stall gives her the quiet she craves.

For Emily, retreat takes the form of non-speaking, especially when she feels sad. Like Lily, Emily connects this experience to one of fatigue. However, in contrast to the other participants, her retreat appears to be one of painful necessity rather than joyful escape:

> *At school, I don't talk when I'm sad so I just nod and shake my head. Normally I'm just sad because I'm tired. It feels like I can't talk when I'm sad because it's too overwhelming. (Emily)*

This is supported by the fact that she says she cannot talk when she is overwhelmed. It does not appear to be a choice for her. It would seem that the effort required in being in school is so great that it sometimes leaves her unable to speak.

5.3.2.3. The effortful search for solitude

The notion of effort is also connected to negotiating access to retreat. The participants describe various ways in which their access to restorative quiet alone time is restricted or not always available when they need it. In the case of Oliver, he finds that peers were not always supportive of his need for space. In the example below, he talks about trying to find some space for himself in a store cupboard that also contains a tap used by the class to access drinking water:

> *I told everyone who was getting a drink to just clear out…I was trying to get everyone to clear out so that I could have some space on my own and I didn't hurt anyone… but Jacob…he was, nah I wanna drink so he just stood there and refused to go. It took ages to get him to come out. (Oliver)*

There is a sense of urgency in Oliver's retelling of this experience. He knows that he is close to losing control of his emotions and he conveys a real sense of anxiety over his fear of dysregulating in a physical way, something he could be sanctioned for and may reflect badly on him. However, the lack of cooperation from his classmate means that his access to much-needed quiet alone time is restricted.

In the case of Lily, her access to the respite of a quiet toilet stall has been limited in the past by a teacher who perhaps did not understand how important a place it was for her:

> *Mr Rogers used to say no, do it at your break time, but now he's kind of OK with it, and when...if as long as Miss Price's not talking about something really important that we need to do now…she'll let me go quickly (Lily)*

Even now that she has a more understanding teacher, her access is still restricted depending on how important the content of the lesson is deemed to be by that teacher. Even when she is permitted to leave the class, her comment '*she'll let me go quickly*' implies an additional time pressure. In the case of Chloe, her access to her chosen quiet space (the school library) is restricted when she needs it most – during break and lunch time:

> *I wish there was a school library we could use at lunch time and break time. There is a library but we can't use it at lunch time or break time. (Lily)*

There is a longing in Chloe's description here and a sense of frustration that what she needs is available but inaccessible due to the policies of the school. In contrast to Lily and Oliver, Jack has access to a quiet space, a bench outside his classroom, whenever he wants it:

> *Jack:…the bench…it's outside our class and it's where I [can go] to…like, make…get calmer and things*
> *Jo: And how often do you go out onto the bench?*
> *Jack: Not very often like like...like, I've barely even...used it. I think I've maybe used it...twice*
> *Jack's mother: It's just nice to have the option isn't it?*
> *Jack: Yeah. (Jack)*

Jack's description suggests that just knowing he has unrestricted access to the retreat of the bench is a great comfort to him. He admits that he rarely uses the bench but he makes frequent mention of it in his interview. It is clearly an important accommodation for him and it is possible that having permission to leave the room when he needs to, and the trust of his teacher that he can handle that permission responsibly might be more valuable to him than the actual bench. The theme of trust is one that featured frequently in the participant's descriptions of the most positive aspects of their school experiences and is central to the third and final theme below.

5.3.3. The vital importance of trusted guardians

he really like...looks out for me
plays with me
when I'm upset he's always there
he's really kind
we go way, way back, like way, way, way, way back
we're the bestest of best friends
he makes me feel a lot better
he helps me calm
he will listen to what I say and understands me
I find it really hard to go to school
when he's not there
I worry that there won't be people there
to play with
(Chloe, Emily, Harry, Jack, and Oliver)

The issue of trust is central to this third and final theme constructed from the data. The struggles the participants have in school have arguably led to a reliance on a small number of trusted people. These people, be they peers or teachers, are central to the participants' enjoyment of school and tolerance of the challenges they face. Without these relationships, it is probable that day-to-day school life would be much more difficult. However, this reliance on others may create a 'high-stakes' environment in the sense that the participants need to ensure that these important people consistently see them in a favourable light.

5.3.3.1. "The bestest of best friends"

While many of the participants struggle with peer relationships, most have at least one friend who is very important to them. For most participants, their closest friends are those who have been known to them for a long time:

> *George and I go way, way back, like way, way, way, way back. Way, way, way, way, way. Like…in nursery we were friends […] I've been with them for so very long, it's like we've got this sort of…special friendship…you know? It's like…we're the bestest of best friends. (Jack)*

The emphasis Jack gives here (repetition of '*way'* and the superlative '*bestest of best friends'*) gives an insight into how important his relationship with George is. It is possible that the length of their friendship has led to a level of familiarity meaning that Jack does not have to work very hard to predict how George will behave. They are more likely to know each other's likes and dislikes and there is possibly a high degree of trust and reliability – a '*special friendship'*.

In addition to longevity, shared interests seem to be of central importance to the participants' friendships. Chloe's contribution below underlines this point:

> *The people I don't like in school are often ones who don't have the same likes as me. The people I get on best with also like the same things as me, such as cats, dragons, craft / art, books, Minecraft. We can talk about the things that we like. I wish there was someone in school who really likes mushrooms and/or cacti because I find them interesting (Chloe)*

We can tell how central shared interests are to Chloe's friendships by the comment that the people she doesn't like '*are often ones who don't have the same likes as me*'. It would appear that shared interests are an absolute prerequisite for friendship for her. Without that basis, a friendship is unlikely to begin or develop. This can be seen as something of a limitation for her in her comment '*I wish there was someone in school who really likes mushrooms and/or cacti*'. Her description here suggests that her interests are distinct from those of her peers, and there is a sense of yearning in this comment that suggests a level of dissatisfaction in her social life. Chloe finds talking difficult and her comment '*we can talk about the things that we like'* might link with the idea that interaction with peers could be less effortful where there is a shared interest on which the conversation can focus.

While having shared interests is a central theme in the data, what is also clear from the descriptions of these friends is that they offer more than companionship and someone to talk to. In the case of Harry, he comments that his closest friend '*looks out for me, plays with me*' which suggests an element of protection. The phrase '*looks out for me'* suggests that his friend guards him against possible dangers or threats. This is understandable when placed in the context of the hostility Harry has experienced from peers (e.g. not including him in social activities and games). He also says that his friend '*plays with me'* and this is important given the previous comments Harry made about not always feeling fully included in games of football in the playground. This comment suggests that the play he engages in with this closest friend might feel more equitable and satisfying. The practical support offered by close friends is also something mentioned by Oliver:

> *Jo: What is it about Zach that makes him such a good friend?*
> *Oliver: Well...when I'm upset he's always there and he's telling teacher and things...and he plays with me lots and he's really kind as well.*
> *Jo: When you say he tells the teacher, can you tell me a bit more about that?*
> *Oliver: When I'm really sad or...something he goes and tell the teacher and they sort it out.*
> *Jo: So what is it like when…Zach's not there? What does it feel like?*
> *Oliver: I find it really hard to go...I worry that [there won't be] people there...to play with.*
> *Jo: Does it make you feel better when Zach is there?*
> *Oliver: Yeah…makes me feel a lot better. (Oliver)*

Like Harry, Oliver mentions a willingness to play as a central component of this important friendship ('*he plays with me lots')*. He also talks about his friend acting as a bridge between him and his teacher suggesting that independent help-seeking may be difficult for him. Oliver goes on to say that this friend is so important that days when he is not at school are particularly challenging, and that he finds it hard to go to school if he knows his friend will not be there. This suggests a significant level of reliance on that one friend. It is clear that without Zach, attending school may not be possible for Oliver ('*I find it really hard to go'*). In the case of Emily, a best friend does not have to be human. Her affinity with animals provides a huge amount of comfort to her:

> *I love animals like my cats because they help me calm. It's almost like they can understand me even though they can't…At school, I see a therapy dog named Buddy. He helps me a lot because he doesn't bark and he will listen to what I say and understands me (Emily)*

Emily's repeated emphasis on animals understanding her is especially interesting when placed in the context of her difficulties with spoken language. In her interview, she expressed that she often feels misunderstood and commented on not always being given the time and space she needs to communicate. It is clear that having an animal to interact with is preferable to the possible pressure she feels when communicating with a speech partner. Her sensitivity to noise is also alluded to when she says that one of the helpful things about the schools' therapy dog is that '*he doesn't bark'*. For Emily, the comfort she experiences around Buddy and her cats is expressed in her comment '*they help me calm'*. This is all the more salient when contrasted with the tension she tends to feel in school generally. For Emily, school is a very stressful experience in which most aspects of her day are fraught with tension. This is most plainly expressed when I ask her about how she copes with this tension:

> *Jo: How do you relax at school if you are feeling sad or overwhelmed?*
> *Emily: I don't relax at school*

Emily’s response here portrays a sense of being in an enduring state of bodily and psychological unease. Much of this appears to be connected to how difficult verbal communication can be for her sometimes. It is possible that, because of the primacy given to oral communication in school, Emily feels she has to remain alert to any communication demands hence her inability to relax while she is in school. Emily’s chosen animals seem to offer her an experience of connection without the pressure of having to talk. In that way, the school therapy dog is perceived as safe to be around in ways that maybe most people are not. The only other person Emily feels comfortable around is her class teacher. This was a feeling shared by several of the participants and forms the focus of the following sub-theme

5.3.3.2. The safety and security of the class teacher

While close friends are very important to the participants, arguably the most important relationship the children have within school is with their class teacher. While some participants talk of having had difficulties with past staff relationships, every participant comments on having a good relationship with their current class teacher. For many participants, though, the relationship with the teacher holds a greater significance than might be typical, as exemplified by Emily below:

> *My teacher is really nice and kind to me and helps me a lot, I’m really lucky and happy that she is my teacher! She makes sure I’m happy in school and if not, she’ll fix it. She asks me if I’m ok when I look sad which makes me feel safe and is showing that she cares. (Emily)*

Emily’s quote illustrates how teacher supportive her teacher is. In particular, she mentions that her teacher ‘*makes me feel safe’* which suggests that there is a possibility that Emily doesn’t necessarily feel safe at school and connects with her comment in the previous sub-theme about not being able to relax in school. She also says her teacher *‘fixes’* things if Emily is not happy. Again, this suggests that her teacher is much more to her than a facilitator of learning. Emily’s comments here suggest that her teacher also provides crucial emotional and psychological support. This high level of non-academic support is also expressed by Lily as she describes how her teacher helps her take time out if she was stressed or overwhelmed by being in the classroom:

> *Whenever I was feeling stressed or tired about the work […] we had this, erm...SEN den which was like a calm place and it was our reading corner where we'd read and we take our shoes off and there was like a nice rug and a seating place where we would just...and...she would give us like a...a timer and when that timer [went off] we would...go back to our work so it was a break when we were feeling...[stressed]. (Lily)*

Lily's comment here describes how her teacher provides the adaptations she needs when she is '*feeling stressed or tired about the work'* which implies that the teacher has a particular understanding of Lily's specific needs and is able to identify when she needs a break. Her comments relating to the '*SEN den'* such as *'we take take our shoes off'* and '*there was like a nice rug*' are also suggestive of a teacher who understands Lily's need for sensory comfort especially when she is experiencing feelings of stress . Harry makes similar remarks suggesting that the teachers in his classroom are able to identify when he needs help and are proactive in their support:

> *If I'm upset or something, they'll…just come over to me…like, they understand the problem…'cause they're like...they try and help me. (Harry)*

Like Lily, Harry is describing how responsive the supporting adults in his class are. The phrase '*they'll…just come over to me'* implies that his distress is noticed and acted on in a timely manner, and his description of '*they understand the problem'* suggests a level of mutual understanding whereby he may not need to work hard to explain himself. Both of these observations possibly indicate a level of subtlety to the support he receives. This is a topic raised by a number of participants who express a preference for teachers who were discrete in their offering of support, as described by Emily:

> *It feels hard to sit still for so long at school so my teacher will normally send me on jobs so that I don't have to. She sends me on jobs like putting rubbish in the bin and handing out things, which is my favourite because I get to walk around the classroom. (Emily)*

Emily's description indicates that her teacher accommodates her need for movement by allowing her to perform useful tasks on behalf of the class. It is possible that by allowing Emily to engage in these practical tasks, her sensory needs are being met in not only a subtle and effective way, but also in a way that supports her self-esteem and allows her to remain in the class with her peers. Her appreciation is clear in her description of this form of support as her '*favourite'*.

This positive and proactive approach was particularly important since many participants report difficulties in asking for help. They find it hard to ask for the support they need when they need it. In some cases, as exemplified by Thomas below, asking for help is easier with trusted teachers than with members of staff he does not have positive relationships with:

> *Jo: Am I right in thinking that asking for help is sometimes difficult?*
> *Thomas: Yes….not to the…the good teacher though. Not to the good teacher.*
> *(Thomas)*

His use of the phrase '*the good teacher'* implies that other teachers may not be 'good' – something that is supported by the discussions in his interview of the difficult relationships he has had with past teachers. However, this reliance on his relationship with this one person, while bringing benefits, also has drawbacks. Thomas goes on to explain that because he is unable to ask for help from other members of staff or his peers, he is sometimes unable to access any help at all:

> *I get confused a lot and I don't understand…[so] I go and ask Miss. But she normally has a long queue of people waiting…[and] I might not get to front of the queue most of the time before work time ends. (Thomas)*

Thomas' description of '*most of the time'* suggests that this is a common experience for him and one that potentially has an impact on his learning given that he also expresses being '*confused a lot*'. The unavailability or unpredictability of such a central person can be distressing. Here, Jack describes his upset when his trusted teacher does not respond to him in the way he has come to expect of her:

> *Miss Brown came in and instead of dealing with [my meltdown] properly, in my opinion...she's she went stop crying, just stop crying like, as if commanding me to stop doing something that she didn't like. And she did *not* [emphasised] help me (Jack)*

> *[When asked how he felt about this] Well...kind of disappointed…like disappointed in this person who I had...so much respect [for] and...good memories with, who...but then she didn't deal with such an extreme thing properly. (Jack)*

In line with Oliver's comment in the first sub-theme, Jack's description hints at feelings of being let down by his teacher ('*disappointed in this person who I had...so much respect [for]*'). It is possible that holding his teacher in such high esteem may make it more difficult to understand why they may occasionally be unavailable or even unhelpful.

The data in this study suggest that the relationship with the class teacher is distinct from the relationships with other adults in the school. In particular, lunch time staff are cited as people who the children do not necessarily feel as close to:

> *…the teachers and teaching assistants are really nice and kind, but the lunch bunch are a bit more harsh…and, like, are a bit more strict…and when you ask them to do something kind of they say it can wait after this person, or...or like, they just say no…so they don't really help when you're in trouble (Amelia)*

Amelia's use of the phrase '*lunch bunch'* suggests an otherness to this particular group of staff. Words such as '*harsh'* and '*strict'* are also suggestive of a lack of warmth. Given how important it seems to be to have the support of trusted adults who are proactive in their care, Amelia's observation that they '*don't really help when you're in trouble*' is particularly notable since the playground is a place where many of the participants feel especially exposed or vulnerable in some way. It is arguable that for many of the participants, their need of support from reliable and sensitive adults is the same if not greater during break times than during class. It is possible that the reduced contact a child has with lunchtime staff means that there is less time for a trusting meaningful relationship to develop. This was alluded to by Emily in her description of her relationship with a cover teacher she has once a week:

> *…one of the teachers that teaches me once a week, makes me very worried and scared in the mornings before I go to school, that makes me have a bad morning and day. This teacher asks me questions when I don't have my hand up and most of the time I don't know the answer because she speaks so loud it's hard to concentrate (Emily)*

The impact of this teacher on Emily's mental health is alluded to when she said she makes her '*very worried'* and '*scared'*. From Emily's earlier contributions, we know that she struggles with answering questions in class and loud noises and people. This particular teacher is either unaware of that or unable to make adjustments to their practice and delivery to accommodate Emily's needs.

This may seem like a minor consideration but as we can see from Emily's contribution, the impact on her is considerable.

5.3.3.3. Feeling the pressure to be a model pupil

Given the importance of the relationship with the class teacher, it is not surprising to find that the children in this study place a lot of importance on being liked by school staff. In the case of Isabelle, being liked is directly related to how she perceives the quality of her school experience:

> *Jo: It sounds to me that it's really important to you that you...that the...the teachers like you, is that right?*
> *Isabelle: Yeah…'cause...if they don't like you they're not gonna treat you well. (Isabelle)*

The broader data from Isabelle's interview contains many references to the effort she makes to be of assistance to her teacher, something which she appears to enjoy and takes pride in. This quote, however, clearly shows the connection the Isabelle makes between being liked by her teacher and how she is treated at school. It suggests that, for Isabelle, the desire to be perceived as a model pupil could be motivated by an awareness of the potential risks associated with not being in the teacher's favour. For Isabelle, her teacher is so admired that she is someone she wants to emulate:

> *Isabelle: I get to erm...sort out the books and...be a mentor…I get to teach the front table cus the front table aren't very good at stuff. Well...well there they are, but they're not as quick…and then my two assistants are Jemima and Ivy…[classmates] call us Miss T, Miss S and Miss P [using surnames as you would for an adult member of staff].*
> *Jo: [laughs] So is it almost like you're teachers for...in that time?*
> *Isabelle: [nods] I get to sit on my teacher's chair.*
> *Jo: [laughs] And what does it feel like when you're on the teacher's chair?*
> *Isabelle: Good cus everyone comes to me.*
> *Jo: It sounds like a lot of fun.*
> *Isabelle: Yes...I'm a Sixer at Brownies, so I'm a teacher*

Isabelle articulates with '*everyone comes to me'* that having a similar status as the teacher in the eyes of her classmates is something valuable to her. It is possible that being seen by her peers as possessing the qualities of a teacher is important to her self-esteem. Her comment '*so I'm a teacher*' hints at the extent to which this aspect of her school life is part of her how she identifies herself.

The topic of identifying as a model pupil is also expressed by Jack who says '*I'm a very good boy and I haven't been told off*'. His comment '*I haven't been told off*' carries with it a sense of pride that he has always been able to follow the rules and do what is required of him. This is clearly important to him and is underlined by his description of how stressed he feels at the prospect of not having '*done enough'*:

> *If I've not...done anything or like, done only a few sentences or whatever in something...that'll make me feel...horrible. Instead, having done...like, multiple...like a paragraph and... gotten...a large amount of stuff on the success criteria and... which is like a list of stuff you need to get into your work. Like if I haven't...got like, a paragraph and stuff like that makes me feel like I have not done enough. (Jack)*

Perhaps most tellingly in this excerpt is Jack's comment about meeting '*a large amount of stuff on the success criteria'.* This suggests that Jack's self-worth, in an academic sense at least, could be defined in relation to how much of the teacher's academic expectations he has been able to meet. This anxiety around completing tasks correctly and the relationship this has to self-concept was also expressed by Amelia:

> *…when [classmates] say I'm wrong it just makes me feel a bit bad about myself…like today...today, erm...we were doing this experiment in science. But...this girl called L kept on saying that I made the car go down this ramp a bit too late when I was doing it exactly on time. (Amelia)*

Amelia indicates that the possibility of not performing as expected '*makes me feel a bit bad about myself*'. Later in her interview, Amelia hints at perfectionism when she says '*I think in English I try to make it...perfect*'. This may be motivated in part by her wish to avoid the negative feelings associated with producing what she perceives as substandard work. In addition to working hard to meet the expectations of their teachers, some participants also speak of striving to ensure they are well regarded with peers, even if that comes at a cost to them, as articulated by Harry:

> *Jo: What are your favourite things to do with friends?*
>
> *Harry: Is probably like, playing something they want to play and I also would want to play.*
>
> *Jo: Yeah...what happens if you don't want to play the same things? Can you find a solution?*
>
> *Harry: I just go along with it, 'cause I wouldn't wanna cause an argument.*

Harry's comment that he '*wouldn't wanna cause an argument*' suggests that he tries to adapt to the wishes of his friends, even when he might rather not. It is possible that his desire for positive peer relationships might come at the cost of pursuing his own interests.

These findings will now be discussed in relation to the wider literature. Their implications for professional practice will also be considered.

5.4. Discussion

This is the first study that has specifically focused on the subjective lived experiences of autistic children attending primary mainstream schools who do not meet the criteria for EHCPs or have access to specialist resources. As such, it makes a novel contribution to this field of research. In contrast to the preference in the extant literature for proxy reports by parents and teachers, and due to the idiographic foundations of IPA, the findings of this study remain firmly rooted in the children's descriptions of their everyday experiences. Furthermore, the voices of autistic children have had a central role in all aspects of this study. The phenomenological nature of IPA augmented with creative methods, namely photo-elicitation and written accounts, have enabled access to a greater understanding of the participants' everyday school experiences, not least by providing alternative ways to describe those experiences thus avoiding a complete reliance on spoken communication.

These approaches resulted in findings consisting of three group experiential themes: 1) enduring a hostile sensory environment, 2) aloneness: enforced vs. chosen, and 3) the vital importance of trusted guardians. These themes and their associated subthemes will now be discussed in relation to the broader literature in order to identify the ways in which this study contributes towards our understanding of the autistic primary school experience.

The participants in this study frequently described their everyday school life in terms of sensory discomfort. This discomfort ranged in intensity from the low-level but ever-present irritation of the school uniform, through to sensations of physical pain caused by the noise of loud people and spaces. The lunch hall and the playground were frequently cited as the most challenging sensory environments. The noise, crowds and smells of these spaces were experienced by some participants as intolerable simultaneous assaults on multiple senses which, combined with the unpredictable social demands of break times, effectively separated them from some aspects of the school day which might typically be associated with feelings of restoration, freedom and enjoyment.

The idea that school can be a challenging and complex sensory environment for autistic children is well-documented in the literature, with studies reporting the impact of sensory integration difficulties on a range of aspects of functioning including emotional regulation and behaviour in the classroom (Ashburner *et al.*, 2008), academic achievement (Butera *et al.*, 2020), attention (Mallory & Keehn, 2021), and social interaction (Baker *et al.*, 2007; Tomchek & Dunn, 2007). Additionally, high levels of sensory reactivity have been associated with increased stress and anxiety in autistic children (Carpenter *et al.*, 2019; Green & Ben-Sasson, 2010; MacLennan *et al.*, 2020).

Therefore, we know that the sensory environment of mainstream school can adversely affect the education of autistic children and cause significant emotional distress. However, in line with a key theme throughout this thesis, much of the previous research into the sensory experiences of autistic children has been concerned with measurement of responses or comparisons with non-autistic children rather than exploring how these differences are subjectively experienced. Furthermore, the comparatively small amount of qualitative research into autistic children's sensory experiences of the school environment has tended to relate to those in secondary school (e.g. Birkett *et al.*, 2022; Howe & Stagg, 2016) with less being known about those of primary school age. This study makes a contribution to the extant literature by documenting how these experiences *feel* and the pervasive impact of sensory discomfort on the quality of young autistic children's lives.

Furthermore, the findings of this study indicate that sensory discomfort, while possibly greater at secondary school due to the typically larger school population and the increased scale and complexity of the buildings, is potentially just as significant in the primary years and therefore could be an enduring and debilitating challenge throughout an autistic child's school life. This is supported by suggestions that sensory discomfort may be a key factor in the elevated incidence of school avoidance and non-attendance in this particular population (Preece & Howley, 2018; Rodgers *et al.*, 2016). However, this is a problem not confined to education and childhood but with implications across the lifespan, as indicated by autistic adults who cite the impact of spaces not designed with autistic people in mind as central to their experiences of social exclusion, reporting that they feel, and are made to feel, out of place in mainstream spaces (Davidson, 2010; Madriaga, 2010).

In the present study, social exclusion was also connected with being uncomfortably and unhappily alone. In this sense, being alone was associated with experiences of bullying and rejection by peers, phenomena which, as discussed in previous chapters, has been well-documented in the literature (e.g. Cappadocia *et al.*, 2012; Cresswell *et al.*, 2019; Feldman *et al.*, 2022; Hebron *et al.*, 2015b; Humphrey & Hebron, 2015; Saggers *et al.*, 2017).

However, feelings of aloneness also appeared to be related to being separated from the everyday business of school by the incompatibility of aspects of school life with the participants' interests, preferences, and ways of being. Many of the participants in this study felt particularly excluded when mandated to engage in neuronormative activities such as outdoor group play during break times, or particular aspects of the academic curriculum which did not align with their interests or capabilities. This is despite broader research highlighting the positive impacts engaging in preferred interests can have on autistic children's academic attainment, social experiences, and general wellbeing (Gunn & Delafield-Butt, 2016; McDonnell & Milton, 2014; Winter-Messiers *et al.*, 2007).

Furthermore, it has been found that incorporating autistic children's interests and preferences into their everyday school experiences can reduce the need for resource-intensive interventions from school staff and can bring about whole-class benefits (R. Wood, 2021). The irony of this situation is that while it is plausible to imagine that school leaders may instigate such rules as enforced outdoor group play during break times in order to encourage a greater degree physical and social wellbeing among pupils, the stress and sensory impact of such policies may have the opposite effect on some autistic children, thereby exacerbating feelings of isolation, loneliness and not fitting in – all themes which feature strongly in the autism education literature (e.g. Goodall, 2018; Kasari & Sterling, 2013; Locke *et al.*, 2010).

However, not all experiences of being alone or separated from peers were negative, with some participants describing being allocated an individual workstation away from peers or a relaxation space in the quieter corner of the classroom as welcome adjustments. Removing oneself, either physically or mentally, seemed to be a key coping strategy and offered respite from the sensory, academic, social and communicative demands of school life which appeared to take a heavy toll on many of the participants. These findings contribute to recently emerging evidence on the experience of autistic burnout. Triggered by the multiple stressors of living without access to appropriate adaptations, autistic burnout is characterised by exhaustion, reduced or complete loss of some fundamental skills such as speech and executive function, and a reduced ability to tolerate sensory stimuli, all of which are exacerbated by feeling the pressure to mask one's differences and difficulties in order to fit in (S. R. Arnold *et al.*, 2023; Higgins *et al.*, 2021; Raymaker *et al.*, 2020).

Autistic burnout has also been linked with mental distress and suicidal behaviours (Mantzalas *et al.*, 2021; Mantzalas *et al.*, 2022).

However, much of this emerging evidence relates to the experiences of autistic adults and while these studies indicate that symptoms of burnout often begin in childhood, there are limited accounts of these experiences in young autistic children. The exception to this is a study by Phung *et al.* (2021) whose qualitative investigation into burnout and other aspects of autistic overwhelm with 8–18-year-olds found that young autistic people's experiences of burnout share many of the characteristics of those described above, comprising overlapping emotional, cognitive and physical manifestations affecting their whole person. Furthermore, they found that supporting adults, particularly educators, often misunderstood these experiences of overwhelm highlighting the need for greater collaboration and understanding between autistic pupils and staff in educational settings.

The role of supporting adults is particularly relevant to the present study. Although limited, especially in terms of the experiences of young autistic children, the previously cited research on autistic burnout underlines the importance of retreat and withdrawal in recovery and wellbeing - a theme which featured prominently in the data in the present study. Some of the participants, such Jack and Lily, were given access to specific places in school where they could retreat to when they needed to destress. These spaces were particularly valued because they came with permission from the teacher to use them whenever they were needed.

However, for other participants, access to retreat was difficult to negotiate. In addition to school policies mandating certain requirements such as being in the noisy and chaotic playground during breaks, several children mentioned people or systems in school that barred them from being able to find relief when feeling stressed. Therefore, having the support of understanding peers and staff seemed to be of central importance to the children in this study, and this again aligns with accounts of autistic adults in the literature who cite supportive and understanding allies as particularly helpful in reducing the stress of being in mainstream spaces (Raymaker *et al.*, 2020). Therefore, when viewed within the context of the wider literature, the findings of this study suggest a continuity of experience from childhood to adulthood, indicating that experiences of burnout may be frequent and prolonged over extensive periods of time.

These feelings of fatigue, frustration and overwhelm were possibly also compounded by feeling unable to ask for help. Many of the participants in the present study expressed difficulties in asking for help and seemed to prefer self-reliance over doing anything that may mark them out as different from their peers – a finding consistent to all three studies in this thesis and connected to avoiding being made a target for bullies or ridicule. It is therefore understandable that the participants relied on the proactivity of a small number of trusted people while at school; friends and members of staff who could detect when the autistic child was beginning to struggle and could step in and offer support without necessarily having to be asked.

However, this reliance on just a few key people suggested that the support network available to the children may have been fragile. These seemed to be vital relationships and therefore much was invested in them. If these relationships were to fail or suffer any kind of breach, the consequences may have been very serious for the child in question. They may have been left with no safety net.

There was a sense in the data that the importance of these key people may have been connected to an increased need to be liked and well-regarded; to be viewed by others as a 'good kid'. For Isabelle, being liked by the teacher appeared to be central to her self-esteem, whereas for Harry being liked by peers also seemed to involve having to work hard to avoid any form of disagreement, even if that meant engaging in activities he did not really want to do. It is possible that this pressure to be liked may have been associated with increased masking of difficulties or differences. As discussed in the previous chapter, masking has serious implications for a child's developing sense of self and, in addition to the connections to burnout discussed above, it has been associated with mental ill health and suicidal behaviours in autistic adults (Cassidy *et al.*, 2020).

Pearson and Rose (2021) argue that autistic (and otherwise neurodivergent) people's need to mask is intrinsically linked to the pathologisation of their differences in accordance with medicalised conceptualisations of neurodiversity. They propose that the stigma and marginalisation associated with outward manifestations of neurodivergence lead stigmatised people "to conceal these [pathologised] aspects of their identity from others, attempting to 'pass' as normal" (Pearson & Rose, 2021, p. 53). In an environment in which normative behavioural expectations are heavily enforced, passing as normal may be a form of protection from victimisation and unfavourable treatment associated with deviations from those expectations – a survival strategy, even. Isabelle voiced this point exactly when she said, '*if they don't like you they're not gonna treat you well*'.

It is arguable that a mainstream school is a good example of such an environment. As has been previously outlined and will be discussed in detail in the concluding chapter, the inclusive education model in England is predicated on medicalised understandings of difference in which the autistic child is often regarded as deviant in some way. This has led to an interventionist approach to the education of autistic children with the broad aim of changing their behaviours towards more accepted norms. However, having been the prevailing ideology in English schools for at least the last fifty years, we know that this interventionist approach has not improved outcomes for autistic children and may be in fact be causing harm. Therefore, an alternative conceptualisation of support is urgently required.

This study indicates that a more fruitful area of intervention may involve a shift in attention from the child and their perceived failings to a more socially-conscious consideration of the school environment in which autistic children are educated – the buildings, the people and the culture. These ideas and their implications for educators and clinicians will be discussed in relation to the findings of all three studies in this thesis in the concluding chapter which follows.

5.5. Strengths and limitations

While brought about by necessity due to the limitations of conducting research in the aftermath of the COVID-19 pandemic, the use of online platforms for interviews was ultimately a strength of this study. Not only did this enable to the children to participant in interviews from the comfort and familiarity of their own homes, it arguably afforded them more control over how the interviews were conducted. Not only did they have the option of easily and conveniently terminating the interviews, they were also able to take advantage of a range of communication modalities. They could turn off their cameras and/or microphones, or communicate with me using text rather than speech. They also had the opportunity to personalise the online interview environment to suit their preferences by adding different backgrounds and sharing images. Fortunately, I experienced no insurmountable technical difficulties in the data collection process although I appreciate this could be a potential drawback to conducting research online. I am also aware that the requirement to own a suitable device and have a stable internet connection may have been a barrier to taking part in this study for some children.

This study was limited by the fact that, because the study involved young children, gatekeepers were required at all stages. Parents were naturally the primary drivers of participation since they not only provided consent and practical support for their children to take part, but they also facilitated permission with the head teacher at their child's school for photographs to be taken of the school environment. Therefore, it is possible that the children who took part in this study were ones with good home-school relationships and this may have had a bearing on the data. Indeed, in my early conversations with parents who expressed an interest in the study, they all described having a good working relationship with staff in their child's school. As outlined in chapter 4, there can often be considerable tension between school staff and families of autistic children, and there is a large literature on how adversarial these relationships can often be. As such, it is possible that the need for permission from the child’s school may have been a barrier to some children taking part in the study and the range and nature of experiences therefore represented here may be limited as a result.

5.6. Implications for future research

Aside from the urgent need for more research into the subjective experience of what it means to be autistic in mainstream spaces, this study indicates we have much to learn from young autistic children about how best to meet their needs. As has been highlighted throughout this thesis, the relative lack of autistic voices in the literature is a significant barrier to knowledge production in autism research and could be part of the reason why, despite much debate among researchers, teachers, parents, policymakers and others about how best to support autistic children in schools (e.g. DfE, 2023; Dillon *et al.*, 2014; McKinlay *et al.*, 2022; Walsh & Hall, 2012; Warnock & Norwich, 2010), their outcomes remain poor. Furthermore, given the connections between the findings of this study and aspects of the research into burnout in autistic adults, there is a strong rationale for increased research into this phenomenon in young autistic children.

6. Chapter 6: Discussion

This chapter begins by summarising the findings of the three studies in this thesis in relation to the overarching research aim of this project. I will then move on to a discussion of what these results mean in relation to other evidence and theory before considering the implications of these findings in terms of educational practice and policy. The chapter ends with a review of the strengths and limitations of this work and how the findings could be used to inform future research.

6.1. Summary of research conducted

As set out in the introduction of this thesis, the overarching aim of this research was to explore what it means to be an autistic child in a mainstream primary school. I set out to achieve this aim by conducting an inductive qualitative investigation into the subjective everyday school experiences of autistic children. In particular, I chose to focus on a population of autistic children who are currently underrepresented in the research literature i.e. those in mainstream primary schools who do not meet the criteria for an EHCP and do not have access to specialist autism support or resources. While the focus on this specific population was maintained throughout this investigation, the paucity of existing research relating to such children meant that I also considered evidence from a broader range of perspectives; namely from studies relating to autistic children of school age including those in secondary school and those with specialist support, and from research with young autistic adults reflecting back on their time in primary school. I will now briefly summarise the findings of each of these three studies in turn before identifying cross-study findings.

6.1.1. Review of study 1

My first study in chapter 3 aimed to establish what was already known about the subjective mainstream school experiences of autistic children and young people by systematically reviewing and synthesising the existing qualitative literature. The findings of this metasynthesis suggested that the autistic mainstream school experience was characterised by frequent experiences of peer rejection and bullying, difficulties in navigating the academic curriculum and normative pedagogical practices, and sensory discomfort caused by the busy noisy school environment. The emotional impact of coping with these challenges resulted in feelings of stress which tended to be externalised as anger and/or internalised as anxiety. This stress was further compounded by feeling under pressure to hide these emotions and aspects of one's autistic identity in an attempt to meet the expectations of others. A key finding in this study was the importance of relationships with a small number of trusted peers and staff who offered both protection from and translation of the often exclusionary and confusing intricacies of the neuronormative culture of mainstream school.

In addition, by systematically reviewing the qualitative literature published over the last twenty-three years, it became clear that most of the research on the lived experiences of autistic children in mainstream schools has focused on those in secondary school and/or those with access to specialist support and resources. While the original aim of this study was to review the literature relating to autistic children in mainstream primary schools without access to specialist resources or EHCPs or equivalent, my searches revealed that there were no published papers which specifically focused on this particular group of children. This study therefore provided strong justification for the detailed investigation into the experiences of primary-aged autistic children which followed.

6.1.2. Review of study 2

In an attempt to contribute towards the gap in the literature identified by the metasynthesis, I designed a study to investigate the lived experiences of children who were underrepresented in the literature. However, given that the metasynthesis had exposed a tendency in the autism qualitative literature to focus on the secondary school experience, it did not necessarily provide sufficient grounding for my planned investigation with autistic children of primary school age. Given the distinctive differences between primary and secondary school in terms of culture, expectations, environment, and teaching practices, I was aware that the foreunderstandings generated by the analysis of the data in the metasynthesis might not provide an adequate basis for study 3. Therefore, in order to prepare the interview schedule for the planned research with younger autistic children, I conducted focus group discussions with parents, teachers and young autistic adults to establish the most salient aspects of the autistic primary school experience.

Having identified that the contributions from the young autistic adult group were most appropriate to my research aims, the data were thematically analysed and findings indicated how, from a very early age, the participants felt different from those around them. They described how their peers, teachers and sometimes their family members responded negatively to their autistic ways of being resulting in various acts of hostility towards them. They described these acts as bullying and cited teachers as well as peers as instrumental in their invalidation at school. The participants described being subject to routine microaggressions which seemed to centre on the notion that if they behaved and related to the world in more neurotypical ways, life would be easier for them and they would better accepted at school and elsewhere. This led some participants to feel pressured to hide their differences as much as possible in an attempt to be liked by others. Not only was this effortful and distressing but it had long-lasting implications for the participants' self-concept and self-esteem.

The findings of this study were pivotal in the development of the research which followed and in my thinking around how changes could be made in mainstream schools to better support autistic children and young people. Prior to this study, I was curious about the ways in which support might be made available *to* autistic children in order to enhance their educational experiences. However, as a result of this study, I became more aware of the role stigma might play in the lives of autistic children, and how stigmatising views may sometimes be wrapped up in the guise of help and support. Combined with the key finding in the metasynthesis of the vital importance of supportive staff and friends, my focus shifted from thinking about within-child approaches to wanting to understand more about the impact of the environment in which the child is educated, and in particular, the impact of other people within the school environment, namely staff and peers.

6.1.3. Review of study 3

The third and final study of my PhD research project aimed to contribute towards the gap in the literature identified by the metasynthesis in chapter 3. Supported by the findings and the foreunderstandings developed by the focus group study in chapter 4, I conducted an investigation into the lived experiences of autistic children in mainstream primary schools who did not have EHCPs or access to specialist autism resources. Using Interpretative Phenomenological Analysis with creative data collection methods and poetic transcription, the themes constructed from the data highlighted the high degree of challenge experienced by the participants at school and the effort they expended in coping with and attempting to overcome those challenges.

The most prominent difficulty described by the participants related to sensory discomfort. The multi-sensory impact of the school environment was often stressful and sometimes physically painful. In order to cope with this stress, the participants described how they would seek quiet spaces in which to be alone but these were hard to find and access needed to be negotiated with peers and staff – a process that could sometimes increase stress levels further. While being alone appeared to be craved at times, the participants also indicated that being alone was not always a restorative choice. Sometimes it was enforced, and many participants described upsetting and confusing instances of being excluded either by peers or by the systems and policies of the school system.

Perhaps as a result of their challenges with the sensory environment and the difficulties experienced in coping with the social demands of school, the participants described the importance of having a small number of trusted people on which they could rely. These trusted peers and staff arguably provided the support and adaptations which made school more tolerable for them and without which, everyday school life may have been much more challenging. However, the reliance on just a few people also made those relationships so important that keeping these key people happy became essential, to the extent that some participants described going to considerable efforts to remain in their teacher's favour or to avoid discord in their friendships. While these allies appeared to play a central role in making school more accessible and enjoyable for this group of children, the pressure to maintain these vital relationships potentially increased the demands on the children.

6.1.4. Cross-study findings

As set out in chapters 1 and 2, the research in this thesis was conducted within the neurodiversity paradigm using an interpretivist qualitative approach. This enabled me to collect rich data using accessible and flexible procedures, resulting in three studies which although distinct in their methods have all contributed meaningfully to the central aim of this thesis: to develop a greater understanding of how autistic children describe and make sense of their experiences of mainstream primary school.

When interpreted collectively, these three studies provide insight into the everyday experiences of autistic children in mainstream primary schools from three different viewpoints 1) from the perspective of the extant qualitative literature, 2) from the perspective of autistic young adults reflecting back on their primary school years and, 3) from the perspective of autistic children currently attending mainstream primary schools. I will now outline the points of convergence across the three studies before turning to the potential implications these findings have for theory, practice and policy.

Setting aside the metasynthesis in study 1 for a moment to focus specifically on the primary school experience as described in the studies 2 and 3, the findings of these two studies indicated that exclusion of some form was a common experience for the participants. As outlined in the introductory chapter, there is an increased incidence of formal and informal exclusion of autistic children in the English education system, but the findings of these two studies allude to a form of exclusion that is potentially more subtle but no less damaging.

Participants in both studies described being excluded in some way by the people, policies and practices within the school system. Some of these experiences stemmed from overt othering involving rejection, bullying and shunning by peers. These subtle but pervasive and routine experiences of exclusion affected not just the participants' sense of self and belonging but also their ability to access support since standing out made them targets for bullies. Some staff also played a key role in the distress experienced by some participants – by misunderstanding their behaviour as disobedience; by being inflexible in their teaching and interaction styles; by showing open hostility towards their differences. Even when trying to be supportive, the neuronormative expectations of some teachers had a detrimental impact on some of the participants in these studies.

Participants in both studies reported finding some of the explicit and implicit rules in schools exclusionary to them: the requirement to eat in crowded noisy lunch halls; the expectation that playing in the playground with peers during lunchtime was best for children rather than engaging in indoor solitary pursuits; the predominance of group work; the relative absence of alternatives to verbal instruction; the lack of opportunity to engage in their interests which may differ from those of other children of a similar age. Essentially, there appeared to be a possible mismatch between the ideas in school about what was 'good' for children and what these autistic children found enjoyable, interesting and accessible.

Sensory overwhelm was a major barrier to inclusion. Places and events typically associated with fun and freedom such as the lunch hall, playground, and school discos were all highly problematic. For many of the participants in these studies, fun and freedom were found elsewhere: in their interests and hobbies, in movement, in creativity and imagination and, most of all, in being in quiet solitude. However, quiet solitude was typically difficult to access, either because quiet places did not exist, or because school rules mandated otherwise, or because adults suggested that to be alone was to be 'selfish'.

These experiences of being othered and excluded were connected with feeling undesirably different or 'not normal'. While this was most clearly articulated by the autistic adults with the benefit of hindsight, the younger children also described ways in which their autism negatively marked them out as different. In addition to possibly contributing towards the children's tendencies to minimise their own difficulties, it is possible that these experiences increased the perception of needing to hide their differences and why their self-worth appeared to be closely tied to how their peers and teachers viewed them.

Interestingly, these are all experiences reflected on by the autistic adults in ways that were only seen as harmful with the passing of time and the development of their sense of autistic identity which, for many, took place after their school years were over. Although this is speculation and warrants future exploration, it is therefore possible that these experiences are normalised in early childhood and are only seen as particularly harmful in later life when the school is no longer a key aspect of daily life.

Another strong connection between the findings of studies 2 and 3 was the need to be self-reliant and find solutions to one's own problems. Perhaps connected with masking one's difficulties, this theme was expressed through descriptions of having to be creative in finding ways to get one's needs met – be that through finding hidden spaces to retreat to or by findings ways in which to do 'jobs' for the teacher to avoid having to go into the playground with classmates. This creativity also sometimes extended into purposely breaking school rules in order to be able to access comfortable spaces.

Essentially, a theme connecting both studies was the sense that the responsibility was on the child to adapt to their environment rather than the other way round, even if the effort required to make these adaptations left them depleted or meant getting into trouble. This notion of depletion fed into a broader theme of fatigue - that trying to fit in was effortful and that the social demands of school were tiring to the point of leaving a child unable to speak. The participants described how this led to a need for retreat but, again, this was not always available or permitted, leading to feelings of powerlessness and increased stress.

These intertwining themes go some way in helping to understand the importance of allies, or 'guardians' as I have described them in study 3. These people provided the necessary support so that the children did not always have to rely on themselves. Trusted peers provided crucial support with the social and academic demands of school, and many of the children in study 3 said that one of the most important things about their friends is that they were willing to play with them. Given the high level of hostility and peer rejection shown to these participants, it is easy to see why this perhaps taken-for-granted quality in a childhood friend was so important. These friends also supported help-seeking from teachers and acted as bridge between the autistic child and the adults in the classroom with the power to make necessary adaptations.

The children in study 3 also held teachers in very high regard. Unlike study 2 in which recollections of teachers were largely negative, the members of the child study were all very attached to their class teacher and described having great affection for them. However, this led to what I referred to as a 'high-stakes' environment in which ensuring they remained well-liked by friends and teachers was of primary importance.

It is important to note that this finding may be connected to the nature of how participants were recruited. As already outlined in the limitations of study 3, participation in the study required permission from the child's school to take photographs and all parents involved described having a good relationship with the staff in their child's school. This may have been a barrier to some families who may have felt unable or unwilling to enter into the permission-seeking process due to more strained relationships with schools which are not uncommon in families of autistic children. Furthermore, study 2 may have appealed more to participants who felt they had had particularly negative experiences of primary school that they wanted to share.

Study 1 stands apart somewhat from the other studies in this thesis. Firstly, it was systematic review of existing literature rather than an empirical study and, given the lack of published studies on my chosen population of children, included children in secondary school settings and those with access to specialist support. However, there are many areas of commonality in the experiences between the descriptions of secondary and primary school experiences shown in all three studies in this thesis. The children and young people represented in the metasynthesis also reported the attitudes of teachers and peers as instrumental in their inclusion or otherwise. They also struggled with the neuronormative behavioural expectations and pedagogical approaches. Sensory discomfort was linked with high levels of stress and feelings of suffocation and pain. All of these challenges, as described in the other two studies, led to the need to mask and a pressure to behave as 'normally' as possible. Having to be self-reliant and the resulting feelings of fatigue and stress were also consistent across all three studies. Like study 3, the metasynthesis also highlighted the importance of allies and the ways in which trusted peers and teachers act as translators and facilitators in a complex and confusing environment.

Whilst the aim of the metasynthesis was to explore what was already known about the mainstream school experiences of autistic children in order to provide a foundation for the empirical studies, the fact that there is so much consistency between the experiences of those in secondary school and the descriptions of primary school outlined in chapters 4 and 5 raises questions for researchers, educators and policy-makers. Perhaps most importantly, these three studies suggest that school may be a hostile environment for autistic children of all ages.

Research on the transition from primary to secondary school for autistic children highlights the challenges of larger secondary schools with different teachers for different subjects and the increased academic and social expectations (Dillon & Underwood, 2012; Maras & Aveling, 2006; Tso & Strnadová, 2017). While this is uncontroversial, there is a sense in this literature that, in contrast, the primary school years place fewer demands on autistic children (e.g. Mandy *et al.*, 2016). The research in this thesis suggests otherwise and indicates that experiences of stigma, exclusion, sensory discomfort and stress are commonplace even in the relatively lower-demand primary school environment. However, despite these difficulties and experiences featuring frequently in the literature relating to children and young people in secondary schools, there remains a paucity of research into younger autistic children's difficulties at school and their subjective experiences remain overlooked. My research indicates that younger autistic children may experience very similar difficulties to those of adolescents.

In short, the findings of my research indicate that being autistic in a mainstream school is an experience which may be characterised by built environments, cultures and people who are frequently intentionally and unintentionally hostile towards autistic people. This can cause significant stress which may be exacerbated by feeling compelled to conform to neuronormative expectations. Furthermore, it is possible that neuronormative school rules and behavioural expectations can restrict autistic children's autonomy to the extent where they are unable to access relief when feeling overwhelmed, or engage in preferred activities which could have a positive or even protective effect on their wellbeing.

6.2. Research aims and contribution made by this research

The aim of my research was to explore how autistic children describe and make sense of their everyday experiences of primary school. In an attempt to achieve this aim, I used a range of rigorous but flexible and creative methods, and augmented my investigation with contributions from older children, autistic young adults, and those with access to high levels of support. As a result, the findings of my literature-based and empirical research are based on the contributions of a combined total of 293 autistic young people and the findings offer good insight into everyday lives of young autistic children in mainstream school settings. Furthermore, this research has led to novel understandings and contains insights into phenomena not previously recorded in the extant literature. As such, it extends our understanding of the autistic school primary school experience in meaningful ways.

However, qualitative findings are not intended to be generalisable (Clarke & Braun, 2022), and the idiographic nature of my epistemological approach required small samples to enable a close and detailed examination of individual experiences. The findings of my empirical research reflect the thoughts, feelings and experiences of my participants at a specific point in time, and are the result of my interpretations of the data. Further research is required to explore the extent to which these findings are reflective of the broader autistic primary school experience. My suggestions for such research are detailed later in this chapter.

Nonetheless, qualitative research plays a key role in theory building. Willig (2019) notes that "qualitative research contributes to theory development by moving beyond descriptions of observable events to consider what may lie beneath them and what may shape and direct them" (p. 803). It is my belief that the findings of my research make a significant contribution to theoretical approaches outlined in the introductory chapter. I will now go on to discuss this point in more detail.

6.3. What do these findings mean in relation to theory?

As outlined in the introductory chapter, the research in this thesis has been conducted in relation to two theoretical perspectives: the double empathy problem (Milton, 2012a) and the minority stress model (Botha & Frost, 2020). To briefly revisit these theories, the double empathy problem is one in which the differences in how autistic and non-autistic people experience and engage with the world can lead to mutual misunderstanding. However, due to the disparity in social power between these two groups, autistic ways of being which deviate from accepted norms tend to be pathologised, with the implication that intervention and adjustment is required on behalf of the autistic person in order for their ways of being to more closely match neuronormative expectations.

In a similar reframing of deficit-based interpretations of the autistic experience, the minority stress model posits that autistic people constitute a stigmatised minority group and as such, the mental ill health and distress frequently experienced by autistic people may stem from their experiences of victimisation and discrimination as opposed to medicalised interpretations of their differences. These theories both indicate that many of the challenges autistic people face could be addressed by greater understanding and acceptance of autism among the neuromajority. Both theories posit that neuronormative societal forces can serve to stigmatise and therefore harm neurominority groups, playing a significant role in the impoverished educational, health and social outcomes autistic people experience across the lifespan.

The findings of this thesis show aspects of the double empathy problem in action. Indeed, it is possible to say that the double empathy problem is writ large in our education system; a system which, despite its inclusive ideology, is designed by and for the neuromajority. Autistic children are expected to adapt to the rules and expectations of the system and when they either cannot adapt or experience stress or fatigue from the effort of trying to adapt, they are pathologised. Their difficulties are seen as problems within them as opposed to understandable consequences of having to adapt to a system ill-equipped to meet their needs.

This is underlined by the Department for Education's guidance relating to children with Special Educational Needs which stipulates that should a child struggle to 'progress', staff should:

> *6.19 "...not delay in putting in place extra teaching or other rigorous interventions designed to secure better progress" Code of Practice (p. 95)*

The SEN Code of Practice (Department of Education and Department for Health, 2015) does not define what constitutes an intervention and gives no further guidance on which interventions should be used and who they should be aimed at. Of course, it is possible that an intervention could be aimed at changing the school environment or aspects of pedagogical practice to ensure greater levels of access and comfort for autistic pupils. However, a common interpretation of this guidance is that it is the child who is removed from their class to receive small group or one-to-one interventions designed to bring about some change in the child (Webster, 2022).

This is borne out by systematic reviews in the research literature which indicate that many school-based interventions for autistic children and young people centre on changing aspects of their social communication and interaction, and reducing behaviours regarded as inappropriate or challenging (C. Bond *et al.*, 2016; Parsons *et al.*, 2011; Watkins *et al.*, 2019; C. Wong *et al.*, 2015). Along similar lines, a survey of UK educational psychologists in the UK and Ireland found that practitioners were most often involved with implementing behavioural interventions and social skills training programmes (Robinson *et al.*, 2018), ostensibly aimed at targeting autistic ways of being which are deemed as inadequate or inappropriate (e.g. Cappadocia & Weiss, 2011; Rao *et al.*, 2008; Williams White *et al.*, 2007).

A detailed examination of such interventions is outside the scope of this investigation, but none of the interventions featured in the reviews cited above are aimed at reducing stigma or identifying environmental and cultural barriers to participation. None require staff and peers to reflect on their own behaviours and consider if they themselves might need to adjust in any way. Instead, the SEND Code of Practice frames autistic children as problems to be solved. This has arguably led to a unidirectional interventionist culture in our education system in which the onus is on the child to change and adapt rather than identifying which adjustments might be needed on the part of teaching staff or peers to increase mutual curiosity, understanding and empathy.

The double empathy theory offers an explanation for why such interventionist approaches are potentially ineffective and unhelpful. This is exemplified in the findings of this thesis where on a practical level, it is difficult to see how any of these interventions would address the concerns of my participants since behaviourist approaches aimed at changing the child do nothing to address possible hostilities and threats in the physical environment, the school culture or in the attitudes of staff and peers.

Furthermore, an undoubtedly unintended but nevertheless harmful consequence of this interventionist approach is that the child develops a sense that they are inherently disordered rather than divergent. The medicalised underpinnings of interventionist approaches mean that rather than the autistic child developing an understanding of what they need to lead a full and flourishing life on their own terms, they are instead encouraged to behave and function as closely as possible to a norm set by non-autistic peers of similar age. However, as has been demonstrated by the research and commentary in this thesis, the effort and resources required to adapt to non-autistic norms can leave autistic children exhausted, distressed and potentially at risk of significant mental health difficulties.

This point leads on to what the results of this thesis mean in relation to the second theoretical framework I have used: the minority stress model. The findings of the three studies in this thesis all show the considerable levels of stress experienced by the participants. It is arguable that much of the stress described stems in large part from having to cope with and adapt to an environment that is ill-suited to the needs of autistic people. The cross-study findings allude to the considerable pressure of having to cope with the sensory environment and the neuronormative academic and social expectations of school on a daily basis for many years.

In addition to these passive hostilities, the participants described routine experiences of active hostility in the form of microaggressions, victimisation and marginalisation –all potentially stemming from stigmatised views of autism which are inextricably tied to the medicalised conceptualisations of neurodivergence and difference more broadly within the education system. Perhaps most worryingly, the findings of my research align strongly with accounts of minority stress in the autistic adult literature with the data pointing to an overwhelming pressure to mask and conceal not only one's differences but also one's distress when faced with hostile people or places (Botha *et al.*, 2022). There is a clear indication that the children featured in my studies assume a considerable amount of personal responsibility for the difficulties they experience as a result of spending prolonged periods of time in an environment which makes little allowance for their unique ways of being.

These theoretical positions and the findings of the studies in this thesis have important implications for educational practice which will now be discussed.

6.4. Implications for educational practice and policy

Arguably key to addressing the issues raised by the findings of my research is the level of autism understanding and acceptance there is in mainstream schools. As already detailed in previous chapters, the level of support that is available to autistic children in English mainstream schools is highly variable and largely teacher-dependent, leading some families to describe the process of securing the right educational support for their child as a lottery (Galpin *et al.*, 2018). The findings of my research lend further support to the idea that teachers play a crucial role not only in an autistic child's academic progress, but also their sense of self. Having a trusting relationship with an understanding and accommodating teacher appeared to be central to the participant's thriving in study 3, whereas the hostility of teachers in study 2 was still being negatively felt by the participants in adulthood. Therefore, it may be possible to say that, particularly in primary school where typically each class is led by a single teacher, individual staff members may have the capacity to make or break an autistic child's school experience.

Given this central role of the individual teacher in the success or otherwise of an autistic child's school experience, and the potential for poor school experiences to contribute to longer-term academic, social and psychological difficulties (Avison, 2010; L. Bond *et al.*, 2007; Eccles & Roeser, 2011; Liu & Chen, 2021), it is troubling to know that some teachers have ambivalent views towards including children with disabilities in mainstream classrooms. In a review of twenty-six papers on teacher attitudes, De Boer *et al.* (2011) found that the majority of teachers consulted held neutral or negative views towards including children with disabilities in mainstream classrooms. Furthermore, they found no clear examples of positive attitudes, with this linked to a lack of experience in teaching children with disabilities and a paucity of specialist training. Other studies have reported similar trends with teachers citing a lack of confidence in their ability to meet the needs of autistic students, exacerbated by insufficient funding, resources and training (Humphrey & Symes, 2013; Ravet, 2018; Roberts & Simpson, 2016).

The idea that staff lack appropriate training to meet the needs of autistic children in mainstream schools has a long history, with Mary Warnock's pivotal 1978 report highlighting the need for SEND training to be embedded in teacher training programmes (Warnock, 1978). In recent years, there have been renewed calls from national autism charities for increased investment in training for school staff and leaders (Ambitious About Autism, 2022; National Autistic Society, 2021). This has been echoed in government with a commitment to increased autism training being made by the All Party Parliamentary Group on Autism (APPGA, 2019) and the Government's *National strategy for* *autistic children, young people and adults: 2021 to 2026* maintaining that “we want more teachers and educational staff to understand the specific needs of their autistic pupils” (Department of Health and Social Care and Department for Education, 2021, p. 17) citing staff training is central to this. However, there are scant details on what this training consists of, who it has been developed by, who will be delivering it, and to whom.

While additional investment in training for staff would no doubt be welcomed, the findings of my research suggest that the primary needs of autistic learners are not necessarily complicated. The participants in these studies appeared to be asking for a greater sense of trust, safety and belonging. They seemed to be asking for permission to make autonomous decisions in order to establish sensory comfort and emotional regulation. Most importantly, they were also asking for their authentic autistic identity to be respected and valued. It is arguable that if these fundamental needs are not met, no amount of investment in other supports is likely to be as effective as it otherwise could be.

Furthermore, it is my view that the focus on funding and training is potentially misleading and distracts from what I see as the bigger issues of equity and social justice. Instead of locating the challenges experienced by autistic pupils solely within the children themselves, framing them in the process as in need of resource-intensive expensive investment, efforts may be better placed in identifying how the structures, practices and cultures in our schools might actively disadvantage neurodivergent pupils and potentially contribute to their poor outcomes.

There has been considerable debate among researchers, teachers, parents, policymakers and others about how best to improve the experiences and outcomes for autistic children and young people in mainstream settings (DfE, 2022f; Dillon *et al.*, 2014; Walsh & Hall, 2012; Warnock & Norwich, 2010). However, this conversation has not fully included autistic people and has often failed to honour and value autistic ways of being (Milton & Bracher, 2013). Instead, the conversation has largely been confined to non-autistic people (adults, mainly) and, as illustrated by the nature of the interventions previously discussed, has tended to focus on the changes autistic children need to make in order to fit into the education system rather than identifying how changes in the structures, practices and cultures in our schools might actively disadvantage neurodivergent pupils and cause them distress (Milton, 2014b).

While we unquestionably still have a long way to go, our education system has progressed in recent years in terms of recognising and celebrating ethnic, cultural, sexual, religious, and gender diversity, not least due to the legal protections such aspects of identity have under the Equality Act (2010).

However, although disability is also a protected characteristic under the same legal framework, it is arguable that neurodiversity is still a largely under-recognised and poorly understood concept in English schools. Rather than an identity worthy of respect and appreciation, autism (and other neurodivergent conditions such as ADHD and dyslexia) is still viewed by many as an economic burden or a problem to be solved (Buescher *et al.*, 2014, p. e.g. ; Knapp *et al.*, 2009; Rogge & Janssen, 2019).

It is my belief that these societal and attitudinal factors are at the heart of the challenges faced by autistic children and young people in mainstream schools, and indeed for autistic people of all ages across society. Additional training might bring about positive change, especially if it is designed, developed and implemented in partnership with autistic people. One such promising example of a co-produced neurodiversity-affirming training programme is The University of Edinburgh's Learning About Neurodiversity at School (LEANS) project (Alcorn *et al.*, 2021). However, it is important to recognise that the current culture towards autistic children in mainstream schools needs to change. In light of this, I repeat the quote from Walker (2021) first mentioned in the introductory chapter where she calls for "…a shift in our fundamental assumptions; a radical shift in our perspective that requires us to redefine our terms, recalibrate our language, rephrase our questions, reinterpret our data, and completely rethink our basic concepts and approaches." (Walker, 2021, p. 14). If staff training is indeed part of the solution, it is my view that it needs to be part of this paradigm shift.

Recent research into neurodiversity-affirming approaches to supporting autistic children offer some suggestions on how this paradigm shift might take shape if it were to be incorporated into staff training. Leadbitter *et al.* (2021) have proposed a move towards a strengths-based approach to support in the early years which, instead of prioritising neuronormative goals and aspirations, prioritises autonomy, pleasure and wellbeing. Similarly, Fletcher-Watson (2018) has called for a greater focus on autistic-led targets and outcome measures as an alternative to the widespread use of interventions based on neuronormative expectations, as well as paying more attention to creating safe and enabling environments for autistic children.

As speaker at University College London's Centre for Research in Autism and Education (CRAE) annual lecture in 2022, Professor Sue Fletcher-Watson also proposed that in order to create a neurodiversity-affirming education system, it needed to: 1) expect diversity instead of defining difference as unusual, 2) teach self-advocacy skills so that autistic learners can ask for help when they need it, 3) actively fight stigma and, 4) profile the individual rather than the label in order to create effective personalised approaches to meeting need (Fletcher-Watson, 2022). In keeping with the first point in her list, it is arguable that if these approaches were incorporated into the culture of our education system, they would benefit all children and young people and not just autistic learners.

However, for the paradigm shift to begin and for these approaches to be adopted and become standard practice within schools, there first needs to be recognition of the fact that school cultures and environments may be harmful to autistic children. It is possible that this is a consideration which runs contrary to prevailing societal views that school is the best possible environment for children to learn and develop. This is seen clearly in the governmental messaging around the issue of school attendance; an issue that has received more attention since the Covid-19 pandemic.

During the Covid-19 pandemic, schools reduced the numbers of children who could attend in person and moved most of their teaching online. During this time, and the aftermath of the lockdowns, the rhetoric around school being the best place for children featured heavily in the Department for Education's messaging around school attendance:

> *"I want every single child to have the opportunity to fulfil their potential, which only time in school with this country's world-class teachers can bring" (The Rt Hon Nadhim Zahawi MP, then Education Secretary, January 2022)*

> *"We know children learn best when they are at school, surrounded by their friends and teachers" (Department for Education, 2023)*

However, research conducted during the pandemic suggested that school might not be the best environment for some autistic children. The Covid-19 pandemic was extremely difficult for autistic children and their families with access to vital educational, social and health supports either restricted or withdrawn entirely (Canning & Robinson, 2021; Patel *et al.*, 2020; National Autistic Society, 2020) and I do not want to minimise this negative impact. Nevertheless, there were a number of small studies conducted at the time which showed that once the initial difficulties in transitioning from school to home learning subsided, many autistic children experienced improvements in wellbeing and academic outcomes.

Findings indicated that home-based online learning enabled autistic participants to achieve sensory comfort more easily, allowed them to more readily engage in their hobbies and passions, experience reduced levels of social stress and autism-related stigma, and reported increases in academic, social and life skills (Heyworth *et al.*, 2021; Pavlopoulou *et al.*, 2020; Vincent *et al.*, 2023). It was also reported that some parents experienced a sense of relief from not having to try to get their child into school or cope with the emotional fallout that comes from their child attending school (C. Hill *et al.*, 2021).

Therefore, in order for staff training to be part of the much-needed paradigm shift, it needs to begin with a consideration of the potential harm caused by neuronormative school cultures to autistic children. It needs to be based on an understanding that the difficulties experienced by autistic children might not be located in the child but perhaps in their environment. Furthermore, it is my view that educators and policy-makers must examine their attitudes towards neurodivergent pupils and explore how these attitudes might shape their interactions with them, their assessment of their strengths and difficulties, and influence the nature of the support which is offered to them.

6.5. Strengths and limitations

The research in this thesis has achieved the overarching research aim by documenting the lived experiences of a group of children significantly underrepresented in the current research literature. While much has been written about the lack of autistic voices in the autism literature (e.g. Milton, 2014a; Milton & Bracher, 2013), the metasynthesis in study 1 highlighted the almost complete lack of representation of autistic children in mainstream primary schools who do not meet the criteria for EHCPs and do not have access to specialist resources. This is despite there being 66843 children of this description in the education system in England in the school year 2020-2021 (DfE, 2020b). The research I have conducted, while small scale, has contributed towards addressing this gap in the literature.

Furthermore, the work I have conducted meets the criteria for quality and validity set out in Chapter 2. To briefly recap, Yardley (2000) maintains that quality qualitative research should demonstrate the following principles: 1) sensitivity to context, 2) commitment and rigour, 3) transparency and coherence, and 4) impact and importance. I will now discuss the extent to which my work demonstrates these principles.

Sensitivity to context

I have demonstrated sensitivity to context by locating my work within relevant theoretical and empirical literature. To enhance my contextual understanding, I have taken a cross-disciplinary approach to the literature and engaged with sources, evidence and theoretical perspectives from psychology, education, sociology, critical disability studies and philosophy. As a non-autistic autism researcher, I have also developed my sensitivity to the socio-cultural context of my investigation through my broader engagement with accounts in the literature by autistic authors and through my online and in-person connections with members of the autistic community. My autistic friends, colleagues and mentors have enhanced my understanding of what it means to be autistic in a mainstream space and I am grateful for their generosity and expertise. I have shown sensitivity to the data by not seeking to avoid the messiness and contradictions of real life. I have not aimed to provide neat interpretations but rather have sought to demonstrate the complexity and nuance which are characteristic of subjective lived experiences.

Commitment and rigour

I have demonstrated commitment and rigour by conducting three detailed studies using methods and participant selection approaches which have been appropriate to meet their objectives. I have demonstrated prolonged and in-depth engagement with the data having taken between 12 and 18 months to complete the analysis of each study. The analysis of the data in each instance has also been conducted in detailed consultation with my supervisors. I have also demonstrated commitment to my participants by engaging sensitively with their experiences and personal circumstances.

Transparency and coherence

I have demonstrated transparency and coherence by creating a body of work which employs different methods but forms a coherent whole with a strong narrative. I believe that the work I have produced represents a good fit between the theoretical and methodological approaches I have employed to address my overarching research aims. Transparency has been demonstrated by prioritising the experiences of my participants and the extensive use of verbatim quotes to support my interpretations. I have taken steps in every study to root my analysis in the voices of my participants and I hope that I have demonstrated that in the reporting of my work. I have also explained in detail the rationale for my research and clearly explained the steps I have taken to reach my findings.

Impact and importance

Finally, this research makes an important contribution and has impact. As previously discussed, this research has made a novel contribution and amplifies the voices of an underrepresented group in the literature. In addition, it is my understanding that this research is aligned with the issues that the autistic community think are important. There are plans to publish studies 2 and 3 as soon as possible and I have been approached by a publisher with a view to potentially adapting this thesis into a guide for teachers.

Limitations

In addition to the study-specific limitations discussed in chapters 2, 3 and 4, there are some notable limitations which apply to all the work presented in this thesis. Firstly, while I have attempted to include autistic people as much as possible in the design and development of my project and I have amplified the voices of autistic people wherever possible, this research cannot be described as participatory.

As previously discussed, there is an urgent need for autism research which actively includes autistic people and is relevant to their needs and priorities (Pellicano *et al.*, 2014). Fletcher-Watson *et al.* (2019) define participatory autism research as that which "[incorporates] the views of autistic people and their allies about what research gets done, how it is done and how it is implemented" (p. 943). In the case of the research in this thesis, I only learned about participatory research practices halfway through my PhD. In collaboration with my non-autistic supervisors, I decided on the aims of my research and the methods I would use to address those aims. I did have conversations about these decisions with my autistic mentors, but it would be fair to say that the lack of formality in these consultations may have rendered them tokenistic since these people held no official positions in my institution and as such had no power over my project.

Ideally, I would have liked to have been taught about participatory research methods as part of my initial doctoral training. I also believe that institutions which carry out autism research should embed participatory practices in every aspect of their work. At the very least, this could involve setting up a panel or steering group of autistic people employed by the university who could be involved in all stages of autism-related research projects.

Participatory autism research practices also prioritise inclusivity by ensuring that approaches and methodologies are employed to include as broad a range of autistic people as possible. This includes members of the autistic community who are underrepresented in the literature such as non-speaking people and those with learning disabilities (Jack & A. Pelphrey, 2017; Long & Clarkson, 2017). Since my research was focused on the mainstream school experiences of those who do not meet the criteria for specialist support, my participants were all able to communicate either in speech or in writing and did not have co-occurring learning disability. Despite the fact that my research identified the under-representation of young autistic children in the qualitative literature, my focus on mainstream settings continued the tendency in autism research to exclude those children who might be described as 'less able'. Furthermore, my participants were predominantly white, and my research design did not take demographic factors such as socio-economic status, ethnicity, and sexuality into account. Therefore, my research has not addressed the problematic lack of representation in autism research – an area of study in which autistic people with ethnic, cultural, linguistic and sexual intersectionalities are significantly underrepresented (Durkin *et al.*, 2017; Maye *et al.*, 2021; Russell *et al.*, 2019).

6.6. Recommendations for future research

As argued throughout this thesis, more research needs to be conducted into the subjective lived experiences of young autistic children, especially those who do not have access to specialist support. Such children represent the majority of autistic children in our primary education system but very little is known about their everyday school experiences. When viewed within the context of the broader literature relating to bullying, stigma, mental distress and academic underachievement, the findings of all three studies suggest that there is an urgent need for a greater understanding of how mainstream school can be made more accessible and less stressful for this group of children.

I would also argue that flexible creative methods should be employed more often in research of this kind since this approach yielded such rich insights in study 3. While all my participants were able to speak, some preferred not to and having alternative ways to communicate ensured that all participants were able to fully contribute to my research. Even those who felt comfortable being interviewed expressed positivity about being able to augment their contributions with photographs and other creative pieces. Providing a range of ways in which autistic children can participate in research would go some way to ensuring that no assumptions are made about preferred ways of communicating.

The findings of my research also indicate that the signs of autistic burnout (i.e. exhaustion, loss of skills, reduced tolerance of sensory stimuli) might be evident from an early age. As discussed in chapter 4, research into autistic burnout is still in its infancy and much of the published research relates to autistic adults (e.g. S. R. Arnold *et al.*, 2023; Higgins *et al.*, 2021; Raymaker *et al.*, 2020). However, one of the few studies to investigate burnout in autistic young people identified that the signs of burnout are often missed or misunderstood by teachers and other supporting adults (Phung *et al.*, 2021). There is a strong rationale for future research which investigate how burnout affects autistic children and for the findings of such research to be used to inform teaching practice.

6.7. Conclusion

In the work that I have done with teachers and families over the last ten years, I have become increasingly aware that mainstream school can be completely intolerable for many autistic children.

For those who are not traumatised to the point of crisis or permanently excluded, school is all too often a place where autistic children need to dig deep, don their masks and try their best to cope. Not only can this pattern of behaviour lead to catastrophic consequences including self-harm and suicide, but coping is also a long way from flourishing and having a rewarding and enjoyable childhood. Many of my participants described school in terms of endurance. Simply trying to just get through each day cannot be our aspiration for this group of young people. However, the idea that school and the attitudes of the people in it could be at the heart of the challenges an autistic child is experiencing is not one that is readily or openly discussed in education. We need to acknowledge that the neuronormative standards inherent in our education system can stigmatise autistic children. Harm can be caused inadvertently and despite the best of intentions. Before we can look at specific support for individual pupils, we first need to acknowledge that maintaining the status quo in our education system is no longer an ethical option.

7. References

Acker, L., Knight, M., & Knott, F. (2018). 'Are they just gonna reject me?'male adolescents with autism making sense of anxiety: An interpretative phenomenological analysis. *Research in Autism Spectrum Disorders, 56*, 9-20.

Adams, R. E., Fredstrom, B. K., Duncan, A. W., Holleb, L. J., & Bishop, S. L. (2014). Using self-and parent-reports to test the association between peer victimization and internalizing symptoms in verbally fluent adolescents with asd. *Journal of autism and developmental disorders, 44*(4), 861-872.

Ahad, A., Thompson, A. M., & Hall, K. E. (2022). Identifying service users' experience of the education, health and care plan process: A systematic literature review. *Review of Education, 10*(1), e3333. doi:https://doi.org/10.1002/rev3.3333

Alcorn, A., McGeown, S., Aitken, D., Mandy, W., Murray, F., & Fletcher-Watson, S. (2021). *Learning about neurodiversity at school: Key concepts for communicating neurodiversity to primary school children, from the leans project participatory design process.* Paper presented at the International Society for Autism Research (INSAR) Virtual Meeting.

Alkhaldi, R. S., Sheppard, E., & Mitchell, P. (2019). Is there a link between autistic people being perceived unfavorably and having a mind that is difficult to read? *Journal of autism and developmental disorders, 49*(10), 3973-3982.

American Psychiatric Association, A. (2013). *Diagnostic and statistical manual of mental disorders (dsm-5®)*: American Psychiatric Pub.

Anderson, J., & Boyle, C. (2015). Inclusive education in australia: Rhetoric, reality and the road ahead. *Support for Learning, 30*(1), 4-22. doi:https://doi.org/10.1111/1467-9604.12074

Anwar, A., Abruzzo, P. M., Pasha, S., Rajpoot, K., Bolotta, A., Ghezzo, A., . . . Rabbani, N. (2018). Advanced glycation endproducts, dityrosine and arginine transporter dysfunction in autism - a source of biomarkers for clinical diagnosis. *Molecular Autism, 9*(1), 3. doi:10.1186/s13229-017-0183-3

APPGA. (2019). The autism act, 10 years on: A report from the all party parliamentary group on autism on understanding, services and support for autistic people and their families in england.

Arnold, L., Milton, D., Beardon, L., & Chown, N. (2021). England and autism *Encyclopedia of autism spectrum disorders* (pp. 1774-1780): Springer.

Arnold, S. R., Higgins, J. M., Weise, J., Desai, A., Pellicano, E., & Trollor, J. N. (2023). Confirming the nature of autistic burnout. *Autism, 0*(0), 13623613221147410. doi:10.1177/13623613221147410

Ashburner, J., Saggers, B., Campbell, M. A., Dillon-Wallace, J. A., Hwang, Y.-S., Carrington, S., & Bobir, N. (2019). How are students on the autism spectrum affected by bullying? Perspectives of students and parents. *Journal of Research in Special Educational Needs, 19*(1), 27-44. doi:https://doi.org/10.1111/1471-3802.12421

Ashburner, J., Ziviani, J., & Rodger, S. (2008). Sensory processing and classroom emotional, behavioral, and educational outcomes in children with autism spectrum disorder. *American Journal of Occupational Therapy, 62*(5), 564-573.

Ashburner, J., Ziviani, J., & Rodger, S. (2010). Surviving in the mainstream: Capacity of children with autism spectrum disorders to perform academically and regulate their emotions and behavior at school. *Research in Autism Spectrum Disorders, 4*(1), 18-27.

Asperger, H. (1943/1991). 'Autistic psychopathy' in childhood. In U. Frith (Ed.), *Autism and asperger syndrome* (pp. 37-92). Cambridge: Cambridge University Press.

Aubineau, M., & Blicharska, T. (2020). High-functioning autistic students speak about their experience of inclusion in mainstream secondary schools. *School Mental Health, 12*(3), 537-555. doi:10.1007/s12310-020-09364-z

Ambitious About Autism. (2022). *Written off: Tackling problems in the send system that hold back autistic children and young people*. Retrieved on 03.05.23 from https://www.ambitiousaboutautism.org.uk/sites/default/files/campaigns/written-off-report-ambitious-about-autism.pdf

Avison, W. R. (2010). Incorporating children's lives into a life course perspective on stress and mental health. *Journal of Health and Social Behavior, 51*(4), 361-375.

Azad, G., & Mandell, D. S. (2016). Concerns of parents and teachers of children with autism in elementary school. *Autism, 20*(4), 435-441. doi:10.1177/1362361315588199

Azad, G., Wolk, C. B., & Mandell, D. S. (2018). Ideal interactions: Perspectives of parents and teachers of children with autism spectrum disorder. *School Community Journal, 28*(2).

Baggs, M. (2007). In my language [video]. Retrieved on 03.05.23 from https://www.youtube.com/watch?v=JnylM1hI2jc.

Bailin, A. (2019). Clearing up some misconceptions about neurodiversity. *Scientific American, 6*.

Baker, A. E. Z., Lane, A., Angley, M. T., & Young, R. L. (2007). The relationship between sensory processing patterns and behavioural responsiveness in autistic disorder: A pilot study. *Journal of autism and developmental disorders, 38*(5), 867-875. doi:10.1007/s10803-007-0459-0

Ballou, E. P. (2018). What the neurodiversity movement does—and doesn't—offer. *Thinking Person's Guide to Autism*.

Baranek, G. T., David, F. J., Poe, M. D., Stone, W. L., & Watson, L. R. (2006). Sensory experiences questionnaire: Discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry, 47*(6), 591-601.

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: A critical review. *BMC medical research methodology, 9*(1), 59.

Baron-Cohen, S. (2019). The concept of neurodiversity is dividing the autism community. *Scientific American, 30*.

Baron-Cohen, S., Ring, H. A., Bullmore, E. T., Wheelwright, S., Ashwin, C., & Williams, S. (2000). The amygdala theory of autism. *Neuroscience & Biobehavioral Reviews, 24*(3), 355-364.

Barr, M. D. (2019). *Singapore: A modern history*: IB Tauris & Company Limited.

Bates, E. A., McCann, J. J., Kaye, L. K., & Taylor, J. C. (2017). "Beyond words": A researcher's guide to using photo elicitation in psychology. *Qualitative Research in Psychology, 14*(4), 459-481. doi:10.1080/14780887.2017.1359352

Bauminger, N., Shulman, C., & Agam, G. (2003). Peer interaction and loneliness in high-functioning children with autism. *Journal of Autism & Developmental Disorders, 33*(5), 489.

Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., . . . Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism, 24*(4), 822-833. doi:10.1177/1362361320908410

Bennett, M., & Goodall, E. (2022). Exploring the lack of research about autistic women *Addressing underserved populations in autism spectrum research* (pp. 27-37): Emerald Publishing Limited.

Birkett, L., McGrath, L., & Tucker, I. (2022). Muting, filtering and transforming space: Autistic children's sensory 'tactics' for navigating mainstream school space following transition to secondary school. *Emotion, Space and Society, 42*, 100872. doi:https://doi.org/10.1016/j.emospa.2022.100872

Blatchford, P., Russell, A., & Webster, R. (2012). *Reassessing the impact of teaching assistants: How research challenges practice and policy*: Routledge.

Bölte, S. (2014). The power of words: Is qualitative research as important as quantitative research in the study of autism? *Autism, 18*(2), 67-68. doi:10.1177/1362361313517367

Bond, C., Symes, W., Hebron, J., Humphrey, N., Morewood, G., & Woods, K. (2016). Educational interventions for children with asd: A systematic literature review 2008–2013. *School Psychology International, 37*(3), 303-320.

Bond, L., Butler, H., Thomas, L., Carlin, J., Glover, S., Bowes, G., & Patton, G. (2007). Social and school connectedness in early secondary school as predictors of late teenage substance use, mental health, and academic outcomes. *Journal of adolescent health, 40*(4), 357. e359-357. e318.

Bonell, C., Humphrey, N., Fletcher, A., Moore, L., Anderson, R., & Campbell, R. (2014). Why schools should promote students' health and wellbeing (Vol. 348): British Medical Journal Publishing Group.

Booth, A., Hannes, K., Harden, A., Noyes, J., Harris, J., & Tong, A. (2014). Coreq (consolidated criteria for reporting qualitative studies). *Guidelines for Reporting Health Research: A User's Manual*, 214-226.

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2018). Parents' voices:"Our process of advocating for our child with autism." a meta-synthesis of parents' perspectives. *Child: care, health and development, 44*(1), 147-160.

Botha, M., & Cage, E. (2022). "Autism research is in crisis": A mixed method study of researcher's constructions of autistic people and autism research. *Frontiers in Psychology, 13*, *7397*.

Botha, M., Dibb, B., & Frost, D. M. (2022). "Autism is me": An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society, 37*(3), 427-453. doi:10.1080/09687599.2020.1822782

Botha, M., & Frost, D. M. (2020). Extending the minority stress model to understand mental health problems experienced by the autistic population. *Society and Mental Health, 10*(1), 20-34. doi:10.1177/2156869318804297

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood, 3*(1), 18-29. doi:10.1089/aut.2020.0014

Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2021). Autistic adults' experiences of camouflaging and its perceived impact on mental health. *Autism in Adulthood, 3*(4), 320-329. doi:10.1089/aut.2020.0071

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa

Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E. (2017). Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school. *Autism & Developmental Language Impairments, 2*, 2396941517737511.

Buescher, A. V. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the united kingdom and the united states. *JAMA Pediatrics, 168*(8), 721-728. doi:10.1001/jamapediatrics.2014.210

Buijsman, R., Begeer, S., & Scheeren, A. M. (2022). 'Autistic person' or 'person with autism'? Person-first language preference in dutch adults with autism and parents. *Autism, 0*(0), 13623613221117914. doi:10.1177/13623613221117914

Butera, C., Ring, P., Sideris, J., Jayashankar, A., Kilroy, E., Harrison, L., . . . Aziz-Zadeh, L. (2020). Impact of sensory processing on school performance outcomes in high functioning individuals with autism spectrum disorder. *Mind, Brain, and Education, 14*(3), 243-254.

Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of autism and developmental disorders, 46*(1), 31-41.

Calder, L., Hill, V., & Pellicano, E. (2013). 'Sometimes i want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. *Autism, 17*(3), 296-316. doi:10.1177/1362361312467866

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*(6), 1431-1441.

Campbell, J. M., Ferguson, J. E., Herzinger, C. V., Jackson, J. N., & Marino, C. A. (2004). Combined descriptive and explanatory information improves peers' perceptions of autism. *Research in Developmental Disabilities, 25*(4), 321-339. doi:http://dx.doi.org/10.1016/j.ridd.2004.01.005

Canning, N., & Robinson, B. (2021). Blurring boundaries: The invasion of home as a safe space for families and children with send during covid-19 lockdown in england. *European Journal of Special Needs Education, 36*(1), 65-79. doi:10.1080/08856257.2021.1872846

Cappadocia, M. C., & Weiss, J. A. (2011). Review of social skills training groups for youth with asperger syndrome and high functioning autism. *Research in Autism Spectrum Disorders, 5*(1), 70-78.

Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of autism and developmental disorders, 42*(2), 266-277.

Chapman, R. & Carel, H. (2022). Neurodiversity, epistemic injustice, and the good human life. *Journal of Social Philosophy, 53, 614– 631*. https://doi.org/10.1111/josp.12456

Carpenter, K. L. H., Baranek, G. T., Copeland, W. E., Compton, S., Zucker, N., Dawson, G., & Egger, H. L. (2019). Sensory over-responsivity: An early risk factor for anxiety and behavioral challenges in young children. *Journal of abnormal child psychology, 47*(6), 1075-1088. doi:10.1007/s10802-018-0502-y

Carrington, S., Templeton, E., & Papinczak, T. (2003). Adolescents with asperger syndrome and perceptions of friendship. *Focus on Autism and Other Developmental Disabilities, 18*(4), 211-218.

Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of autism and developmental disorders, 50*(10), 3638-3648. doi:10.1007/s10803-019-04323-3

Catala, A., Faucher, L., & Poirier, P. (2021). Autism, epistemic injustice, and epistemic disablement: A relational account of epistemic agency. *Synthese, 199*(3-4), 9013-9039.

Chamberlain, B., Kasari, C., & Rotheram-Fuller, E. (2007). Involvement or isolation? The social networks of children with autism in regular classrooms. *Journal of autism and developmental disorders, 37*(2), 230-242.

Chapman, R. (2020). Defining neurodiversity for research and practice *Neurodiversity studies* (pp. 218-220): Routledge.

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). ‘Transitions are scary for our kids, and they're scary for us’: Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities, 28*(6), 548-560.

Cibralic, S., Kohlhoff, J., Wallace, N., McMahon, C., & Eapen, V. (2019). A systematic review of emotion regulation in children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 68*, 101422. doi:https://doi.org/10.1016/j.rasd.2019.101422

Clark-IbáÑez, M. (2004). Framing the social world with photo-elicitation interviews. *American Behavioral Scientist, 47*(12), 1507-1527. doi:10.1177/0002764204266236

Clark, A. M. (1998). The qualitative-quantitative debate: Moving from positivism and confrontation to post-positivism and reconciliation. *Journal of Advanced Nursing, 27*(6), 1242-1249.

Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners. *Successful Qualitative Research*, 1-400.

Clarke, V., & Braun, V. (2022). *Thematic analysis: A practical guide*. London: SAGE publications Ltd.

Cluley, V. (2018). From “learning disability to intellectual disability”—perceptions of the increasing use of the term “intellectual disability” in learning disability policy, research and practice. *British Journal of Learning Disabilities, 46*(1), 24-32. doi:https://doi.org/10.1111/bld.12209

Cohen, D. J., & Crabtree, B. F. (2008). Evaluative criteria for qualitative research in health care: Controversies and recommendations. *The Annals of Family Medicine, 6*(4), 331-339.

Commons, H. o. (2019). *Great britain parliament education committee. Special educational needs and disabilities first report of session 2019.* . Parliamentary Copyright (HC; 20).

Connor, M. (2000). Asperger syndrome (autistic spectrum disorder) and the self-reports of comprehensive school students. *Educational Psychology in Practice, 16*(3), 285-296.

Cook, J., Crane, L., Hull, L., Bourne, L., & Mandy, W. (2022). Self-reported camouflaging behaviours used by autistic adults during everyday social interactions. *Autism, 26*(2), 406-421. doi:10.1177/13623613211026754

Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical psychology review, 89*, 102080.

Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of us parents of children with autism spectrum disorders: A systematic review and meta-synthesis. *Journal of Intellectual Disabilities, 19*(4), 356-366.

Cresswell, L., Hinch, R., & Cage, E. (2019). The experiences of peer relationships amongst autistic adolescents: A systematic review of the qualitative evidence. *Research in Autism Spectrum Disorders, 61*, 45-60. doi:https://doi.org/10.1016/j.rasd.2019.01.003

Croghan, R., Griffin, C., Hunter, J., & Phoenix, A. (2008). Young people's constructions of self: Notes on the use and analysis of the photo-elicitation methods. *International journal of social research methodology, 11*(4), 345-356.

Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism, 24*(7), 1704-1712.

Cunningham, M. (2020). ‘This school is 100% not autistic friendly!’ listening to the voices of primary-aged autistic children to understand what an autistic friendly primary school should be like. *International Journal of Inclusive Education*, 1-15. doi:10.1080/13603116.2020.1789767

Dahlberg, H., & Dahlberg, K. (2019). The question of meaning—a momentous issue for qualitative research. *International Journal of Qualitative Studies on health and Well-being, 14*(1), 1598723.

Dalrymple, E. (2022). School attendance and anxiety: A parental perspective. In D. A. Moore, K. Finning, & T. Ford (Eds.), *Mental health and attendance at school* (pp. 162-180). Cambridge: Cambridge University Press.

Daniels, H., & Cole, T. (2010). Exclusion from school: Short-term setback or a long term of difficulties? *European Journal of Special Needs Education, 25*(2), 115-130.

Danker, J., Strnadová, I., & Cumming, T. M. (2019a). Picture my well-being: Listening to the voices of students with autism spectrum disorder. *Research in Developmental Disabilities, 89*, 130-140. doi:https://doi.org/10.1016/j.ridd.2019.04.005

Danker, J., Strnadová, I., & Cumming, T. M. (2019b). “They don’t have a good life if we keep thinking that they’re doing it on purpose!”: Teachers’ perspectives on the well-being of students with autism. *Journal of autism and developmental disorders, 49*(7), 2923-2934. doi:10.1007/s10803-019-04025-w

Davidson, J. (2010). ‘It cuts both ways’: A relational approach to access and accommodation for autism. *Social science & medicine, 70*(2), 305-312. doi:https://doi.org/10.1016/j.socscimed.2009.10.017

De Boer, A., Pijl, S. J., & Minnaert, A. (2011). Regular primary schoolteachers’ attitudes towards inclusive education: A review of the literature. *International Journal of Inclusive Education, 15*(3), 331-353.

De Bruin, K. (2020). Does inclusion work? *Inclusive education for the 21st century* (pp. 55-76): Routledge.

Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. *Autism, 21*(6), 678-689.

Dean, M., Kasari, C., Shih, W., Frankel, F., Whitney, R., Landa, R., . . . Harwood, R. (2014). The peer relationships of girls with asd at school: Comparison to boys and girls with and without asd. *Journal of Child Psychology and Psychiatry, 55*(11), 1218-1225. doi:https://doi.org/10.1111/jcpp.12242 den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism, 23*(2), 271-273. doi:10.1177/1362361318820762

Denzin, N. K., & Lincoln, Y. S. (2011). *The sage handbook of qualitative research*: sage.

DePape, A.-M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative health research, 25*(4), 569-583. doi:10.1177/1049732314552455

DePape, A.-M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities, 31*(1), 60-71. doi:10.1177/1088357615587504

Department for Education. (2019). National curriculum assessments: Key stage 2, 2019 (revised). Retrieved on 04.05.23 from https://www.gov.uk/government/statistics/national-curriculum-assessments-key-stage-2-2019-revised.

Department for Education. (2020a). Key stage 4 performance 2019 (*revised*). Retrieved on 04.05.23 from https://www.gov.uk/government/statistics/key-stage-4-performance-2019-revised

Department for Education. (2020b). Special educational needs in england. Retrieved on 04.05.23 from https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2020

Department for Education. (2022a). Behaviour in schools - advice for headteachers and school staff. Retrieved on 04.05.23 from https://www.gov.uk/government/publications/behaviour-in-schools--2

Department for Education. (2022b). Suspension and Permanent Exclusion from maintained schools, academies and pupil referral units in England, including pupil movement. Retrieved on 04.05.23 from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1101498/Suspension_and_Permanent_Exclusion_from_maintained_schools__academies_and_pupil_referral_units_in_England__including_pupil_movement.pdf

Department for Education. (2022c). Permanent exclusions and suspensions in england. Retrieved on 04.05.23 from https://explore-education-statistics.service.gov.uk/find-statistics/permanent-and-fixed-period-exclusions-in-england/2021-22-autumn-term.

Department for Education. (2022d). Schools, pupils and their characteristics. Retreived on 04.05.23 from https://www.gov.uk/government/statistics/schools-pupils-and-their-characteristics-january-2022

Department for Education. (2022e). Send review: Right support, right place, right time – government consultation on the send and alternative provision system in england. Retreived on 04.05.23 from https://www.gov.uk/government/consultations/send-review-right-support-right-place-right-time

Department for Education. (2022f). Special educational needs and disabilities (SEND) and alternative provision (AP) improvement plan: Right support, right place, right time. Retreived on 04.05.23 from https://www.gov.uk/government/publications/send-and-alternative-provision-improvement-plan

Department for Education. (2023). Analysis of the consultation responses to the send review: Right support, right place, right time. Retreived on 04.05.23 from https://www.gov.uk/government/consultations/send-review-right-support-right-place-right-time

Department of Health and Social Care and Department for Education. (2021). National strategy for autistic children, young people and adults: 2021 to 2026. Retreived on 04.05.23 from https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026

Dillon, G. V., & Underwood, J. D. (2012). Parental perspectives of students with autism spectrum disorders transitioning from primary to secondary school in the united kingdom. *Focus on Autism and Other Developmental Disabilities, 27*(2), 111-121.

Dillon, G. V., Underwood, J. D. M., & Freemantle, L. J. (2014). Autism and the u.K. Secondary school experience. *Focus on Autism and Other Developmental Disabilities*. doi:10.1177/1088357614539833

Docherty, S., & Sandelowski, M. (1999). Focus on qualitative methods: Interviewing children. *Research in nursing & health, 22*(2), 177-185.

Donaldson, A. L., corbin, e., & McCoy, J. (2021). “Everyone deserves aac”: Preliminary study of the experiences of speaking autistic adults who use augmentative and alternative communication. *Perspectives of the ASHA Special Interest Groups, 6*(2), 315-326. doi:doi:10.1044/2021_PERSP-20-00220

Dowling, P. J. (1961). History of education in the republic of ireland. *Paedagogica Historica, 1*(2), 213-224. doi:10.1080/0030923610010202

Durkin, M. S., Maenner, M. J., Baio, J., Christensen, D., Daniels, J., Fitzgerald, R., . . . Van Naarden Braun, K. (2017). Autism spectrum disorder among us children (2002–2010): Socioeconomic, racial, and ethnic disparities. *American journal of public health, 107*(11), 1818-1826.

Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. *The Sage handbook of qualitative research in psychology, 179*, 194.

Eatough, V., & Smith, J. A. (2017). The sage handbook of qualitative research in psychology. London: SAGE Publications Ltd. doi:10.4135/9781526405555

Eccles, J. S., & Roeser, R. W. (2011). Schools as developmental contexts during adolescence. *Journal of research on adolescence, 21*(1), 225-241.

Eguiguren Istuany, O., & Wood, R. (2020). Perspectives on educational inclusion from a small sample of autistic pupils in santiago, chile. *Scandinavian Journal of Disability Research, 22*(1), 210-220.

Eisenman, L. T., Rolón-Dow, R., Freedman, B., Davison, A., & Yates, N. (2020). " Disabled or not, people just want to feel welcome": Stories of microaggressions and microaffimations from college students with intellectual disability. *Critical Education, 11*(17).

English, D., Rendina, H. J., & Parsons, J. T. (2018). The effects of intersecting stigma: A longitudinal examination of minority stress, mental health, and substance use among black, latino, and multiracial gay and bisexual men. *Psychology of violence, 8*(6), 669.

Feldman, M., Hamsho, N., Blacher, J., Carter, A. S., & Eisenhower, A. (2022). Predicting peer acceptance and peer rejection for autistic children. *Psychology in the Schools, 59*(11), 2159-2182. doi:https://doi.org/10.1002/pits.22739

Felepchuk, E. (2021). Stimming, Improvisation, and COVID-19: (Re)negotiating Autistic Sensory Regulation During a Pandemic. *Disability Studies Quarterly*, *41*(3). https://doi.org/10.18061/dsq.v41i3.8426

Fletcher-Watson, S. (2018). Is early autism intervention compatible with neurodiversity. Retrieved on 04.05.23 from https://dart.ed.ac.uk/intervention-neurodiversity/

Fletcher-Watson, S. (2022). *Neurodiversity affirmative education for autistic learners*. Paper presented at the CRAE annual lecture. Retrieved on 04.05.23 from https://figshare.com/articles/presentation/Neurodiversity-Affirmative_Education_for_Autistic_Learners/19355570/1

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., . . . Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943-953.

Fleury, V. P., Hedges, S., Hume, K., Browder, D. M., Thompson, J. L., Fallin, K., . . . Vaughn, S. (2014). Addressing the academic needs of adolescents with autism spectrum disorder in secondary education. *Remedial and Special Education, 35*(2), 68-79.

Frith, U., & Happé, F. (1999). Theory of mind and self-consciousness: What is it like to be autistic? *Mind & Language, 14*(1), 82-89.

Frost, D. M., Lehavot, K., & Meyer, I. H. (2015). Minority stress and physical health among sexual minority individuals. *Journal of behavioral medicine, 38*, 1-8.

Gadow, K. D., Devincent, C. J., Pomeroy, J., & Azizian, A. (2005). Comparison of dsm-iv symptoms in elementary school-age children with pdd versus clinic and community samples. *Autism, 9*(4), 392-415.

Galpin, J., Barratt, P., Ashcroft, E., Greathead, S., Kenny, L., & Pellicano, E. (2018). 'The dots just don't join up': Understanding the support needs of families of children on the autism spectrum. *Autism, 22*(5), 571-584. doi:10.1177/1362361316687989

Gilbert, T. (2004). Involving people with learning disabilities in research: Issues and possibilities. *Health & social care in the community, 12*(4), 298-308.

Glaser, B. G., & Strauss, A. L. (1971). *Status passage*. London: Routledge and Kegan Paul.

Glesne, C. (1997). That rare feeling: Re-presenting research through poetic transcription. *Qualitative Inquiry, 3*(2), 202-221.

Goodall, C. (2018). 'I felt closed in and like i couldn't breathe': A qualitative study exploring the mainstream educational experiences of autistic young people. *Autism & Developmental Language Impairments, 3*, 2396941518804407. doi:10.1177/2396941518804407

Goodall, C. (2020). Inclusion is a feeling, not a place: A qualitative study exploring autistic young people's conceptualisations of inclusion. *International Journal of Inclusive Education, 24*(12), 1285-1310. doi:10.1080/13603116.2018.1523475

Goodall, C., & MacKenzie, A. (2019). Title: What about my voice? Autistic young girls' experiences of mainstream school. *European Journal of Special Needs Education, 34*(4), 499-513. doi:10.1080/08856257.2018.1553138

Goodley, D. (2016). *Disability studies: An interdisciplinary introduction*: Sage.

Green, S. A., & Ben-Sasson, A. (2010). Anxiety disorders and sensory over-responsivity in children with autism spectrum disorders: Is there a causal relationship? *Journal of autism and developmental disorders, 40*(12), 1495-1504. doi:10.1007/s10803-010-1007-x

Griswold, D. E., Barnhill, G. P., Myles, B. S., Hagiwara, T., & Simpson, R. L. (2002). Asperger syndrome and academic achievement. *Focus on Autism and Other Developmental Disabilities, 17*(2), 94-102.

Guenther, K. M. (2009). The politics of names: Rethinking the methodological and ethical significance of naming people, organizations, and places. *Qualitative Research*, *9*(4), 411-421.

Guldberg, K., Wallace, S., Bradley, R., Perepa, P., Ellis, L., & MacLeod, A. (2021). Investigation of the causes and implications of exclusion for autistic children and young people.

Gunn, K. C., & Delafield-Butt, J. T. (2016). Teaching children with autism spectrum disorder with restricted interests: A review of evidence for best practice. *Review of Educational Research, 86*(2), 408-430.

Haegele, J. A., & Maher, A. J. (2022). Male autistic youth experiences of belonging in integrated physical education. *Autism, 26*(1), 51-61. doi:10.1177/13623613211018637

Halsall, J., Clarke, C., & Crane, L. (2021). “Camouflaging” by adolescent autistic girls who attend both mainstream and specialist resource classes: Perspectives of girls, their mothers and their educators. *Autism, 25*(7), 2074-2086. doi:10.1177/13623613211012819

Hannes, K., & Lockwood, C. (2011). *Synthesizing qualitative research: Choosing the right approach*: John Wiley & Sons.

Happé, F., & Frith, U. (2020). Annual research review: Looking back to look forward – changes in the concept of autism and implications for future research. *Journal of Child Psychology and Psychiatry, 61*(3), 218-232. doi:https://doi.org/10.1111/jcpp.13176

Harrington, C., Foster, M., Rodger, S., & Ashburner, J. (2014). Engaging young people with autism spectrum disorder in research interviews. *British Journal of Learning Disabilities, 42*(2), 153-161.

Harris, J. (2011). Chapter 2: Using qualitative research to develop robust effectiveness questions and protocols for cochrane systematic reviews. *Supplementary guidance for inclusion of qualitative research in Cochrane systematic reviews of interventions. Version, 1*.

Hasson, L., Keville, S., Gallagher, J., Onagbesan, D., & Ludlow, A. K. (2022). Inclusivity in education for autism spectrum disorders: Experiences of support from the perspective of parent/carers, school teaching staff and young people on the autism spectrum. *International Journal of Developmental Disabilities*, 1-12. doi:10.1080/20473869.2022.2070418

Hatton, C. (2018). School absences and exclusions experienced by children with learning disabilities and autistic children in 2016/17 in england. *Tizard Learning Disability Review, 23*(4), 207-212.

Hay, I., & Winn, S. (2005). Students with asperger's syndrome in an inclusive secondary school environment: Teachers', parents', and students' perspectives. *Australasian Journal of Special Education, 29*(2), 140-154.

Department for Education and Department for Health. (2015). Special educational needs and disability code of practice. Retrieved on 04.05.23 from https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

Healy, S., Msetfi, R., & Gallagher, S. (2013). ‘Happy and a bit nervous’: The experiences of children with autism in physical education. *British Journal of Learning Disabilities, 41*(3), 222-228.

Hebron, J., & Humphrey, N. (2012). Mental health difficulties among young people on the autistic spectrum in mainstream secondary schools: A comparative study. *Journal of Research in Special Educational Needs, 14*(1), 22-32.

Hebron, J., & Humphrey, N. (2014). Exposure to bullying among students with autism spectrum conditions: A multi-informant analysis of risk and protective factors. *Autism, 18*(6), 618-630. doi:10.1177/1362361313495965

Hebron, J., Humphrey, N., & Oldfield, J. (2015a). Vulnerability to bullying of children with autism spectrum conditions in mainstream education: A multi-informant qualitative exploration. *Journal of Research in Special Educational Needs, 15*(3), 185-193. doi:10.1111/1471-3802.12108

Hebron, J., Humphrey, N., & Oldfield, J. (2015b). Vulnerability to bullying of children with autism spectrum conditions in mainstream education: A multi-informant qualitative exploration. *Journal of Research in Special Educational Needs, 15*(3), 185-193.

Heffernan, T. (2021). The history of education in australia: Oxford University Press.

Henwood, K. L., & Pidgeon, N. F. (1992). Qualitative research and psychological theorizing. *British Journal of Psychology, 83*(1), 97-111. doi:https://doi.org/10.1111/j.2044-8295.1992.tb02426.x

Heyworth, M., Brett, S., Houting, J. d., Magiati, I., Steward, R., Urbanowicz, A., . . . Pellicano, E. (2021). “It just fits my needs better”: Autistic students and parents’ experiences of learning from home during the early phase of the covid-19 pandemic. *Autism & Developmental Language Impairments, 6*, 23969415211057681. doi:10.1177/23969415211057681

Hibbert, P., Coupland, C., & MacIntosh, R. (2010). Reflexivity: Recursion and relationality in organizational research processes. *Qualitative Research in Organizations and Management: An International Journal, 5*(1), 47-62. doi:10.1108/17465641011042026

Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded delphi method investigating# autisticburnout. *Autism, 25*(8), 2356-2369.

Hill, C., Keville, S., & Ludlow, A. K. (2021). Inclusivity for children with autism spectrum disorders: Parent’s reflections of the school learning environment versus home learning during covid-19. *International Journal of Developmental Disabilities*, 1-9. doi:10.1080/20473869.2021.1975253

Hill, L. (2014). Some of it i haven’t told anybody else’: Using photo elicitation to explore the experiences of secondary school education from the perspective of young people with a diagnosis of autistic spectrum disorder. *Educational and Child Psychology, 31*(1), 79-89.

Hodge, N., Douglas, P., Kruth, M., Connolly, S., Martin, N., Gowler, K., & Smith, C. (2022). Contemplating teacher talk through a critical autism studies lens *The routledge international handbook of critical autism studies* (pp. 242-254): Routledge.

Hodge, N., & Runswick-Cole, K. (2018). “You say… I hear…”: Epistemic gaps in practitioner-parent/carer talk. In K. Runswick-Cole, T. Curran, & K. Liddiard (Eds.), *The palgrave handbook of disabled children’s childhood studies* (pp. 537-555). London: Palgrave Macmillan UK.

Hodges, A., Joosten, A., Bourke-Taylor, H., & Cordier, R. (2020). School participation: The shared perspectives of parents and educators of primary school students on the autism spectrum. *Research in Developmental Disabilities, 97*, 103550.

Holmes, A. G. D. (2020). Researcher positionality--a consideration of its influence and place in qualitative research--a new researcher guide. *Shanlax International Journal of Education, 8*(4), 1-10.

Horgan, F., Kenny, N., & Flynn, P. (2022). A systematic review of the experiences of autistic young people enrolled in mainstream second-level (post-primary) schools. *27(2), 526-538.*. doi:10.1177/13623613221105089

Hosozawa, M., Sacker, A., Mandy, W., Midouhas, E., Flouri, E., & Cable, N. (2020). Determinants of an autism spectrum disorder diagnosis in childhood and adolescence: Evidence from the uk millennium cohort study. *Autism, 24*(6), 1557-1565.

Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism, 23*(7), 1871-1876. doi:10.1177/1362361318823902

Howe, F. E., & Stagg, S. D. (2016). How sensory experiences affect adolescents with an autistic spectrum condition within the classroom. *Journal of autism and developmental disorders, 46*(5), 1656-1668.

Hull, L., Petrides, K., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). “Putting on my best normal”: Social camouflaging in adults with autism spectrum conditions. *Journal of autism and developmental disorders, 47*(8), 2519-2534.

Hummerstone, H., & Parsons, S. (2020). What makes a good teacher? Comparing the perspectives of students on the autism spectrum and staff. *European Journal of Special Needs Education*, 1-15. doi:10.1080/08856257.2020.1783800

Humphrey, N., & Hebron, J. (2015). Bullying of children and adolescents with autism spectrum conditions: A ‘state of the field’ review. *International Journal of Inclusive Education, 19*(8), 845-862. doi:10.1080/13603116.2014.981602

Humphrey, N., & Lewis, S. (2008). `make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism, 12*(1), 23-46. doi:10.1177/1362361307085267

Humphrey, N., & Symes, W. (2010). Responses to bullying and use of social support among pupils with autism spectrum disorders (asds) in mainstream schools: A qualitative study. *Journal of Research in Special Educational Needs, 10*(2), 82-90.

Humphrey, N., & Symes, W. (2011). Peer interaction patterns among adolescents with autistic spectrum disorders (asds) in mainstream school settings. *Autism*. doi:10.1177/1362361310387804

Humphrey, N., & Symes, W. (2013). Inclusive education for pupils with autistic spectrum disorders in secondary mainstream schools: Teacher attitudes, experience and knowledge. *International Journal of Inclusive Education, 17*(1), 32-46. doi:10.1080/13603116.2011.580462

Husserl, E. (1976). Ideen zu einer reinen phänomenologie und phänomenologischen philosophie. Erstes buch: Allgemeine einführung in die reine phänomenologie 1. Halbband: Text der 1.–. *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy. First book: General introduction to a pure phenomenology*.

Hutchinson, J., Timimi, S., & McKay, N. (2021). Trends in sen identification: Contexts, causes and consequences: May 2020. *Journal of Research in Special Educational Needs, 21*(1), 19-38.

Huws, J., & Jones, R. (2010). ‘They just seem to live their lives in their own little world’: Lay perceptions of autism. *Disability & Society, 25*(3), 331-344.

Jaarsma, P., & Welin, S. (2012). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health care analysis, 20*, 20-30.

Jack, A., & A. Pelphrey, K. (2017). Annual research review: Understudied populations within the autism spectrum – current trends and future directions in neuroimaging research. *Journal of Child Psychology and Psychiatry, 58*(4), 411-435. doi:https://doi.org/10.1111/jcpp.12687

Jacobs, P., Beamish, W., & McKay, L. (2021). Please listen to us: Adolescent autistic girls speak about learning and academic success. *Improving Schools, 24*(3), 196-209. doi:10.1177/1365480220973112

John, R. P. S., Knott, F. J., & Harvey, K. N. (2018). Myths about autism: An exploratory study using focus groups. *Autism: The International Journal of Research & Practice, 22*(7), 845-854. doi:10.1177/1362361317714990

Jones, C., Happé, F., Golden, H., Marsden, A. J., Tregay, J., Simonoff, E., . . . Charman, T. (2009). Reading and arithmetic in adolescents with autism spectrum disorders: Peaks and dips in attainment. *Neuropsychology, 23*(6), 718.

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the united kingdom. *Journal of autism and developmental disorders, 44*(12), 3033-3044. doi:10.1007/s10803-014-2161-3

Kanner, L. (1943). Autistic disturbances of affective contact.

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental psychology, 49*(1), 59.

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*, *23*(7), 1782–1792. https://doi.org/10.1177/1362361319829628

Kasari, C., Locke, J., Gulsrud, A., & Rotheram-Fuller, E. (2011). Social networks and friendships at school: Comparing children with and without asd. *Journal of autism and developmental disorders, 41*(5), 533-544. doi:10.1007/s10803-010-1076-x

Kasari, C., & Sterling, L. (2013). Loneliness and social isolation in children with autism spectrum disorders. *The handbook of solitude: Psychological perspectives on social isolation, social withdrawal, and being alone*, 409-426.

Kavale, K. A., & Forness, S. R. (2000). What definitions of learning disability say and don't say: A critical analysis. *Journal of learning disabilities, 33*(3), 239-256.

Keeffe-Martin, M. (2001). Legislation, case law and current issues in inclusion: An analysis of trends in the united states and australia. *Austl. & NZJL & Educ., 6*, 25.

Keen, D., Webster, A., & Ridley, G. (2016). How well are children with autism spectrum disorder doing academically at school? An overview of the literature. *Autism, 20*(3), 276-294. doi:10.1177/1362361315580962

Keller, R. M., & Galgay, C. E. (2010). Microaggressive experiences of people with disabilities. *Microaggressions and marginality: Manifestation, dynamics, and impact*, 241-268.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the uk autism community. *Autism, 20*(4), 442-462. doi:10.1177/1362361315588200

Kidder, L. H., & Fine, M. (1987). Qualitative and quantitative methods: When stories converge. *New Directions for Program Evaluation, 1987*(35), 57-75. doi:https://doi.org/10.1002/ev.1459

Kiger, M. E., & Varpio, L. (2020). Thematic analysis of qualitative data: Amee guide no. 131. *Medical Teacher, 42*(8), 846-854. doi:10.1080/0142159X.2020.1755030

Kim, S. H., Bal, V. H., & Lord, C. (2018). Longitudinal follow-up of academic achievement in children with autism from age 2 to 18. *Journal of Child Psychology and Psychiatry, 59*(3), 258-267. doi:https://doi.org/10.1111/jcpp.12808

Kisely, S., & Kendall, E. (2011). Critically appraising qualitative research: A guide for clinicians more familiar with quantitative techniques. *Australasian Psychiatry, 19*(4), 364-367.

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the uk. *Autism, 13*(3), 317-336. doi:10.1177/1362361309104246

Knott, F., & Taylor, A. (2014). Life at university with asperger syndrome: A comparison of student and staff perspectives. *International Journal of Inclusive Education, 18*(4), 411-426.

Koffer Miller, K. H., Mathew, M., Nonnemacher, S. L., & Shea, L. L. (2018). Program experiences of adults with autism, their families, and providers: Findings from a focus group study. *Autism, 22*(3), 345-356. doi:10.1177/1362361316679000

Lahman, M. K., Rodriguez, K. L., Moses, L., Griffin, K. M., Mendoza, B. M., & Yacoub, W. (2015). A rose by any other name is still a rose? Problematizing pseudonyms in research. *Qualitative Inquiry*, *21*(5), 445-453.

Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., . . . Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry, 6*(10), 819-829.

Lai, M.-C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., . . . Baron-Cohen, S. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism, 21*(6), 690-702. doi:10.1177/1362361316671012

Lamb, B. (2009). *Lamb inquiry: Special educational needs and parental confidence*: DCSF publications.

Lamb, P., Firbank, D., & Aldous, D. (2016). Capturing the world of physical education through the eyes of children with autism spectrum disorders. *Sport, Education and Society, 21*(5), 698-722.

Lane, A. E., Dennis, S. J., & Geraghty, M. E. (2011). Brief report: Further evidence of sensory subtypes in autism. *Journal of autism and developmental disorders, 41*, 826-831.

Lang, R., Regester, A., Lauderdale, S., Ashbaugh, K., & Haring, A. (2010). Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: A systematic review. *Developmental neurorehabilitation, 13*(1), 53-63.

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology, 12*. doi:10.3389/fpsyg.2021.635690

Leadbitter, K., Macdonald, W., Taylor, C., Buckle, K. L., & Consortium*, P. (2020). Parent perceptions of participation in a parent-mediated communication-focussed intervention with their young child with autism spectrum disorder. *Autism, 24*(8), 2129-2141.

Leekam, S. R., Nieto, C., Libby, S. J., Wing, L., & Gould, J. (2007). Describing the sensory abnormalities of children and adults with autism. *Journal of autism and developmental disorders, 37*(5), 894-910. doi:10.1007/s10803-006-0218-7

Little, L. (2002). Middle-class mothers' perceptions of peer and sibling victimization among children with asperger's syndrome and nonverbal learning disorders. *Issues in Comprehensive Pediatric Nursing, 25*(1), 43-57. doi:10.1080/014608602753504847

Liu, R. X., & Chen, Z.-y. (2021). Negative school experiences in early adolescence on depressive affect in middle adulthood. *Advances in Life Course Research, 48*, 100398. doi:https://doi.org/10.1016/j.alcr.2020.100398

Livingston, L. A., Shah, P., & Happé, F. (2019). Compensatory strategies below the behavioural surface in autism: A qualitative study. *The Lancet Psychiatry, 6*(9), 766-777.

Locke, J., Ishijima, E. H., Kasari, C., & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *Journal of Research in Special Educational Needs, 10*(2), 74-81. doi:10.1111/j.1471-3802.2010.01148.x

Lombardo, M. V., Barnes, J. L., Wheelwright, S. J., & Baron-Cohen, S. (2007). Self-referential cognition and empathy in autism. *PLoS One, 2*(9), e883.

Long, J., & Clarkson, A. (2017). Towards meaningful participation in research and support practice: Effecting change in autism services. *Autism and intellectual disability in adults, 2*, 41-45.

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry, 56*(6), 466-474.

Loth, E., Charman, T., Mason, L., Tillmann, J., Jones, E. J. H., Wooldridge, C., . . . Buitelaar, J. K. (2017). The eu-aims longitudinal european autism project (leap): Design and methodologies to identify and validate stratification biomarkers for autism spectrum disorders. *Molecular Autism, 8*(1), 24. doi:10.1186/s13229-017-0146-8

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of consulting and clinical psychology, 55*(1), 3.

Lovelace, T. S., Comis, M. P., Tabb, J. M., & Oshokoya, O. E. (2021). Missing from the narrative: A seven-decade scoping review of the inclusion of black autistic women and girls in autism research. *Behavior Analysis in Practice*, 1-13.

Loyd, D. (2013). Obtaining consent from young people with autism to participate in research. *British Journal of Learning Disabilities, 41*(2), 133-140.

MacLennan, K., Roach, L., & Tavassoli, T. (2020). The relationship between sensory reactivity differences and anxiety subtypes in autistic children. *Autism Research, 13*(5), 785-795. doi:https://doi.org/10.1002/aur.2259

MacLeod, A. (2019). Interpretative phenomenological analysis (ipa) as a tool for participatory research within critical autism studies: A systematic review. *Research in Autism Spectrum Disorders, 64*, 49-62.

Madriaga, M. (2010). 'I avoid pubs and the student union like the plague': Students with asperger syndrome and their negotiation of university spaces. *Children's Geographies, 8*(1), 39-50.

Maïano, C., Normand, C. L., Salvas, M.-C., Moullec, G., & Aimé, A. (2016). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. *Autism Research, 9*(6), 601-615. doi:https://doi.org/10.1002/aur.1568

Major, C. H., & Savin-Baden, M. (2010). An introduction to qualitative research synthesis: London: Routledge.

Mallory, C., & Keehn, B. (2021). Implications of sensory processing and attentional differences associated with autism in academic settings: An integrative review. *Frontiers in Psychiatry, 12*, 695825.

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of autism and developmental disorders, 42*(7), 1304-1313.

Mandy, W., Murin, M., Baykaner, O., Staunton, S., Hellriegel, J., Anderson, S., & Skuse, D. (2016). The transition from primary to secondary school in mainstream education for children with autism spectrum disorder. *Autism, 20*(1), 5-13.

Mantzalas, J., Richdale, A. L., Adikari, A., Lowe, J., & Dissanayake, C. (2021). What is autistic burnout? A thematic analysis of posts on two online platforms. *Autism in Adulthood, 4*(1), 52-65. doi:10.1089/aut.2021.0021

Mantzalas, J., Richdale, A. L., & Dissanayake, C. (2022). A conceptual model of risk and protective factors for autistic burnout. *Autism Research, 15*(6), 976-987. doi:https://doi.org/10.1002/aur.2722

Maras, P., & Aveling, E.-L. (2006). Students with special educational needs: Transitions from primary to secondary school. *British Journal of Special Education, 33*(4), 196-203. doi:https://doi.org/10.1111/j.1467-8578.2006.00439.x

Marks, S. U., Schrader, C., Longaker, T., & Levine, M. (2000). Portraits of three adolescent students with asperger's syndrome: Personal stories and how they can inform practice. *Journal of the Association for Persons with Severe Handicaps, 25*(1), 3-17.

Martin-Denham, S. (2020). A review of school exclusion on the mental health, well-being of children and young people in the city of sunderland. Project Report. University of Sunderland.

Maye, M., Boyd, B. A., Martínez-Pedraza, F., Halladay, A., Thurm, A., & Mandell, D. S. (2021). Biases, barriers, and possible solutions: Steps towards addressing autism researchers under-engagement with racially, ethnically, and socioeconomically diverse communities. *Journal of autism and developmental disorders*, 1-6.

Mayes, S. D., & Calhoun, S. L. (2007). Learning, attention, writing, and processing speed in typical children and children with adhd, autism, anxiety, depression, and oppositional-defiant disorder. *Child Neuropsychology, 13*(6), 469-493. doi:10.1080/09297040601112773

Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *Bmj, 320*(7226), 50-52.

Mayton, M. R. (2005). The quality of life of a child with asperger's disorder in a general education setting: A pilot case study. *International Journal of Special Education, 20*(2), 85-101.

McCarthy, R., Blackburn, C., Mukherjee, R., Fleming, K., Allely, C., Kirby, L., & Cook, P. A. (2022). ‘I'm always up against a brick wall with them’: Parents' experiences of accessing support for their child with a newly recognised developmental disorder. *British Journal of Special Education, 49*(1), 41-63. doi:https://doi.org/10.1111/1467-8578.12398

McDonnell, A., & Milton, D. (2014). Going with the flow: Reconsidering ‘repetitive behaviour’through the concept of ‘flow states’. In: Jones, Glenys and Hurley, Elizabeth, eds. *Good Autism Practice: autism, happiness and wellbeing*. BILD, Birmingham, UK, pp. 38-47. ISBN 978-1-905218-35-6.

McDougal, E., Riby, D. M., & Hanley, M. (2020). Teacher insights into the barriers and facilitators of learning in autism. *Research in Autism Spectrum Disorders, 79*, 101674. doi:https://doi.org/10.1016/j.rasd.2020.101674

McKinlay, J., Wilson, C., Hendry, G., & Ballantyne, C. (2022). “It feels like sending your children into the lions’ den” – a qualitative investigation into parental attitudes towards asd inclusion, and the impact of mainstream education on their child. *Research in Developmental Disabilities, 120*, 104128. doi:https://doi.org/10.1016/j.ridd.2021.104128

McNerney, C., Hill, V., & Pellicano, E. (2015). Choosing a secondary school for young people on the autism spectrum: A multi-informant study. *International Journal of Inclusive Education, 19*(10), 1096-1116.

Menezes, M., Harkins, C., Robinson, M. F., & Mazurek, M. O. (2020). Treatment of depression in individuals with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders, 78*, 101639. doi:https://doi.org/10.1016/j.rasd.2020.101639

Mesa, S., & Hamilton, L. G. (2022). "We are different, that's a fact, but they treat us like we're different-er": Understandings of autism and adolescent identity development. *Advances in Autism, 8*(3), 217-231. doi:10.1108/AIA-12-2020-0071

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological bulletin, 129*(5), 674.

Milton, D. (2012a). On the ontological status of autism: The 'double empathy problem'. *Disability & Society, 27*(6), 883-887. doi:10.1080/09687599.2012.710008

Milton, D. (2012b). So what exactly is autism? *Autism Education Trust*, 15 pp. Online article

Milton, D. (2014a). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism, 18*(7), 794-802.

Milton, D. (2014b). So what exactly are autism interventions intervening with? *Good Autism Practice (GAP), 15*(2), 6-14.

Milton, D., & Bracher, M. (2013). Autistics speak but they are heard. *Journal of the BSA MedSoc Group, 7*, 61-69.

Milton, D., Ridout, S., Murray, D., Martin, N., & Mills, R. (2020). *The neurodiversity reader: Exploring concepts, lived experiences and implications for practice*: Pavilion.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The, P. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The prisma statement. *PLOS Medicine, 6*(7), e1000097. doi:10.1371/journal.pmed.1000097

Moore, I., Morgan, G., Welham, A., & Russell, G. (2022). The intersection of autism and gender in the negotiation of identity: A systematic review and metasynthesis. *Feminism & Psychology*, 09593535221074806.

Morgan, D. L., Krueger, R. A., & Scannell, A. U. (1998). *Planning focus groups*: Sage.

Moseley, R. L., Druce, T., & Turner-Cobb, J. M. (2020). 'When my autism broke': A qualitative study spotlighting autistic voices on menopause. *Autism, 24*(6), 1423-1437. doi:10.1177/1362361319901184

Moyse, R., & Porter, J. (2015). The experience of the hidden curriculum for autistic girls at mainstream primary schools. *European Journal of Special Needs Education, 30*(2), 187-201.

Myles, B. S., & Simpson, R. L. (2001). Understanding the hidden curriculum an essential social skill for children and youth with asperger syndrome. *Intervention in School and Clinic, 36*(5), 279-286.

Nasaw, D. (1981). *Schooled to order: A social history of public schooling in the united states* (Vol. 626): Oxford University Press, USA.

National Autistic Society. (2020). Left stranded: The impact of coronavirus on autistic people and their families in the UK. Retrieved on 04.05.23 from https://www.autism.org.uk/what-we-do/news/coronavirus-report

National Autistic Society. (2021). School report 2021. Retrieved on 04.05.23 from https://www.autism.org.uk/what-we-do/news/school-report-2021

Nicolaidis, C. (2012). What can physicians learn from the neurodiversity movement? *ama Journal of Ethics, 14*(6), 503-510.

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (ipa): Four markers of high quality. *Qualitative Research in Psychology, 18*(3), 369-386. doi:10.1080/14780887.2020.1854404

Nowicki, E. (2006). A cross-sectional multivariate analysis of children's attitudes towards disabilities. *Journal of Intellectual Disability Research, 50*(5), 335-348. doi:https://doi.org/10.1111/j.1365-2788.2005.00781.x

Nowicki, E., & Sandieson, R. (2002). A meta-analysis of school-age children's attitudes towards persons with physical or intellectual disabilities. *International Journal of Disability, Development and Education, 49*(3), 243-265.

O'Nions, E., Happé, F., Evers, K., Boonen, H., & Noens, I. (2017). How do parents manage irritability, challenging behaviour, non-compliance and anxiety in children with autism spectrum disorders? A meta-synthesis. *Journal of autism and developmental disorders*, 1-15.

Ofsted. (2010). The special educational needs and disability review. A statement is not enough. Retrieved on 04.05.23 from https://www.bl.uk/collection-items/special-educational-needs-and-disability-review-a-statement-is-not-enough

Oliver, M. (2009). *Understanding disability : From theory to practice* (Second edition ed.). Houndmills, Basingstoke, Hampshire ; New York: Palgrave Macmillan.

Olkin, R., Hayward, H. S., Abbene, M. S., & VanHeel, G. (2019). The experiences of microaggressions against women with visible and invisible disabilities. *Journal of Social Issues, 75*(3), 757-785. doi:https://doi.org/10.1111/josi.12342

Olweus, D. (1993). Victimization by peers: Antecedents and long-term outcomes. *Social withdrawal, inhibition, and shyness in childhood, 315*, 341.

Oswald, T. M., Beck, J. S., Iosif, A. M., McCauley, J. B., Gilhooly, L. J., Matter, J. C., & Solomon, M. (2016). Clinical and cognitive characteristics associated with mathematics problem solving in adolescents with autism spectrum disorder. *Autism Research, 9*(4), 480-490.

Ozsivadjian, A., Hibberd, C., & Hollocks, M. J. (2013). Brief report: The use of self-report measures in young people with autism spectrum disorder to access symptoms of anxiety, depression and negative thoughts. *Journal of autism and developmental disorders, 44*(4), 969-974. doi:10.1007/s10803-013-1937-1

Parsons, S., Guldberg, K., MacLeod, A., Jones, G., Prunty, A., & Balfe, T. (2011). International review of the evidence on best practice in educational provision for children on the autism spectrum. *European Journal of Special Needs Education, 26*(1), 47-63. doi:10.1080/08856257.2011.543532

Parsons, S., Lewis, A., & Ellins, J. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: Comparisons with parents of children with other disabilities from an online survey. *European Journal of Special Needs Education, 24*(1), 37-58. doi:10.1080/08856250802596790

Patel, J. A., Badiani, A. A., Nielsen, F. B. H., Assi, S., Unadkat, V., Patel, B., . . . Hallas, L. (2020). Covid-19 and autism: Uncertainty, distress and feeling forgotten. *Public Health Pract (Oxf), 1*, 100034. doi:10.1016/j.puhip.2020.100034

Paterson, B. L., & Canam, C. (2001). *Meta-study of qualitative health research: A practical guide to meta-analysis and meta-synthesis* (Vol. 3): Sage.

Pavlopoulou, G., Wood, R., & Papadopoulos, C. (2020). Impact of covid-19 on the experiences of parents and family carers of autistic children and young people in the uk.

Pearson, A., & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood, 3*(1), 52-60. doi:10.1089/aut.2020.0043

Pellicano, E., & den Houting, J. (2022). Annual research review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry, 63*(4), 381-396. doi:https://doi.org/10.1111/jcpp.13534

Pellicano, E., Dinsmore, A., & Charman, T. (2013). A future made together: Shaping autism research in the UK. Retrieved on 04.05.23 from https://discovery.ucl.ac.uk/id/eprint/10017703/1/A_Future_Made_Together_1.2_LR.pdf

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the united kingdom. *Autism, 18*(7), 756-770. doi:10.1177/1362361314529627

Pelton, M. K., & Cassidy, S. (2017). Are autistic traits associated with suicidality? A test of the interpersonal-psychological theory of suicide in a non-clinical young adult sample. *Autism Research, 10*(11), 1891-1904.

Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). Understanding suicide risk in autistic adults: Comparing the interpersonal theory of suicide in autistic and non-autistic samples. *Journal of autism and developmental disorders, 50*(10), 3620-3637.

Phung, J., Penner, M., Pirlot, C., & Welch, C. (2021). What i wish you knew: Insights on burnout, inertia, meltdown, and shutdown from autistic youth. *Frontiers in Psychology*, 4981.

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological journal, 20*(1), 7-14.

Polanczyk, G. V., Salum, G. A., Sugaya, L. S., Caye, A., & Rohde, L. A. (2015). Annual research review: A meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. *Journal of Child Psychology and Psychiatry, 56*(3), 345-365. doi:doi:10.1111/jcpp.12381

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of counseling psychology, 52*, 126-136. doi:10.1037/0022-0167.52.2.126

Poon, K. K., Soon, S., Wong, M.-E., Kaur, S., Khaw, J., Ng, Z., & Tan, C. S. (2014). What is school like? Perspectives of singaporean youth with high-functioning autism spectrum disorders. *International Journal of Inclusive Education, 18*(10), 1069-1081. doi:10.1080/13603116.2012.693401

Preece, D. (2002). Consultation with children with autistic spectrum disorders about their experience of short-term residential care. *British Journal of Learning Disabilities, 30*(3), 97-104.

Preece, D., & Howley, M. (2018). An approach to supporting young people with autism spectrum disorder and high anxiety to re-engage with formal education–the impact on young people and their families. *International journal of adolescence and youth, 23*(4), 468-481.

Preece, D., & Jordan, R. (2010). Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. *British Journal of Learning Disabilities, 38*(1), 10-20.

Public Health England. (2022). Chapter 1: Education and children’s social care. Retrieved on 04.05.23 from https://www.gov.uk/government/publications/people-with-learning-disabilities-in-england/chapter-1-education-and-childrens-social-care-updates.

Putwain, D. W. (2007). Test anxiety in uk schoolchildren: Prevalence and demographic patterns. *British Journal of Educational Psychology, 77*(3), 579-593. doi:https://doi.org/10.1348/000709906X161704

QSR International Pty Ltd. (2018). Nvivo (version 12).

Rao, P. A., Beidel, D. C., & Murray, M. J. (2008). Social skills interventions for children with asperger’s syndrome or high-functioning autism: A review and recommendations. *Journal of autism and developmental disorders, 38*, 353-361.

Ravet, J. (2018). ‘But how do i teach them?’: Autism & initial teacher education (ite). *International Journal of Inclusive Education, 22*(7), 714-733. doi:10.1080/13603116.2017.1412505

Raymaker, D. (2020). Shifting the system: Aaspire and the loom of science and activism. *Autistic community and the neurodiversity movement: Stories from the frontline*, 133-145.

Raymaker, D., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., . . . Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism Adulthood, 2*(2), 132-143. doi:10.1089/aut.2019.0079

Retief, M., & Letšosa, R. (2018). Models of disability: A brief overview. *HTS Teologiese Studies/Theological Studies, 74*(1).

Richardson, L. (2002). Poetic representations of interviews. In J. Gubrium, F. & Holstein, J, A. (Ed.), *Handbook of interview research: Context and method* (pp. 877-891). Thousand Oaks, CA: Sage.

Rimland, B. (1964). Infantile autism.

Roberts, J., & Simpson, K. (2016). A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education, 20*(10), 1084-1096.

Robertson, A. E., & Simmons, D. R. (2015). The sensory experiences of adults with autism spectrum disorder: A qualitative analysis. *Perception, 44*(5), 569-586. doi:10.1068/p7833

Robinson, L., Bond, C., & Oldfield, J. (2018). A uk and ireland survey of educational psychologists’ intervention practices for students with autism spectrum disorder. *Educational Psychology in Practice, 34*(1), 58-72. doi:10.1080/02667363.2017.1391066

Roche, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism, 25*(2), 336-348.

Rodgers, J., Wigham, S., McConachie, H., Freeston, M., Honey, E., & Parr, J. R. (2016). Development of the anxiety scale for children with autism spectrum disorder (asc-asd). *Autism Research, 9*(11), 1205-1215. doi:https://doi.org/10.1002/aur.1603

Rogge, N., & Janssen, J. (2019). The economic costs of autism spectrum disorder: A literature review. *Journal of autism and developmental disorders, 49*(7), 2873-2900. doi:10.1007/s10803-019-04014-z

Rotheram-Fuller, E., Kasari, C., Chamberlain, B., & Locke, J. (2010). Social involvement of children with autism spectrum disorders in elementary school classrooms. *Journal of Child Psychology and Psychiatry, 51*(11), 1227-1234. doi:https://doi.org/10.1111/j.1469-7610.2010.02289.x

Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization and bullying in children with an autism spectrum disorder: Associations with child characteristics and school placement. *Research in Autism Spectrum Disorders, 6*(3), 1126-1134. doi:http://dx.doi.org/10.1016/j.rasd.2012.03.004

Runswick-Cole, K. (2014). 'Us' and 'them': The limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability & Society, 29*(7), 1117-1129. doi:10.1080/09687599.2014.910107

Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T., & Ford, T. (2019). Selection bias on intellectual ability in autism research: A cross-sectional review and meta-analysis. *Molecular Autism, 10*(1), 9. doi:10.1186/s13229-019-0260-x

Ryan, S., & Cole, K. R. (2009). From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*(1), 43-53.

Saggers, B., Campbell, M., Dillon-Wallace, J., Ashburner, J., Hwang, Y.-S., Carrington, S., & Tones, M. (2017). Understandings and experiences of bullying: Impact on students on the autism spectrum. *Australasian Journal of Special Education, 41*(2), 123-140. doi:10.1017/jse.2017.6

Saggers, B., Hwang, Y.-S., & Mercer, K. L. (2011). Your voice counts: Listening to the voice of high school students with autism spectrum disorder. *Australasian Journal of Special Education, 35*(02), 173-190.

Sahlgren, G. (2018). The achievement-wellbeing trade-off in education. London: Centre for Education Economics.

Sandelowski, M., & Barroso, J. (2006). *Handbook for synthesizing qualitative research*: Springer Publishing Company.

Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports, 7*, 40700. doi:10.1038/srep40700

Savin-Baden, M., & Major, C. H. (2013). *Qualitative research : The essential guide to theory and practice*. Abingdon: Routledge.

Schroeder, J. H., Cappadocia, M. C., Bebko, J. M., Pepler, D. J., & Weiss, J. A. (2014). Shedding light on a pervasive problem: A review of research on bullying experiences among children with autism spectrum disorders. *Journal of autism and developmental disorders, 44*(7), 1520-1534. doi:10.1007/s10803-013-2011-8

Scott-Barrett, J., Cebula, K., & Florian, L. (2018). Listening to young people with autism: Learning from researcher experiences. *International Journal of Research & Method in Education*, 1-22. doi:10.1080/1743727X.2018.1462791

Seale, C. (1999). The quality of qualitative research. *The Quality of Qualitative Research*, 1-224.

Sheppard, E., Pillai, D., Wong, G. T.-L., Ropar, D., & Mitchell, P. (2016). How easy is it to read the minds of people with autism spectrum disorder? *Journal of autism and developmental disorders, 46*(4), 1247-1254.

Shevlin, M., Winter, E., & Flynn, P. (2013). Developing inclusive practice: Teacher perceptions of opportunities and constraints in the republic of ireland. *International Journal of Inclusive Education, 17*(10), 1119-1133. doi:10.1080/13603116.2012.742143

Sibeoni, J., Massoutier, L., Valette, M., Manolios, E., Verneuil, L., Speranza, M., & Revah-Levy, A. (2022). The sensory experiences of autistic people: A metasynthesis. *Autism*, 13623613221081188.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(8), 921-929. doi:http://dx.doi.org.idpproxy.reading.ac.uk/10.1097/CHI.0b013e318179964f

Sinclair, J. (1993/2012). Don't mourn for us. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies, 1*(1).

Singer, J. (2017). Neurodiversity: The birth of an idea.

Singh, J. S., & Bunyak, G. (2019). Autism disparities: A systematic review and meta-ethnography of qualitative research. *Qualitative health research, 29*(6), 796-808. doi:10.1177/1049732318808245

Skiba, R., Reynolds, C. R., Graham, S., Sheras, P., Conoley, J. C., Garcia-Vazquez, E., . . . Sickler, H. (2006). Are zero tolerance policies effective in the schools? An evidentiary review and recommendations an official report of the apa.

Skiba, R. J. (2000). Zero Tolerance, Zero Evidence: An Analysis of School Disciplinary Practice. Policy Research Report.

Slee, R. (2018). Inclusive education isn't dead, it just smells funny: Routledge.

Smart, J. F. (2009). The power of models of disability. *Journal of Rehabilitation, 75*(2), 3-11.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and health, 11*(2), 261-271.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39-54.

Smith, J. A. (2015). *Qualitative psychology: A practical guide to research methods*: Sage.

Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: Theory, method and research* (2nd ed.): SAGE Publications.

South, M., Ozonoff, S., & McMahon, W. M. (2005). Repetitive behavior profiles in asperger syndrome and high-functioning autism. *Journal of autism and developmental disorders, 35*(2), 145-158.

Spiers, J., & Riley, R. (2019). Analysing one dataset with two qualitative methods: The distress of general practitioners, a thematic and interpretative phenomenological analysis. *Qualitative Research in Psychology, 16*(2), 276-290. doi:10.1080/14780887.2018.1543099

Sproston, K., Sedgewick, F., & Crane, L. (2017). Autistic girls and school exclusion: Perspectives of students and their parents. *Autism & Developmental Language Impairments, 2*, 2396941517706172. doi:10.1177/2396941517706172

Stack, K., Symonds, J. E., & Kinsella, W. (2020). Student and parent perspectives of the transition from primary to secondary school for students with autism spectrum disorder. *Frontiers in Education, 5*. doi:10.3389/feduc.2020.551574

Stenning, A., & Rosqvist, H. B. (2021). Neurodiversity studies: Mapping out possibilities of a new critical paradigm. *Disability & Society, 36*(9), 1532-1537. doi:10.1080/09687599.2021.1919503

Sterzing, P., Shattuck, P., Narendorf, S., Wagner, M., & Cooper, B. (2012). Bullying involvement and autism spectrum disorders: Prevalence and correlates of bullying involvement among adolescents with an autism spectrum disorder. *Archives of pediatrics & adolescent medicine, 166*(11), 1058-1064.

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *The British Journal of Sociology, 47*(4), 699-716. doi:10.2307/591081

Sue, D. W. (2010). *Microaggressions and marginality: Manifestation, dynamics, and impact*: John Wiley & Sons.

Sue, D. W., Capodilupo, C. M., Torino, G. C., Bucceri, J. M., Holder, A., Nadal, K. L., & Esquilin, M. (2007). Racial microaggressions in everyday life: Implications for clinical practice. *American psychologist, 62*(4), 271.

Sukhodolsky, D. G., Scahill, L., Gadow, K. D., Arnold, L. E., Aman, M. G., McDougle, C. J., . . . Lecavalier, L. (2008). Parent-rated anxiety symptoms in children with pervasive developmental disorders: Frequency and association with core autism symptoms and cognitive functioning. *Journal of abnormal child psychology, 36*(1), 117-128.

Sullivan, C., & Forrester, M. A. (2018). *Doing qualitative research in psychology: A practical guide*: Sage.

Swaim, K. F., & Morgan, S. B. (2001). Children's attitudes and behavioral intentions toward a peer with autistic behaviors: Does a brief educational intervention have an effect? *Journal of autism and developmental disorders, 31*(2), 195-205.

Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & Society, 15*(4), 569-582. doi:10.1080/09687590050058189

Sweileh, W. M., Al-Jabi, S. W., Sawalha, A. F., & Zyoud, S. e. H. (2016). Bibliometric profile of the global scientific research on autism spectrum disorders. *Springerplus, 5*, 1-12.

Symes, W., & Humphrey, N. (2010). Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (asd) in mainstream secondary schools: A comparative study. *School Psychology International, 31*(5), 478-494.

Symes, W., & Humphrey, N. (2012). Including pupils with autistic spectrum disorders in the classroom: The role of teaching assistants. *European Journal of Special Needs Education, 27*(4), 517-532.

Tavassoli, T., Bellesheim, K., Siper, P. M., Wang, A. T., Halpern, D., Gorenstein, M., . . . Buxbaum, J. D. (2016). Measuring sensory reactivity in autism spectrum disorder: Application and simplification of a clinician-administered sensory observation scale. *Journal of autism and developmental disorders, 46*, 287-293.

Tavernor, L., Barron, E., Rodgers, J., & McConachie, H. (2013). Finding out what matters: Validity of quality of life measurement in young people with asd. *Child: care, health and development, 39*(4), 592-601.

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology, 8*(1), 45.

Thorne, S., Jensen, L., Kearney, M. H., Noblit, G., & Sandelowski, M. (2004). Qualitative metasynthesis: Reflections on methodological orientation and ideological agenda. *Qualitative health research, 14*(10), 1342-1365.

Tissot, C. (2011). Working together? Parent and local authority views on the process of obtaining appropriate educational provision for children with autism spectrum disorders. *Educational Research, 53*(1), 1-15.

Tomchek, S. D., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the short sensory profile. *American Journal of Occupational Therapy, 61*(2), 190-200. doi:10.5014/ajot.61.2.190

Tomlinson, C., Bond, C., & Hebron, J. (2022). The mainstream school experiences of adolescent autistic girls. *European Journal of Special Needs Education, 37*(2), 323-339. doi:10.1080/08856257.2021.1878657

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (coreq): A 32-item checklist for interviews and focus groups. *International journal for quality in health care, 19*(6), 349-357.

Totsika, V., Hastings, R. P., Dutton, Y., Worsley, A., Melvin, G., Gray, K., . . . Heyne, D. (2020). Types and correlates of school non-attendance in students with autism spectrum disorders. *Autism, 24*(7), 1639-1649. doi:10.1177/1362361320916967

Tso, M., & Strnadová, I. (2017). Students with autism transitioning from primary to secondary schools: Parents’ perspectives and experiences. *International Journal of Inclusive Education, 21*(4), 389-403. doi:10.1080/13603116.2016.1197324

UNESCO. (1994). The salamanca statement and framework for action on special needs education: Adopted by the world conference on special needs education; access and quality. Salamanca, spain, june 7–10. *United Nations educational, Scientific Cultural Organization, Paris and Ministry of Education Science, Madrid.*

UN General Assembly. (1989). Convention on the Rights of the Child, United Nations, Treaty Series, vol. 1577, p. 3, Retrieved on 04.05.23 from https://www.refworld.org/docid/3ae6b38f0.html

United Nations. (2006). Convention on the rights of persons with disabilities. Retrieved on 04.05.23 from https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.aspx.

UPIAS. (1975). Fundamental principles of disability.

Van Auken, P. M., Frisvoll, S. J., & Stewart, S. I. (2010). Visualising community: Using participant-driven photo-elicitation for research and application. *Local Environment, 15*(4), 373-388. doi:10.1080/13549831003677670

Van Deurzen, E. (1997). Everyday mysteries: Existential dimensions of psychotherapy. East Sussex: Routledge van Schalkwyk, G. I., & Dewinter, J. (2020). Qualitative research in the journal of autism and developmental disorders. *Journal of autism and developmental disorders, 50*(7), 2280-2282. doi:10.1007/s10803-020-04466-8

van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review, 14*(3), 302. doi:10.1007/s10567-011-0097-0

Vincent, C., Oliver, C., & Pavlopoulou, G. (2023). Lessons from lockdown: Autistic students, parents and mainstream schools. *British Educational Research Journal, n/a*(n/a). doi:https://doi.org/10.1002/berj.3854

Walker, N. (2021). *Neuroqueer heresies: Notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Arkansas, USA: Autonomous Press.

Walsh, N., & Hall, I. (2012). The autism strategy: Implications for people with autism and for service development. *Advances in Mental Health and Intellectual Disabilities, 6*(3), 113-120. doi:10.1108/20441281211227166

Waltz, M. (2005). Reading case studies of people with autistic spectrum disorders: A cultural studies approach to issues of disability representation. *Disability & Society, 20*(4), 421-435. doi:10.1080/09687590500086575

Waltz, M. (2013). *Autism: A social and medical history*: Springer.

Warnock, M. (1978). *Special educational needs: Report of the committee of enquiry into the education of handicapped children and young people* (Vol. 7212): Stationery Office Books (TSO).

Warnock, M., & Norwich, B. (2010). *Special educational needs: A new look*: Bloomsbury Publishing.

Warren, A., Buckingham, K., & Parsons, S. (2020). Everyday experiences of inclusion in primary resourced provision: The voices of autistic pupils and their teachers. *European Journal of Special Needs Education*, 1-16. doi:10.1080/08856257.2020.1823166

Warren, A., Buckingham, K., & Parsons, S. (2021). Everyday experiences of inclusion in primary resourced provision: The voices of autistic pupils and their teachers. *European Journal of Special Needs Education, 36*(5), 803-818. doi:10.1080/08856257.2020.1823166

Watkins, L., Ledbetter-Cho, K., O'Reilly, M., Barnard-Brak, L., & Garcia-Grau, P. (2019). Interventions for students with autism in inclusive settings: A best-evidence synthesis and meta-analysis. *Psychological bulletin, 145*(5), 490.

Wearmouth, J. (2017). Special educational needs and disabilities in schools: A critical introduction: Bloomsbury.

Webster, R. (2022). *The inclusion illusion: How children with special educational needs experience mainstream schools*: UCL Press.

Webster, R., & De Boer, A. (2019). Teaching assistants: Their role in the inclusion, education and achievement of pupils with special educational needs. *European Journal of Special Needs Education, 34*(3), 404-407. doi:10.1080/08856257.2019.1615746

Wertz, F. J. (2014). Qualitative inquiry in the history of psychology. *Qualitative Psychology, 1*(1), 4.

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical psychology review, 29*(3), 216-229.

Wilkinson, S. (2015). Focus groups. In J. Smith, A (Ed.), *Qualitative psychology: A practical guide to research methods*. London: Sage Publications Ltd.

Williams, E., Gleeson, K., & Jones, B. (2017). How pupils on the autism spectrum make sense of themselves in the context of their experiences in a mainstream school setting: A qualitative metasynthesis. *Autism, 0*(0), 1362361317723836. doi:10.1177/1362361317723836

Williams, J., & Hanke, D. (2007). 'Do you know what sort of school I want?': Optimum features of school provision for pupils with autistic spectrum disorder. *Good Autism Practice (GAP), 8*(2), 51-63.

Williams White, S., Keonig, K., & Scahill, L. (2007). Social skills development in children with autism spectrum disorders: A review of the intervention research. *Journal of autism and developmental disorders, 37*, 1858-1868.

Willig, C. (2013). *Introducing qualitative research in psychology*: McGraw-Hill Education (UK).

Willig, C. (2019). What can qualitative psychology contribute to psychological knowledge? *Psychological Methods, 24*(6), 796.

Willig, C. (2021). *Introducing qualitative research in psychology*. New York: McGraw-Hill Education.

Winter-Messiers, M. A., Herr, C. M., Wood, C. E., Brooks, A. P., Gates, M. A. M., Houston, T. L., & Tingstad, K. I. (2007). How far can brian ride the daylight 4449 express? A strength-based model of asperger syndrome based on special interest areas. *Focus on Autism and Other Developmental Disabilities, 22*(2), 67-79.

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., . . . Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of autism and developmental disorders, 45*, 1951-1966.

Wong, M. E., Poon, K. K., Kaur, S., & Ng, Z. J. (2015). Parental perspectives and challenges in inclusive education in singapore. *Asia Pacific Journal of Education, 35*(1), 85-97. doi:10.1080/02188791.2013.878309

Wood, J. J., & Gadow, K. D. (2010). Exploring the nature and function of anxiety in youth with autism spectrum disorders. *Clinical Psychology: Science and Practice, 17*(4), 281.

Wood, R. (2021). Autism, intense interests and support in school: From wasted efforts to shared understandings. *Educational Review, 73*(1), 34-54. doi:10.1080/00131911.2019.1566213

Wood, R., & Happé, F. (2020). Barriers to tests and exams for autistic pupils: Improving access and longer-term outcomes. *International Journal of Inclusive Education*, 1-17. doi:10.1080/13603116.2020.1866685

World Health Organization (WHO). (2019). *ICD-10: International classification of diseases* (10th revision).

World Health Organization (WHO). (2022). *ICD-11: International classification of diseases* (11th revision).

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health, 15*(2), 215-228.

Yardley, L. (2015). Demonstrating validity in qualitative psychology. *Qualitative psychology: A practical guide to research methods, 3*, 257-273.

Zablotsky, B., Bradshaw, C. P., Anderson, C., & Law, P. A. (2013). The association between bullying and the psychological functioning of children with autism spectrum disorders. *Journal of Developmental & Behavioral Pediatrics, 34*(1), 1-8.

8. Appendices

8.1. Appendix A: Potentially ableist terms and discourse that commonly appear in autism research and suggested alternatives - Bottema-Beutel *et al.* (2020, p. 20)

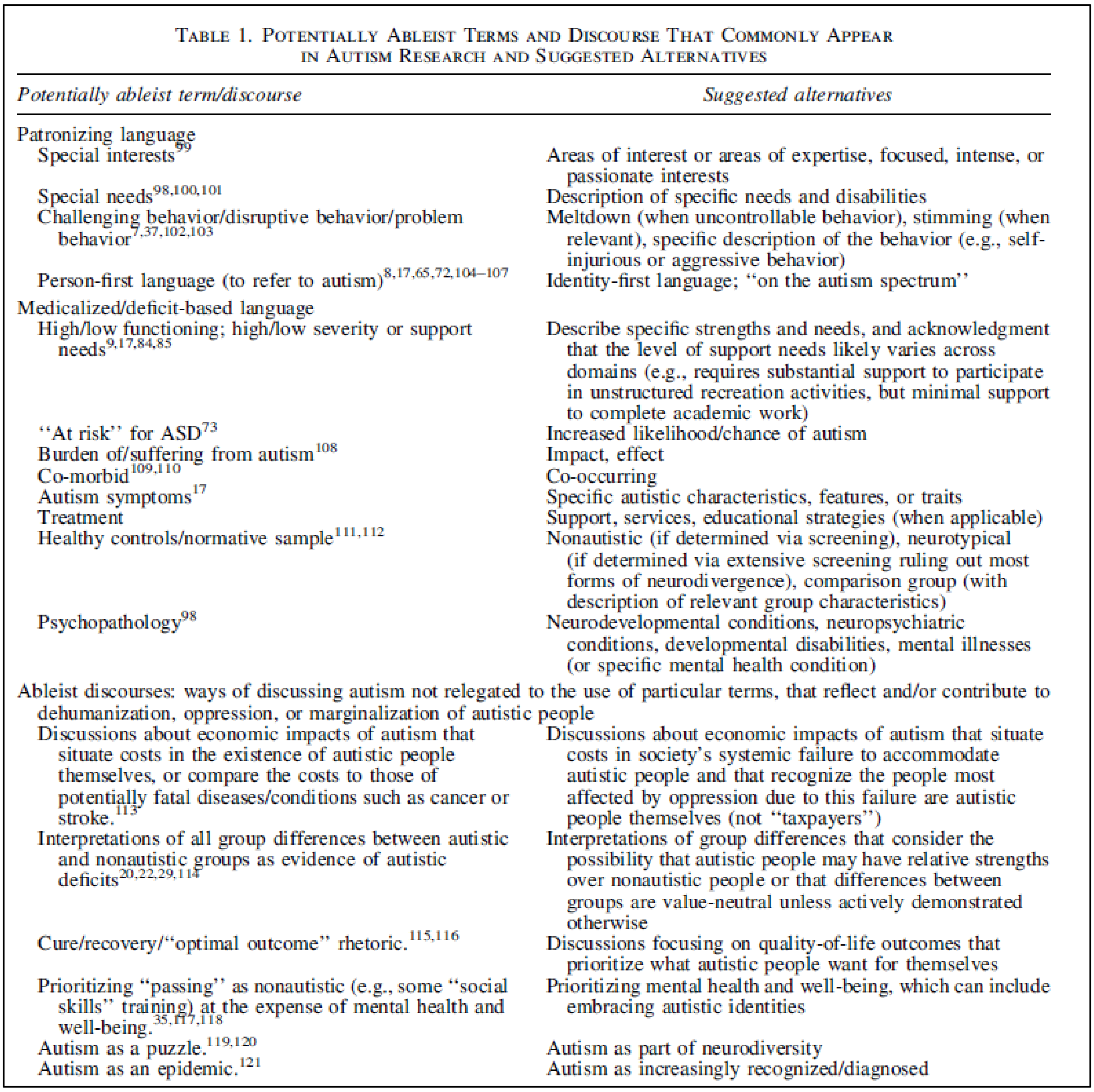


TABLE 1. POTENTIALLY ABLEIST TERMS AND DISCOURSE THAT COMMONLY APPEAR IN AUTISM RESEARCH AND SUGGESTED ALTERNATIVES

Potentially ableist term/discourse	*Suggested alternatives*
Patronizing language	
Special interests[99]	Areas of interest or areas of expertise, focused, intense, or passionate interests
Special needs[98,100,101]	Description of specific needs and disabilities
Challenging behavior/disruptive behavior/problem behavior[7,37,102,103]	Meltdown (when uncontrollable behavior), stimming (when relevant), specific description of the behavior (e.g., self-injurious or aggressive behavior)
Person-first language (to refer to autism)[8,17,65,72,104–107]	Identity-first language; ''on the autism spectrum''
Medicalized/deficit-based language	
High/low functioning; high/low severity or support needs[9,17,84,85]	Describe specific strengths and needs, and acknowledgment that the level of support needs likely varies across domains (e.g., requires substantial support to participate in unstructured recreation activities, but minimal support to complete academic work)
''At risk'' for ASD[73]	Increased likelihood/chance of autism
Burden of/suffering from autism[108]	Impact, effect
Co-morbid[109,110]	Co-occurring
Autism symptoms[17]	Specific autistic characteristics, features, or traits
Treatment	Support, services, educational strategies (when applicable)
Healthy controls/normative sample[111,112]	Nonautistic (if determined via screening), neurotypical (if determined via extensive screening ruling out most forms of neurodivergence), comparison group (with description of relevant group characteristics)
Psychopathology[98]	Neurodevelopmental conditions, neuropsychiatric conditions, developmental disabilities, mental illnesses (or specific mental health condition)
Ableist discourses: ways of discussing autism not relegated to the use of particular terms, that reflect and/or contribute to dehumanization, oppression, or marginalization of autistic people	
Discussions about economic impacts of autism that situate costs in the existence of autistic people themselves, or compare the costs to those of potentially fatal diseases/conditions such as cancer or stroke.[113]	Discussions about economic impacts of autism that situate costs in society's systemic failure to accommodate autistic people and that recognize the people most affected by oppression due to this failure are autistic people themselves (not ''taxpayers'')
Interpretations of all group differences between autistic and nonautistic groups as evidence of autistic deficits[20,22,29,114]	Interpretations of group differences that consider the possibility that autistic people may have relative strengths over nonautistic people or that differences between groups are value-neutral unless actively demonstrated otherwise
Cure/recovery/''optimal outcome'' rhetoric.[115,116]	Discussions focusing on quality-of-life outcomes that prioritize what autistic people want for themselves
Prioritizing ''passing'' as nonautistic (e.g., some ''social skills'' training) at the expense of mental health and well-being.[35,117,118]	Prioritizing mental health and well-being, which can include embracing autistic identities
Autism as a puzzle.[119,120]	Autism as part of neurodiversity
Autism as an epidemic.[121]	Autism as increasingly recognized/diagnosed

8.2. Appendix B: Study 1 supplementary material

8.2.1. COREQ checklist: items and guide questions

Topic	Item No.	Guide Questions/Description
Domain 1: Research team and reflexivity		
Personal characteristics		
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?
Credentials	2	What were the researcher's credentials? E.g. PhD, MD
Occupation	3	What was their occupation at the time of the study?
Gender	4	Was the researcher male or female?
Experience and training	5	What experience or training did the researcher have?
Relationship with participants		
Relationship established	6	Was a relationship established prior to study commencement?
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic
Domain 2: Study design		
Theoretical framework		
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis
Participant selection		
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email
Sample size	12	How many participants were in the study?
Non-participation	13	How many people refused to participate or dropped out? Reasons?
Setting		

Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace
Presence of non-participants	15	Was anyone else present besides the participants and researchers?
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date
Data collection		
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?
Field notes	20	Were field notes made during and/or after the interview or focus group?
Duration	21	What was the duration of the interviews or focus group?
Data saturation	22	Was data saturation discussed?
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
Number of data coders	24	How many data coders coded the data?
Description of the coding tree	25	Did authors provide a description of the coding tree?
Derivation of themes	26	Were themes identified in advance or derived from the data?
Software	27	What software, if applicable, was used to manage the data?
Participant checking	28	Did participants provide feedback on the findings?
Reporting		
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number
Data and findings consistent	30	Was there consistency between the data presented and the findings?
Clarity of major themes	31	Were major themes clearly presented in the findings?
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?

8.2.2. COREQ checklist: scores for included papers

COREQ Item No	Carrington et al., 2003	Connor, 2000	Dillon et al., 2014	Healy et al., 2013	Hebron & Humphrey, 2012	Hill, 2014	Humphrey & Lewis, 2008	Humphrey & Symes, 2010	Lamb et al., 2016	Marks et al., 2000	Mayton, 2005	McNerney et al., 2015	Moyse & Porter, 2015	Poon et al., 2014	Saggers et al., 2011	Count	%
1	✓	✓		✓	✓	✓			✓	✓				✓	✓	9	60
2	✓					✓			✓		✓			✓		5	36
3	✓	✓		✓					✓	✓		✓		✓		7	47
4	✓	✓	✓	✓	✓	✓	✓			✓		✓		✓	✓	11	73
5	✓			✓					✓	✓				✓		5	36
6	✓		✓			✓	✓	✓	✓					✓		7	50
7			✓						✓							2	14
8				✓												1	7
9	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	15	100
10	✓	✓		✓	✓				✓	✓	✓	✓	✓	✓	✓	11	73
11				✓	✓		✓			✓		✓	✓			6	40
12	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	15	100
13	✓				✓			✓		✓		✓				5	36
14	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	14	100
15				✓	✓				✓	✓	✓			✓		6	40
16	✓		✓	✓	✓			✓	✓	✓	✓	✓	✓	✓	✓	12	80
17	✓	✓	✓	✓	✓	✓			✓	✓	✓			✓		10	67
18						✓			✓				✓		✓	4	29
19	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	12	80
20						✓					✓		✓	✓		4	29
21	✓		✓						✓	✓	✓	✓		✓	✓	8	57
22																0	0
23							✓		✓							2	14
24			✓	✓										✓	✓	4	29
25					✓		✓	✓			✓					4	29
26	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	14	93
27	✓				✓		✓	✓						✓		5	36
28							✓									1	7
29	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	15	100
30	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	15	100
31	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	15	100
32		✓		✓	✓	✓	✓			✓		✓	✓	✓	✓	10	67
Count	20	13	16	19	19	16	16	13	21	19	16	15	13	23	16		
%	63	41	50	59	59	50	50	41	66	59	50	47	41	72	50		

8.2.3. Summary of the characteristics of papers found in the 2022 updated literature search

Author, year, country	Number of autistic CYP	Ages	Gender	Level of support	Additional participant groups	School setting	Aim(s)	Method(s)	Analysis	Themes/findings
Aubineau & Blicharska, 2020 (France and Canada)	26	12 - 16	2 female 24 male	17 participants received a level of assistance ranging from full time 1-1 to occasional support when required	N/A	Mainstream secondary	To identify inhibitors and enablers to promoting successful educational experiences [of autistic children] in a Francophone context'	Semi-structured interviews	Thematic analysis	**Inhibitors:** (1) Managing sensory aspects, (2) Peers' behaviour considered as immature and peer bullying, (3) Fatigue **Enablers:** (1) Motivation to study, (2) Being enrolled in a curriculum where students can share their passions, (3) Having a friend inside the school
Birkett, McGrath & Tucker, 2022 (UK)	4	11 – 13	1 female 3 male	Some support from SEN staff but not explicitly reported	N/A	Mainstream secondary with specialist SEN resource	To explore children's [sensory] experience of school spaces	Structured interviews	Thematic analysis	**Sensory tactics**: filtering, muting and ordering spaces Finding muted space: the library **Filtering space**: the playground Transforming space: using metaphor and imagination

Author, year, country	**Number of autistic CYP**	**Ages**	**Gender**	**Level of support**	**Additional participant groups**	**School setting**	**Aim(s)**	**Method(s)**	**Analysis**	**Themes/findings**
Cunningham, 2020 (UK)	11	Years 4 – 7 (i.e. approx. 8-12 yrs.)	3 female 8 male	Not reported	N/A	Mainstream primary with specialist autism resource	[To determine] autistic pupils' perceptions of what an autistic-friendly primary school is like	Group & individual semi-structured interviews	Thematic analysis	Understand Me - teacher/peer understandings of autism Help me to understand - myself and others Hide support for me or I won't use it
Danker, Strnadová, & Cumming, 2019 (Australia)	16	13 – 17	1 female 15 male	Not specifically reported but participants spent varying amounts of time in mainstream vs specialist classes	N/A	Mainstream secondaries – some with specialist resources	To explore the conceptualisation, barriers, and ways to enhance the well-being of students with ASD from their perspectives	Photovoice	Grounded theory	**Domains of student well-being**: Emotional well-being Social well-being Academic well-being Well-becoming **Barriers to student well-being**: Sensory barriers Social barriers Barriers associated with learning **Supporting students with ASD to enhance their well-being:** What helps with a good life in school Who helps with a good life in school

Author, year, country	**Number of autistic CYP**	**Ages**	**Gender**	**Level of support**	**Additional participant groups**	**School setting**	**Aim(s)**	**Method(s)**	**Analysis**	**Themes/findings**
Eguiguren Istuany & Wood, 2020 (Chile)	5	10 – 19	5 male	Not reported	N/A	Mainstream secondary	[To determine] what autistic pupils think could improve their mainstream school experience	Combination of interviews, online questionnaires and focus groups	Thematic analysis	**Sensory issues** Noise, space, textures **Safety** **Approaches to learning** **Social interaction** Desire for social interaction, difficulties with social interaction, need for support
Haegele & Maher, 2022 (USA)	8	13 – 18	8 male	Not reported	N/A	Mainstream secondary	To [explore] the perspectives of autistic youth toward the inclusiveness of their experiences in integrated PE	Semi-structured interviews	Thematic analysis	Bullying can lead to self-harm and self-isolation Peer interactions and relationships in the locker room Peer relationships are based on shared interests and take time to develop

Author, year, country	Number of autistic CYP	Ages	Gender	Level of support	Additional participant groups	School setting	Aim(s)	Method(s)	Analysis	Themes/findings
Halsall, Clarke & Crane, 2021 (UK)	8	12 - 15	8 female	Not reported	Parents and teachers	Mainstream secondary schools with specialist resources	To examine whether autistic girls educated in resource bases attached to mainstream schools used camouflaging strategies	Semi-structured interviews	Thematic analysis	Inconsistencies, contradictions and conflicts in attempts to camouflage Using camouflaging to overcome challenges in making and maintaining friends Camouflaging learning needs and the challenges of learning and inclusion Consequences of camouflaging on social interaction, learning and mental health
Hummerstone & Parsons, 2020 (UK)	12	11 – 15	1 female 11 male	Not reported	Teachers	Mainstream secondary	{To determine] what pupils on the autism spectrum think about the teaching they experience	Photo-elicitation and semi-structured interviews	Thematic analysis	The needs of the individual vs. the needs of the group The importance of being understood to feel supported
Jacobs, Beamish & McKay, 2021 (Australia)	5	12 – 14	5 female	Not reported	Parents	Mainstream secondary	[To explore] what autistic girls say about the factors that helped and hindered their learning and academic success	Semi-structured interviews	IPA	Academic progress at school Feelings about school Facilitators of learning Barriers to learning

Author, year, country	**Number of autistic CYP**	**Ages**	**Gender**	**Level of support**	**Additional participant groups**	**School setting**	**Aim(s)**	**Method(s)**	**Analysis**	**Themes/findings**
Mesa & Hamilton, 2021 (UK)	14	10 – 14	1 female 13 male	Not reported	Parents and teachers	Mainstream primary and secondary	To explore identity development, foregrounding young people's experiences within mainstream educational settings	Interviews	Thematic analysis	**Identifying with autism:** Negotiating difference Changing understanding over time Social camouflaging at school **Social construction of autism:** The autism label Individuality and sameness in autism
Stack, Symonds & Kinsella, 2020 (Ireland)	6	Not explicitly reported but approx. 10-12 yrs.	1 female 5 male	Not reported	Parents	Mainstream primary and secondary	To explore the perspectives of students with ASD and their parents on their transition from primary to secondary school	Semi-structured interviews	Thematic analysis	Not presented as themes but as fits and misfits pre and post transition

Author, year, country	**Number of autistic CYP**	**Ages**	**Gender**	**Level of support**	**Additional participant groups**	**School setting**	**Aim(s)**	**Method(s)**	**Analysis**	**Themes/findings**
Tomlinson, Bond & Hebron, 2022 (UK)	3	14 – 16	3 female	Not reported	Parents and school psychotherapist	Mainstream secondary with unit for CYP with physical disabilities	[To determine] how autistic adolescent girls experience a mainstream secondary school	Semi-structured interviews	Thematic analysis	Anxieties relating to the school environment Difficulties with social relationships The usefulness of specialised interventions to develop social skills in relation to friendships Relationships with staff were perceived as positive when teachers were familiar with individual needs Inconsistency of personalised accommodations was linked to lack of staff awareness
Warren, Buckingham & Parsons, 2021 (UK)	5	9 – 11	5 male	Not reported	Teachers	Mainstream primary with specialist autism resource	To explore the daily experiences, including transitions between the special and mainstream parts of the school, of autistic pupils within resourced provision	Semi-structured interviews	Categorisation analysis	Structure and routine Friendship and peers Support and communication Dual identity

8.3. Appendix C: Study 2 supplementary material

8.3.1. Recruitment sheet

University of Reading

CENTRE for AUTISM

Understanding the autistic primary school experience

An invitation to take part in a study to explore the experiences of autistic pupils in mainstream primary schools

What's involved?

We're running a study to learn more about the experiences of autistic primary school children. We are looking for people with a wide range of experiences to take part in focus group discussions so that we can gain an understanding of the challenges and opportunities autistic children face at primary school. Your involvement will take a maximum of 2 hours and if you take part in a focus group, your travel expenses will be reimbursed.

Who's involved?

We are looking for the following people to be part of our study:

- **Autistic adults (aged 18-25)** who attended a mainstream primary school
- **Parents of autistic children** who attend a mainstream primary school
- **Teachers of autistic children** who work in a mainstream primary school

What next?

Please email the lead researcher, Jo Billington, to register your interest in this study. She will be able to explain more about study and answer any questions. She will then send you an information sheet explaining the study in more detail. You can then decide if you want to take part but you can change your mind and withdraw from the study at any time.

Jo Billington
Lead Researcher
Email:

8.3.2. Information sheets

8.3.2.1. Autistic adults

School of Psychology and Clinical Language Sciences

Harry Pitt Building
Earley Gate, Whiteknights,
Reading RG6 6AL

phone
email
Web www.reading.ac.uk/autism

Information Sheet

Principle Investigator:

Dr Fiona Knott	Email:	Tel:

Lead Researcher:

Jo Billington	Email:	Tel:

We would be grateful to you if you could assist us by participating in our study into the school experiences of young autistic children. We are specifically interested in the challenges and opportunities experienced by autistic children in mainstream primary schools. The data we collect in this study will help us to design a future research project in which we hope to document the views of autistic children.

Your participation will take between one and two hours, during which time you will be asked to take part in a conversation with other autistic adults about your experience of attending a mainstream primary school when you were a child. The conversation will be audio recorded and the research team will take notes while the conversation is taking place. The notes and the transcriptions of the audio recordings will then be analysed and used to create a report that will be submitted for publication in an academic journal. This study will also form part of the Lead Researcher's PhD thesis.

The session will also be video recorded but the footage will only be used to help with transcription of the conversation. The video data will not be analysed or published. When the first phase of the analysis has been completed, you will be sent a summary of the initial results. You do not have to make any comment but if you choose to, we will incorporate your contributions into the final analysis of the data.

All data will be treated as confidential except in instances where a participant discloses information that the research team feels may indicate that someone may be at risk. In the unlikely event of this happening, the research team will pass on the issue to the principle investigator with full disclosure to you so that support may be offered.

All data will be securely stored, with an anonymous identification number connecting you to the data you provide. Information linking that number to your name will be stored securely and separately from the data you share with us. All published data will be anonymised and will contain no identifying details.

All information collected for the project will be destroyed a period of three years after publication with the exception of consent forms which will be retained for a period of five years. Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct

Thank you for your help.

Jo Billington and Fiona Knott

8.3.2.2. Parents of autistic children

School of Psychology and Clinical Language Sciences

Harry Pitt Building
Earley Gate, Whiteknights,
Reading RG6 6AL

phone
email
Web www.reading.ac.uk/autism

Information Sheet

Principle Investigator:

Dr Fiona Knott	Email:	Tel:

Lead Researcher:

Jo Billington	Email:	Tel:

We would be grateful to you if you could assist us by participating in our study into the school experiences of young autistic children. We are specifically interested in the challenges and opportunities experienced by autistic children in mainstream primary schools. The data we collect in this study will help us to design a future research project in which we hope to document the views of autistic children.

Your participation will take between one and two hours, during which time you will be asked to take part in a conversation with other parents of autistic children about your child's experience of attending a mainstream primary school. The conversation will be audio recorded and the research team will take notes while the conversation is taking place. The notes and the transcriptions of the audio recordings will then be analysed and used to create a report that will be submitted for publication in an academic journal. This study will also form part of the Lead Researcher's PhD thesis.

The session will also be video recorded but the footage will only be used to help with transcription of the conversation. The video data will not be analysed or published. When the first phase of the analysis has been completed, you will be sent a summary of the initial results. You do not have to make any comment but if you choose to, we will incorporate your contributions into the final analysis of the data.

All data will be treated as confidential except in instances where a participant discloses information that the research team feels may indicate that someone may be at risk. In the unlikely event of this happening, the research team will pass on the issue to the principle investigator with full disclosure to you so that support may be offered.

All data will be securely stored, with an anonymous identification number connecting you to the data you provide. Information linking that number to your name will be stored securely and separately from the data you share with us. All published data will be anonymised and will contain no identifying details.

All information collected for the project will be destroyed a period of three years after publication with the exception of consent forms which will be retained for a period of five years. Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct

Thank you for your help.

Jo Billington and Fiona Knott

8.3.2.3. Teachers of autistic children

University of Reading

CENTRE for AUTISM

School of Psychology and Clinical Language Sciences

Harry Pitt Building
Earley Gate, Whiteknights,
Reading RG6 6AL

phone
email
Web www.reading.ac.uk/autism

Information Sheet

Principle Investigator:
Dr Fiona Knott Email: Tel:

Lead Researcher:
Jo Billington Email: Tel:

We would be grateful to you if you could assist us by participating in our study into the school experiences of young autistic children. We are specifically interested in the challenges and opportunities experienced by autistic children in mainstream primary schools. The data we collect in this study will help us to design a future research project in which we hope to document the views of autistic children.

Your participation will take between one and two hours, during which time you will be asked to take part in a conversation with other teachers about your experience of teaching autistic children in a mainstream primary school. The conversation will be audio recorded and the research team will take notes while the conversation is taking place. The notes and the transcriptions of the audio recordings will then be analysed and used to create a report that will be submitted for publication in an academic journal. This study will also form part of the Lead Researcher's PhD thesis.

The session will also be video recorded but the footage will only be used to help with transcription of the conversation. The video data will not be analysed or published. When the first phase of the analysis has been completed, you will be sent a summary of the initial results. You do not have to make any comment but if you choose to, we will incorporate your contributions into the final analysis of the data.

All data will be treated as confidential except in instances where a participant discloses information that the research team feels may indicate that someone may be at risk. In the unlikely event of this happening, the research team will pass on the issue to the principle investigator with full disclosure to you so that support may be offered.

All data will be securely stored, with an anonymous identification number connecting you to the data you provide. Information linking that number to your name will be stored securely and separately from the data you share with us. All published data will be anonymised and will contain no identifying details.

All information collected for the project will be destroyed a period of three years after publication. Taking part in this study is completely voluntary; you may withdraw at any time without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct

Thank you for your help.

Jo Billington and Fiona Knott

8.3.3. Consent form

University of Reading

CENTRE *for* AUTISM

School of Psychology and Clinical Language Sciences

Harry Pitt Building
Earley Gate, Whiteknights,
Reading RG6 6AL

phone
email
Web www.reading.ac.uk/autism

Title of Study: Understanding the autistic primary school experience

Lead Researcher: Jo Billington

Principle Investigator and Supervisor: Dr Fiona Knott

Please read the following declarations and initial each box if you agree and understand. If you have any questions or concerns please email

1. I have read and understood the Participants Information Sheet. ☐
2. I have had the opportunity to ask questions about the study and any questions I have asked have been answered to my satisfaction. ☐
3. I understand that all personal information will remain confidential. ☐
4. I understand that any matters involving risk of harm will be referred to the Principle Investigator for further guidance and I will be informed if this is the case. ☐
5. Arrangements for the storage and eventual disposal of any identifiable material have been made clear to me. ☐
6. I understand that participation in this study is voluntary. ☐
7. I understand that I can withdraw from this study at any time without giving an explanation. ☐
8. I understand that data gathered in this study will be used to create a report that will be submitted to an academic journal for publication. ☐
9. I understand that data gathered in this study will be used in the Lead Researcher's PhD thesis. ☐
10. I agree to take part in this study. ☐

Signature ---

Name (in capitals) ---

Date ---

8.3.4. Focus group visual guide

University of Reading

CENTRE for AUTISM

Understanding the autistic primary school experience

Thank you for agreeing to take part in our focus group study into the school experience of young autistic children. We appreciate the time you are taking to be part of our research and we value your contribution.

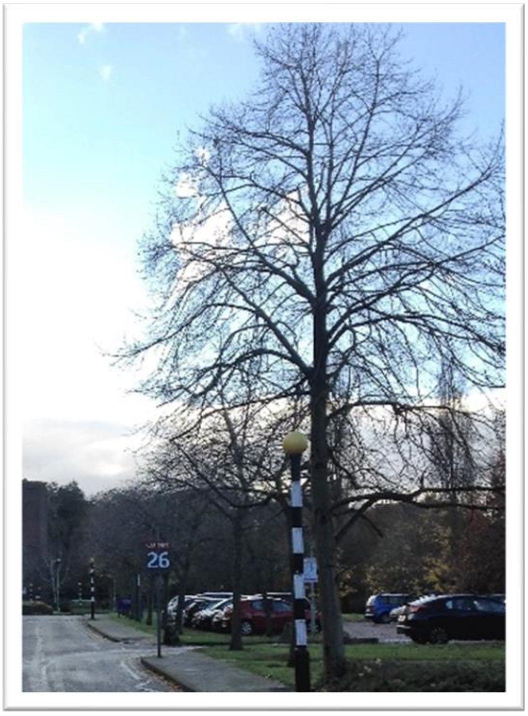
This document is intended as a visual guide to getting to where your interview will be held. If after reading this guide, you have any questions, please contact Jo Billington (j.billington@pgr.reading.ac.uk). Please also contact Jo is there is anything she can do to help you feel more comfortable while taking part in the focus group.

The focus group will take place within the Centre for Autism at the University of Reading. We are located within the School of Psychology and Clinical Language Sciences which is close to the Earley Gate entrance to the University on Whiteknights Road, as shown in the photograph below:

If you need a map of the campus, you can find one here:

https://www.reading.ac.uk/web/files/whiteknights-campus-map-and-keys-2016.pdf

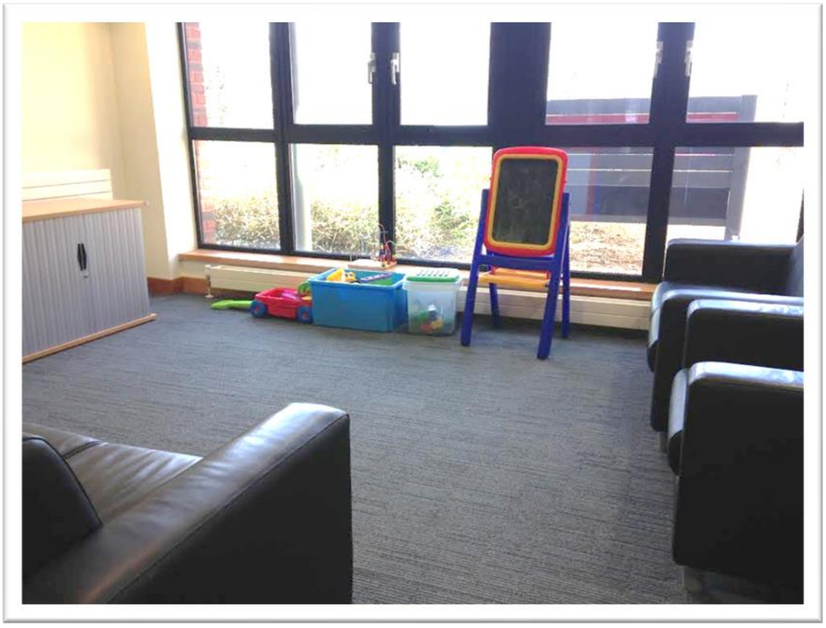
If you have driven to the University, you can leave your car in car park number 26 which is shown in the photograph below. If the focus group is scheduled before 5pm, we will organise a parking permit for you. Permits are not needed after 5pm.



Follow signs to the Psychology building which is building number 62.

This is the entrance to the Psychology building. Please enter through the two sets of doors:

After entering the building, you will see our waiting area to the right of the doors you came through:



Please wait here and I will collect you and take you to the room where the focus group will be held, which looks like this:

Please email me if you have any questions about taking part in this study. Thank you again for your involvement. It’s very much appreciated.

Very best wishes

Jo Billington and Fiona Knott

8.4. Appendix D: Study 3 supplementary material

8.4.1. Recruitment sheet

University of Reading

CENTRE *for* AUTISM

Understanding the autistic primary school experience

An invitation to take part in a photographic study to explore the experiences of autistic pupils in mainstream primary schools

What's involved?

We're running a study to learn more about how autistic children describe and make sense of their everyday school experiences. We would like to interview autistic children so that we can gain an understanding of the challenges and opportunities they face at primary school. The interviews will be supported by photographs taken by the children of aspects of their school life that are meaningful to them. These photographs will only be used to scaffold the interviews and will not be published or shared beyond the research team. The children's involvement will take a maximum of 3 hours spread over a number of weeks, and they will receive a £25 Amazon voucher as a thank you for taking part.

Who's involved?

We are looking for the children who meet the following criteria to be part of our study:

- Clinical diagnosis of autism
- Aware of their diagnosis
- Currently enrolled in years 5 or 6 of a mainstream primary school without a specialist autism resource
- Not in receipt of an Education Health and Care Plan, or in the process of being assessed for one
- Willing to be interviewed via Zoom or another digital platform
- Able to communicate via speech or text (with support where preferred/appropriate)
- Access to, and familiarity with, a camera or photographic device (e.g camera phone or tablet with a camera)

What next?

Please email the lead researcher, Jo Billington, to register your interest in this study. After taking a few details, Jo will be able to explain more about study and answer any questions. She will then send you a document explaining the study in more detail, and provide you with information you can share with parents and carers of autistic children who attend your school.

Jo Billington

Lead Researcher

Email:

8.4.2. Information sheets

8.4.2.1. Parent/carers

School of Psychology and Clinical Language Sciences

Whiteknights,
Reading RG6 6AL

Understanding the lived experiences of autistic children in years 5 and 6 of mainstream primary school

Parent/Carer Information Sheet

Principle Investigator:
Dr Fiona Knott Email: Tel:

Lead Researcher:
Jo Billington Email: Tel:

Dear Parent/Carer

My name is Jo Billington and I am currently completing a PhD in Psychology at the University of Reading. My research is focussed on the lived experiences of autistic children in mainstream primary schools, and I am being supervised by Dr Fiona Knott, a Clinical Psychologist, and Dr Tom Loucas, a Speech and Language Therapist. We would be very grateful if you could assist us by permitting your child to take part in our latest study.

Title of the research

Understanding the lived experiences of autistic children in years 5 and 6 of mainstream primary school

Aims of the research

We would like to know more about how autistic children describe their school experiences. We would like to know what everyday school life is like for them so that we can develop a better understanding of the challenges and opportunities they face.

Why is this research important?

There is a lot of research showing that many autistic children struggle in school for lots of different reasons. Most of that research has involved talking to parents and teachers, or asking autistic children to take tests and assessments. We still do not know a lot about the personal views and experiences of young autistic children, as expressed by them in their own words. We think it is important that autistic children's experiences are researched so that we can learn what matters most to them and then share that information with teachers and school staff so that it can be used in practical positive ways.

What will the research involve?

We would like to conduct one-to-one interviews with autistic children about their everyday school lives. Given the ongoing concerns about face-to-face contact due to the Coronavirus pandemic, all interviews will be conducted online using whichever video meeting software your child feels most comfortable with (e.g. Zoom, Microsoft Teams, Google Meet etc). We know that this might be the first time they have been involved in a research project so if it would make them more comfortable, they don't have to have their video switched on and they can choose to type their responses in the chat rather than speak directly to the researcher via the microphone.

To further support these conversations, we would like participants to create and share photographs using their own devices (e.g. camera, smartphone, or tablet) based on aspects of their school experience that are most meaningful to them. So that we can make sure that the privacy of your child and members of their school community is protected, we will not be asking them to share images that identify people. Instead, we will be asking them to focus on spaces, places and objects which they will photograph either before or after the school day with the support of a member of school staff.

Participants can take as many photographs as they choose over a 2-week period. We will then ask them to select just two or three images for discussion in the online interview. Participants, parents/carers and schools will be given support and guidance on what kinds of images are acceptable. This will take the form of a 'how-to' guide. Support will also be given on how to share the images with the researcher during the interview. Participants are also very welcome to create other forms of visual images such as drawings or diary entries if they prefer. They can also choose to not create any visuals and just talk during the interview if that is their preference.

How long will the research take, and over how many sessions?

Your child's participation will take a maximum of three hours plus the time they choose to spend taking the photographs or creating the images, and take place over three conversations with the researcher. Each of these sessions will take between 30 minutes and an hour:

1. Introductory briefing
    1. Introduction to the researcher and the study
    2. Review of the ‘how-to’ guide
    3. Technical/software overview
    4. Explain the two-week period for photograph-taking

2. Main interview (2-3 weeks after the introductory briefing)
    1. Discussion of the images shared by the child

3. Review meeting (a week after the main interview)
    1. Recap of the main points raised in the interview
    2. Checking that the child is comfortable with what they have shared and making any changes they might ask for

How will the information from the interviews be collected and stored?

The conversations from the three sessions will be audio and video recorded and the researcher will take notes while the conversations are taking place. Session 2, the main interview, will also be transcribed. The notes, recordings, transcription and any visuals created by the child will then be analysed and used to create a report that will be submitted for publication in an academic journal and will form part of the researcher’s PhD thesis.

The images (photographs, diary entries, and drawings) created by the participants will also be used when the results of this study are shared once it has been completed. This will take the form of research papers and presentations at academic conferences and school staff training events. Any identifiable features within the images (e.g. writing, logos etc) will be blurred before publication or dissemination and the identity of your child and their school will remain anonymous.

How will confidentiality be maintained?

All data will be treated as confidential except in instances where a participant discloses information that could indicate that someone may be at risk. In the unlikely event of this happening, the information will be passed on to the investigator with full disclosure to you so that support may be offered.

All data will be securely stored, with an anonymous identification number connecting you and your child to the data you provide. Information linking that number to your name will be stored securely and separately from the data you share with us. All published data will be anonymised and will contain no identifying details. All information collected for the project will be destroyed a period of three years after publication with the exception of consent forms which will be retained for a period of five years.

Are there any risks involved in this study, and what happens if we change our minds about taking part once it has started?

We foresee few risks during this study, but your child may choose to discuss topics which might make them emotional, especially if they struggle with some parts of school life. Therefore, the study may include a mild risk of anxiety, sadness or other emotional reactions. However, these are the very common emotions that we all experience in our daily life from time to time. But, if during one the sessions, your child shows signs of distress, I will pause the interview and ask if they would like to continue or stop. You child can end any of the sessions at any time without giving me an explanation. Similarly, if you are concerned about any aspect of the study then you may discontinue your child's participation at any time.

Taking part in this study is completely voluntary; you may withdraw at any time prior to the publication of the data without having to give any reason. Please feel free to ask any questions that you may have about this study at any point.

What happens after the three research sessions have been completed?

After completion of the third meeting, your child will receive a £25 Amazon voucher by email as a thank you for taking part.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct

If you have any questions or concerns, about the research, please feel free to contact the Researcher, Jo Billington, Tel: (*temporary mobile number exclusively used for this study only was provided)

Thank you for your help.

Jo Billington and Fiona Knott

8.4.2.2. Head teachers

University of Reading
CENTRE for AUTISM

School of Psychology and Clinical Language Sciences

Whiteknights,
Reading RG6 6AL

Understanding the lived experiences of autistic children in years 5 and 6 of mainstream primary school

Headteacher Information Sheet

Principle Investigator:
Dr Fiona Knott Email: Tel:

Lead Researcher:
Jo Billington Email: Tel:

Dear Head teacher

My name is Jo Billington and I am currently completing a PhD in Psychology at the University of Reading. My research is focussed on the lived experiences of autistic children in mainstream primary schools, and I am being supervised by Dr Fiona Knott, a Clinical Psychologist, and Dr Tom Loucas, a Speech and Language Therapist.

We are currently conducting a study into how autistic children describe their everyday school experiences so that we can develop a better understanding of the challenges and opportunities they face at primary school. One of our study participants is a pupil at your school and we would be very grateful for your assistance.

Title of the research

Understanding the lived experiences of autistic children in years 5 and 6 of mainstream primary school

Aims of the research

We would like to know more about how autistic children describe their school experiences. We would like to know what everyday school life is like for them so that we can develop a better understanding of the challenges and opportunities they face.

Why is this research important?

There is a lot of research showing that many autistic children struggle in school for lots of different reasons. Most of that research has involved talking to parents and teachers, or asking autistic children to take tests and assessments. We still do not know a lot about the personal views and experiences of young autistic children, as expressed by them in their own words. We think it is important that autistic children's experiences are researched so that we can learn what matters most to them and then share that information with teachers and school staff so that it can be used in practical positive ways.

What will the research involve?

We will be conducting one-to-one online interviews with autistic children about their everyday school lives. To further support these conversations, we are asking participants to create and share photographs using their own devices (e.g. camera, smartphone, or tablet) based on aspects of their school experience that are most meaningful to them. So that we can make sure that the privacy of the participants and members of their school community is protected, we will not be asking them to share images that identify people. Instead, we will be asking them to focus on spaces, places and objects. We will then discuss the images during the interviews.

What support will be needed from schools?

In order to ensure that people do not feature in these photographs, we are asking schools to support participants in taking the images either before or after school when there are fewer people onsite. We would appreciate your support with this activity and ask that a member of staff is available to supervise the child and allow them access to spaces within school that may not be accessible outside the standard school day. Participants are free to choose what they photograph and they may need to take images at different times or different days in order to capture the images they are looking for. However, we do not expect participants to spend longer than 30 minutes in total on this exercise. They will have a period of two weeks in which to take the images and this period can be agreed with you in advance so that arrangements can be made and boundaries can be established.

What guidance will be offered to participants and their families?

Participants and parents/carers will be given support and guidance on what kinds of images are acceptable. This will take the form of a 'how-to' guide and care will be taken to ensure that no identifiable people or features appear in any of the images shared in the interview. A copy of the 'how-to- guide is enclosed for your information. We would be very grateful if this guide could be shared with the member(s) of staff who will be supervising the child while they take the photographs.

How will the images be used?

The images created by the participants will be used in the wider dissemination of this research. This will take the form of research papers and presentations at academic conferences and school staff training events. Any identifiable features within the images (e.g. writing, logos etc) will be blurred before publication or dissemination and the identity of the child and your school will remain anonymous.

How will confidentiality be maintained?

All data will be treated as confidential except in instances where a participant discloses information that could indicate that someone may be at risk. In the unlikely event of this happening, the information will be passed on to the investigator with full disclosure to the parents/carers so that support may be offered.

All data will be securely stored, with an anonymous identification number system connecting participants to the data they provide. All published data will be anonymised and will contain no identifying details.

All information collected for the project will be destroyed a period of three years after publication with the exception of consent forms which will be retained for a period of five years.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct

If you have any questions or concerns, about the research, please feel free to contact the Researcher, Jo Billington, Tel: (*temporary mobile number exclusively used for this study only was provided)

Thank you for your help.

Jo Billington and Fiona Knott

8.4.3. Consent and permission forms

8.4.3.1. Parent/carers consent form

School of Psychology and Clinical Language Sciences

Whiteknights,
Reading RG6 6AL

Title of Study: Understanding the lived experiences of autistic children in years 5 and 6 of mainstream primary school

Investigator: Dr Fiona Knott

Researcher: Jo Billington

Please read the following declarations and check each box if you agree and understand. If you have any questions or concerns please email

11. I have read and understood the Participant Information Sheet. ☐
12. I have had the opportunity to ask questions about the study and any questions I have asked have been answered to my satisfaction. ☐
13. I understand that all personal information will remain confidential. ☐
14. I understand that any matters involving risk of harm will be referred to the Investigator for further guidance and I will be informed if this is the case. ☐
15. Arrangements for the storage and eventual disposal of any identifiable material have been made clear to me. ☐
16. I understand that participation in this study is voluntary. ☐
17. I understand that I can withdraw from this study without giving an explanation. ☐
18. I understand that data gathered in this study will be used to create a report that will be submitted to an academic journal for publication and will be disseminated in presentations at academic conferences and school training events. ☐
19. I understand that data gathered in this study will be used in the researcher's PhD thesis. ☐
20. I agree for my child to take part in this study. ☐

Signature --

Name (in capitals) --

Date --

8.4.3.2. Head teachers permission form

University of Reading

School of Psychology and Clinical Language Sciences

Whiteknights,
Reading RG6 6AL

CENTRE for AUTISM

Title of Study: Understanding the lived experiences of autistic children in years 5 and 6 of mainstream primary school

Investigator: Dr Fiona Knott

Researcher: Jo Billington

Please read the following declarations and tick each box if you agree and understand. If you have any questions or concerns please email

1. I have read and understood the Headteacher Information Sheet. ☐
2. I have had the opportunity to ask questions about the study and any questions I have asked have been answered to my satisfaction. ☐
3. I understand that the participant will be using their own device (e.g. camera, tablet, or camera-phone) to take photographs of spaces, places and objects before or after the school day. ☐
4. I understand that the photographic capture process should take no more than a total of 30 minutes over the course of a two-week period. ☐
5. I understand that the participant is free to choose what to photograph so long as it is acceptable according to the rules in the ‘how-to’ guide. ☐
6. I agree to provide staff supervision while the participant takes the photographs. ☐
7. I understand that data gathered in this study, including images, will be used to create reports that will be submitted to academic journals for publication and will be disseminated in presentations at academic conferences and school training events. ☐
8. I understand that no identifiable features or people will be visible in the published images, and that the participant and their school will remain anonymous. ☐
9. I agree to support the participant’s involvement in this study. ☐

Signature --

Name (in capitals) ---

Name of School ---

Date ---

8.4.4. Child information pack

8.4.4.1. Easy-read information sheet

Autistic children’s primary school experiences

Hello. My name is Jo and I am a student at the University of Reading.

I am doing a project about what school is like for autistic children, and I hope you can help me.

Please read this information carefully and talk to your mum, dad or carer about the project.

Please ask me if there is anything that isn’t clear or if you want some more information.

Please take your time to think about if you want to take part. It’s up to you and it’s OK if you’d rather not.

What is the project about?

I would like to find out more about what school life is like for autistic children in primary schools. I would like to know more about the parts of school you like and the parts of school that might be tricky for you.

About 10 children will be taking part in this project and I will use what they tell me to write a report that I will share with people so that we can learn how to make school better for young autistic children.

Why have you been asked to take part?

You have been chosen because you are autistic and you are in either year 5 or year 6 of a primary school.

Do you have to take part?
No, it’s your choice. If you do decide to take part, you will be asked to complete a form to say that you agree to be part of the project.
But, if you change your mind, you can stop being part of the project at any time and you don’t have to tell me why.

What would I like you to do?
I would like to meet with you and your parents or carers and ask you some questions about school. We will meet online using video software such as Zoom, Microsoft Teams or another application that you prefer to use.

You will also be offered the chance to take some photos of the parts of school life that are most important to you. You can decide what to photograph and then we can talk about your photos in one of our meetings. If you don’t want to take photos, you can draw a picture or keep a short diary instead. If you’d rather not do any of those things and just talk to me instead, that’s OK too.

What questions will I ask?

- How do you feel about school?
- What do you enjoy most about school?
- Which parts of school do you find tricky or difficult?
- Who are the people you like to spend time with at school?
- Who do you not enjoy spending time with?
- How do your teachers help you?

I might also ask some other questions about the things you tell me. You can choose not to answer any question I ask.

What will happen if you decide to take part in the project?

1st meeting

First of all, we will meet each other online and have a quick chat to get to know each other a little bit. We will talk about the project in more detail and you can ask me any questions.

We will also chat about taking the photos and whether you would prefer to do something different.

More information about the photos is in the ‘how-to’ guide.

This meeting should take no longer than 30 minutes

2nd meeting

A couple of weeks later, we will meet again to talk about the photos you have taken. You can take as many photos as you like, but I will ask you to choose only 2 or 3 of the most important ones to share during our conversation.

This meeting should take between 30 minutes and one hour.

3rd meeting

I will then go away and think about our conversation and write up a few notes about the things you have told me.

A few weeks later, we will meet again for the last time so I can check if you agree with my notes. You can change your mind about anything you have said and you can also correct me if I have got anything wrong.

A few important extra details about the project

I will record our three meetings so that I can remember all the things we talk about.

You can choose to have your camera switched off. You can also choose to turn off your microphone as well and use the chat box to type your answers if that feels easier for you.

You can decide if you would like your mum, dad or carer to be with you during the interviews, or you can talk to me on your own.

Everything you tell me will be private. At the end of the project, the photographs, drawings or diaries you share with me and the things you tell me will become part of a report that I will write and share with other people, but I will not be sharing your real name, the name of your school or any other information that could identify you.

All of that information will be confidential and kept in a safe place here at the University.

But, if you tell me something that makes me worried about your or someone else's safety, I will need to tell someone so that we can help keep everyone safe.

If you feel upset or uncomfortable at any point, you can end the meetings at any time and you don’t need to tell me why.

£

When the project is finished, you will receive a £25 Amazon voucher to say thank you.

What next?

If you would like to take part in the project, please read the **‘how-to’ guide** and fill in the **child assent form**. Please ask your mum, dad or carer for help if you need it and ask them to send it back to me.

Thank you!

Jo Billington

8.4.4.2. Child assent form

University of Reading

CENTRE for AUTISM

Autistic children's primary school experiences

Please tick one box to answer each of the questions below:

1. I have read the information sheet and agree to take part in this study

   Yes ☐ **No** ☐

2. I have read the 'how-to' guide and understand the rules about what I can and can't photograph in school

   Yes ☐ **No** ☐

3. I understand that my real name will not be used when the results of the study are published

   Yes ☐ **No** ☐

4. I know that I can chose whether or not to take part in the study and that I can leave at any time if I want to

   Yes ☐ **No** ☐

5. I am happy for the images I create (e.g. photographs, drawings, diary entries) to be used in the study

   Yes ☐ **No** ☐

Signature --

Name (in capitals) --

Date --

8.4.4.3. “How-to” guide for photography

Autistic children’s primary school experiences

Thank you for being part of this study. We would like to understand the parts of school life that are important to you. To help us do that, we would like to you to take part in an activity.

You can choose to take photographs, draw pictures, keep a diary or just talk to us. It’s up to you.

If you decide to take photographs, here are some rules you will need to follow:

1. **You will need to use your own device**

   This might be a digital camera, a tablet or a mobile phone with a camera.

2. **You can choose what to photograph but you must not take photos of people. You can photograph spaces, places and objects.**

   For example, this photo would not be allowed because it contains people who can be identified:

But these photos would be OK because they don't contain any people

3. **To help you with this activity, a teacher or member of school staff will supervise you taking the photographs just before or after the school day when there are not so many people around.**
   It's important that you follow their instructions about what you can and can't photograph.

4. **If there's something you wanted to photograph but weren't able to, you could choose to draw it, write about it, or talk about it instead.**

5. **You can take as many photos as you like. Then you will be asked to choose just 2 or 3 photos to talk about in the interview.**

6. **You will have 2 weeks to take your photos, draw or make other images. You need to check with your teacher about the best times to bring your device in to school.**

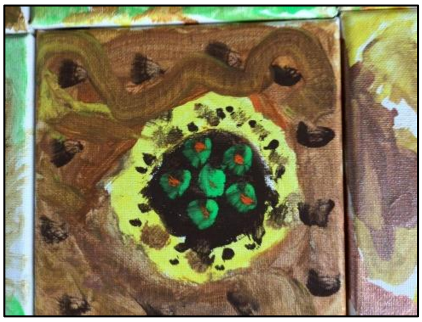
7. **You can also choose to take photos at home or outside school if you want to.**
   For example, homework might be an important part of school life for you, or perhaps there's something about the journey to and from school that you would like to talk about.

8. **You will be able to talk about these rules with the researcher and you can ask a question at any time if you are struggling or if there is something you don't**

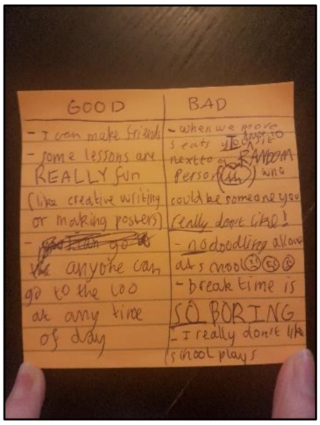
understand. Please ask your mum, dad or carer to contact the researcher if you need to talk to them.

8.4.5. Selection of submitted creative materials

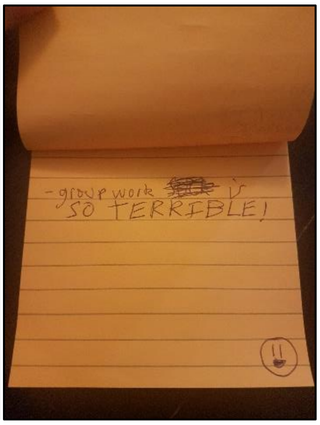
8.4.5.1. Photographs



8.4.5.2. Notes

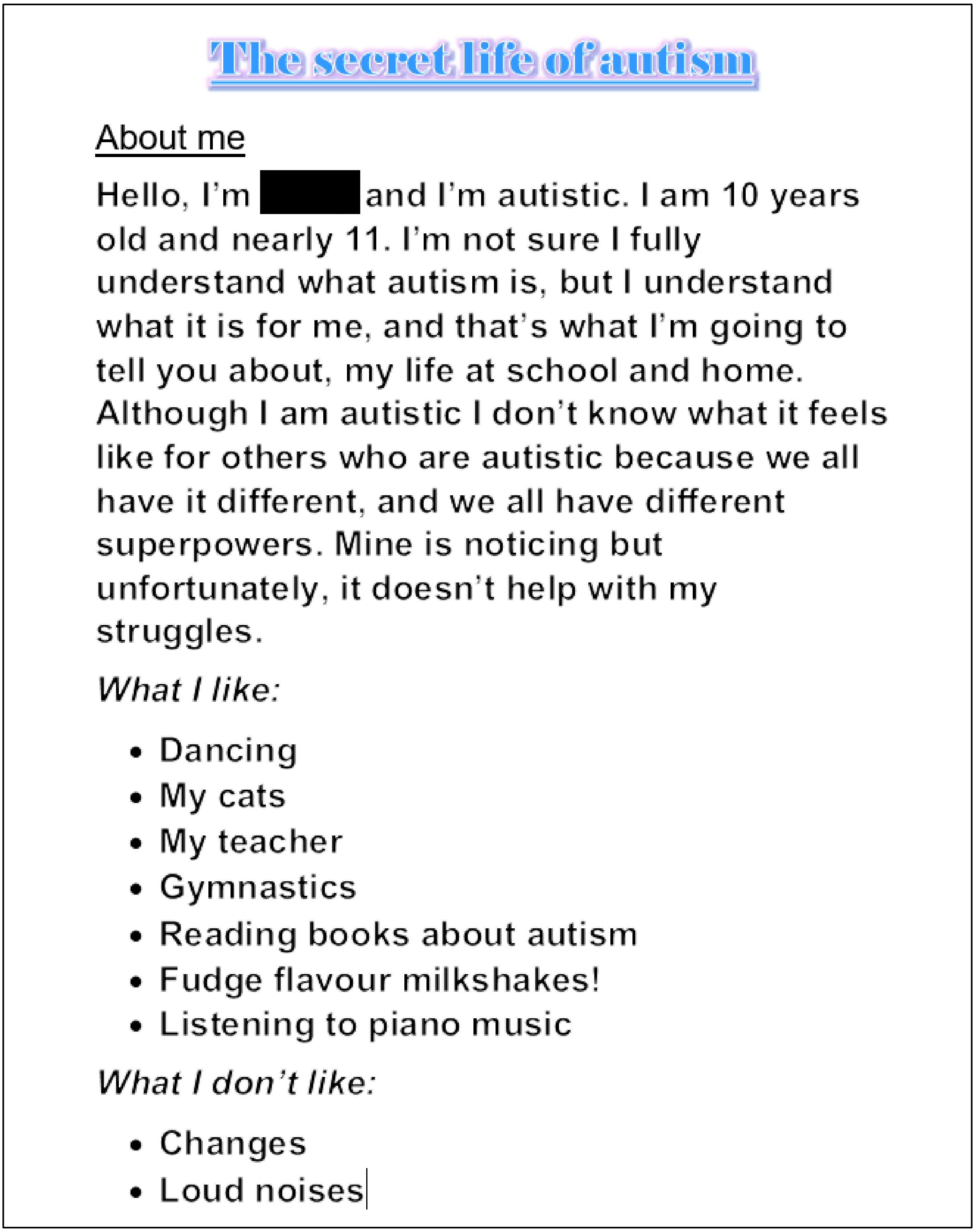


GOOD	BAD
- I can make friends	- when we move seats ~~you~~ I have to sit next to a RANDOM person (uh) who could be someone you really don't like!
- some lessons are REALLY fun (like creative writing or making posters)	- no doodling allowed at school
- ~~I can go to the~~ anyone can go to the loo at any time of day	- break time is SO BORING
	- I really don't like school plays



- group work SO TERRIBLE!

8.4.5.3. A self-written book



The secret life of autism

About me

Hello, I'm [redacted] and I'm autistic. I am 10 years old and nearly 11. I'm not sure I fully understand what autism is, but I understand what it is for me, and that's what I'm going to tell you about, my life at school and home. Although I am autistic I don't know what it feels like for others who are autistic because we all have it different, and we all have different superpowers. Mine is noticing but unfortunately, it doesn't help with my struggles.

What I like:

- Dancing
- My cats
- My teacher
- Gymnastics
- Reading books about autism
- Fudge flavour milkshakes!
- Listening to piano music

What I don't like:

- Changes
- Loud noises

8.4.5.4. Example of a PowerPoint slide used to share photographs during the interviews